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**Cross-Cultural Views of Dementia: A Focus on African Americans,  
Asians, Caucasians and Hispanics**

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**Cross-Cultural Views of Dementia:  
A focus on African Americans, Asians, Caucasians and Hispanics**

**by**

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## Dedication

# OLÓDUMARÈ

For your grace upon grace and mercy upon mercy

I am thankful!

Dedicated to all the families that have worked through and walked with their loved ones  
through the unpredictable journey of dementia.

## **Acknowledgments**

This dissertation would not have been a reality without the guidance, encouragement and assistance of several individuals. I am indeed very thankful.

My children and husband – thank you for your support. Thank you for all the comments you made when I repeatedly said, “I am in school” that made the journey easy and bearable. Omiete and Tekena for being the best children that I could ever have asked for. Love you

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To my family – Mom, siblings, aunts and cousins. Thank you so much for cheering me on. Though we can’t pick our families, I think God was partial when he gave me mine. I would not have picked this well if I was given the opportunity. He gave me the best.

To my friends – I have those that are like sisters and brothers. I love you and thank you. Thank you for not getting tired of hearing “I am working on it” when you ask me how is it going? I appreciate you all. I am so blessed to have you as friends. I can surely say I have friends and for this I am thankful.

To me for sticking with it, for not giving up and for accomplishing this. Saving the best for last, I acknowledge that I would not have been capable of doing any of this without God. You are acknowledged and many thanks with a heart full of gratitude for being You.

## **Cross-Cultural Views of Dementia:**

### **A focus on African Americans, Asians, Caucasians and Hispanics**

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Dementia affects about 5,000,000 Americans and unfortunately this number will only continue to rise as the United States (US) population ages. It is a financially burdening disease, costing billions of dollars and hundreds of thousands of hours of unpaid assistance by family members annually. As the US demographics continue to change, it is important to understand the perception and lived experience of dementia across different cultures. The understanding of this concept will improve education and communication, which in turn is likely to improve early detection of the disease and reduce cost by avoiding unnecessary treatments and providing a culturally appropriate care plan through the journey of the disease.

***Objective:*** The purpose of this study was to understand the lived experience of having a close family member diagnosed with dementia and to explore the cultural perspectives of dementia.

**Method:** The study utilized phenomenology and four to six participants from four ethnic groups were included in the study. All participants were direct relatives of the patient diagnosed with dementia. The participants included spouses, children and siblings. Data was collected using semi-structured interview method, chosen from four cultural groups African Americans, Asians, Caucasians, and Hispanics representing the population in a long-term care facility. Interviews were recorded.

**Data Analysis:** All data collected was coded and similar themes were collated together. Four major themes and seven sub-themes were identified. Themes were viewed across cultures and within cultures.

**Conclusion:** It was concluded that there are similarities within cultures and across cultures, and more significant differences across cultures than within cultures.

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## List of Abbreviations

AA	African Americans
AD	Alzheimer's Disease
ADL	Activities of Daily Living
AS	Asians
CALD	Culturally and Linguistically Diverse
CARP	Center for Advanced Research in Phenomenology
CAU	Caucasians
CC	Cultural Competence
CDC	Center for Disease Control and Prevention
CITI	Collaborative Institutional Training Initiative
DLB	Dementia with Lewy Body
EC	Ethnicity Codes
FATE	Foundations Aiding the elderly
FTLD	Fronto-Temporal Lobar Degeneration
GSBS	Graduate School of Biomedical Science
HIS	Hispanics
IADL	Instrumental Activities of Daily Living
IC	Informed Consent
IOM	Institute of Medicine
IRB	Institutional Review Board
NPH	Normal Pressure Hydrocephalus

PCC Patient Centered Care

### **List of Abbreviations**

PI Principal Investigator

PP Participants

QOL Quality of Life

QRCA Qualitative Research Consultants Association

US United States

UTMB University of Texas Medical Branch

## Chapter 1: Introduction

### PHENOMENON OF INTEREST

In this phenomenological study, the phenomenon of interest is the perspectives of dementia across various cultures, with a focus on African Americans, Asians, Caucasians and Hispanics. Dementia is a non-reversible loss of brain function that affects memory, thinking, language, judgment, and behavior. It involves memory loss and difficulty with at least one of the following areas: logical speaking or writing, recognizing familiar surroundings, planning and/or carrying out multiple task activities. It predominantly occurs in people older than 60 (Alexander, Larson, DeKosky, & Eichler, 2017).

The United States (US) population is culturally diverse, and as the population ages, this diversity is increasingly reflected among older generations. According to the US Census Bureau (2011),

“America’s elderly population is now growing at a moderate pace and not far into the future, the growth will become rapid. So, rapid in fact, that by the middle of the next century, it might be completely inaccurate to think of ourselves as a nation of the young: there could be more persons who are elderly (65 and over) than young (14 or younger)!” (para. 1)

Older people from culturally and linguistically diverse (CALD) backgrounds make up a significant portion of the United States population, and this sector is expected to continue growing at a moderate pace (US Census Bureau, 2011).

Furthermore, in relation to population growth, in 1900, the number of people aged 65 or older was only one in every 25 Americans, jumping to a significant one in eight (33.2 million) in 1994. This population is predicted to more than double in size between now and

2050, to about 80 million. By 2050, it is estimated that one in every five Americans will be over 65 years of age, with most of this growth expected to happen between 2010 and 2030 when the baby boomer generation enters their elderly years. Advancements in medicine have resulted in declining mortality rates and are likely to continue to influence this enormous growth (U.S. Census Bureau, 2011, para. 2–3).

In 2012, the US over-65 population comprised 86% Caucasians, 8.8% Blacks, 7.3% Latino-Hispanics, 3.8% Asian/Pacific Islanders and about 0.6% American Indians. It is predicted that by 2030, this will be 82.2% Caucasians, 11% Latino-Hispanics, 10.7% Blacks, 4.8% Asians and 0.9% American Indians. It is also predicted that, by 2050, while all ethnicities will be trending up, the Caucasian race will be trending down: Caucasians 77.3% (down 10% from 2012), Latino-Hispanics 18%, Blacks 12.3%, Asians 7.1%, and American Indians 1.2% (Vincent & Velkoff, 2010; Ortman, Velkoff, & Hogan, 2014). These changing demographics of the US elderly population provide a strong rationale for a clear understanding of dementia from a cultural perspective so that communication and education can be crafted more effectively.

In summary, the US has over the centuries welcomed diverse immigrant and cultural groups, and as the country becomes more technologically advanced, the ethnic and cultural makeup of the population will continue to change from one generation to another. Because of the robust economy of the US and the opportunities available, the US will continue to attract people from all over the globe. The US population is projected to become more diverse. As the Black; Asian and Pacific Islander; American Indian, Eskimo, and Aleut; and Hispanic-origin populations increase as a proportion of the total population, the proportion comprised by the non-Hispanic White population will decrease. According to



the US Census Bureau, from 2000–2009, the country experienced an increase of 37% in the Hispanic population, 32% in the Asian population, 18% in American Indians and Alaskan Natives, and 13% in the African American population, while the non-Hispanic White population only increased by 2%. The bureau adjusted the ethnic demographics of the country in 2009, with non-Hispanic Whites representing 65.1%, significantly down from 2000 when the population of non-Hispanic Whites was about 84%. Hispanics represented 15.8%, African Americans 13.6%, Asians 4.6%, and American Indians and Alaskan Natives, Native Hawaiians and other Pacific Islanders representing about 1.2% of the total 307 million inhabitants of the US. The adjustment of the US demographics in 2009 by the US Census Bureau are close to the trends required for the bureau’s predictions regarding the US’s ethnic demographics by 2050 to be proved correct. That is, the bureau has projected that, by 2050, there will be a decline in the percentage of the total population made up by Whites to about 47%, an increase in the Hispanic (from 14% to 29%) and Asian (5% to 9%) components, with the Black population staying stable at about 13% (The American College of Obstetricians and Gynecologists, 2011; US Census Bureau, 2011; Passel & Cohn, 2008).

## **THEORETICAL FRAMEWORK**

Campinha-Bacote’s (2003) cultural competence theory was the theoretical framework used in this study. This theory involves five dimensions: cultural desire, cultural awareness, cultural knowledge, cultural skill and cultural encounters. Campinha-Bacote (2003) describes,

- cultural desire as the desire to understand cultures;
- cultural awareness as the recognition that there are cultural issues;

- cultural knowledge as learning the beliefs and values of other cultures, the disease incidence for specific groups and appropriate corresponding management strategies; and
- cultural skill as possessing cultural desire and awareness by using cultural knowledge and
- cultural encounters as applying cultural knowledge and skills to the care of specific patients.

The principal investigator (PI) aims to understand the perspectives of dementia across different cultures. Having worked for the last 8 years in nursing homes in the Houston area with a very diverse population mix and being originally from a different culture in the US has made this paramount. The PI is highly aware that there are cultural differences existing in Texas and the US, and that sound understanding of these cultural differences is crucial to provide individualized and holistic care. The PI was also interested in contributing to the cultural knowledge that exists in nursing to provide cultural-specific healthcare. Research has shown that providing healthcare that is culturally specific enhances compliance: acquiring cultural skills and applying them to the care of patients improves compliance and outcomes (McLaughlin & Braun, 1998). This cultural understanding will make the journey for a debilitating, irreversible condition like dementia one that is filled with respect and dignity for the patient and their loved ones.

#### **IDENTIFICATION OF RESEARCH QUESTION**

The PI is an immigrant from Nigeria. In some parts of Nigeria, dementia is viewed as some form of witchcraft or evil illness. The illogical communication frequently characteristic of the illness is interpreted as the elderly with dementia recounting all the

evil things they have done. The elderly that exhibit this disease can sometimes face general ostracism and instill fear in the people around them. Unfortunately, some of these individuals can also bring shame to their families. Asians who have Buddhism as their primary religion and believe in the law of karma will sometimes believe that dementia is a consequence of a bad behavior by the person suffering from the disease or a family member (Alzheimer's Australia Vic, 2008). This study seeks to find out if the perception of dementia varies by ethnicity or cultural differences in the US. The research question this study seeks to answer is "Do all ethnicities view dementia as an irreversible disease process, or is there some cultural influence that affects the perception of this medical condition?"

#### **AIM OF STUDY**

Dementia is common among the elderly, but the understanding of the disease differs across cultures. These differences in understanding may make it challenging to get an actual estimate of its occurrence. While some cultures think dementia is a real disease process, other cultures believe that it is a normal part of the aging process, while others still believe that it is simply "mysterious" and science cannot really understand, explain or manage it. In some cultures, forgetfulness in the elderly is perceived as normal, making the early detection of dementia difficult and challenging even in the US (Hendrie, Baiyewu, Eldemir, & Prince, 1998). According to Mahonney, Clouttlebuck, Neary, and Zhan (2005), there is a clearly growing racial and ethnic diversity among older adults in the US which will eventually affect the perception of this disease.

The purpose of this phenomenological study was to define and fill the gap in the literature regarding dementia by addressing the cross-cultural perceptions of dementia

among four ethnic groups in the Houston area. According to the US Census Bureau (2016), Houston ranks as the fourth most populous city in the United States with a population of well over 2,000,000 people and has been described as the largest in the Southern US and Texas. The ethnic demographics of Houston in 2015 were 43.9% Hispanics, 25.5% White, 22.7% African Americans, and 6.4% Asians. This represents only slight variation when compared to the 2010 census, when it was described as 43.8% Hispanics, 25.6% Whites alone, 23.1% African Americans and 6.1% Asians (US Census Bureau, 2016; City of Houston Planning and Development Department, 2013, 2017; City of Houston, 2017).

As the population of the US changes and the population of immigrants continues to shift, it is important to understand how dementia is perceived from these various cultural perspectives. What does dementia mean to people from their lived experiences, and is this affected by their culture?

The aim of this study is to understand the lived experience of close family members who have a relative with a dementia diagnosis.

Aim 1: Explore how dementia is perceived differently across cultures.

Aim 2: Explore how dementia is perceived similarly across cultures.

Aim 3: Explore how dementia is perceived differently within cultures.

Aim 4: Explore how dementia is perceived similarly within specific cultures.

#### **JUSTIFICATION FOR DESIGN AND SIGNIFICANCE OF STUDY**

Nkwi, Nyamongo, and Ryan (2001) defined qualitative research as research involving the use of non-ordinal data. Denzin and Lincoln (2005) described qualitative research as a situated activity that locates the observer in the world consisting of interpretive and material practices that make the world visible. To conclude, qualitative

principal investigators study things in their natural settings, and attempt to make sense of or interpret phenomena in terms of the meanings people bring to them. There are various designs of qualitative studies which include but are not limited to ethnography, phenomenology and case studies.

Phenomenological design was determined to be the most appropriate for this study as it deals with “lived experiences” and the PI examined the lived experience or perspectives of dementia across four ethnicities in the US.

The significance of this study cannot be overestimated. According to the Administration on Aging (2001), cultural sensitivity is an awareness of how culture shapes another person’s beliefs and worldviews, with not only an acknowledgment that personal differences exist but also a respect for these differences. The healthcare system in the US continues to place emphasis on compliance, detection, treatment, education and management of many disease states, which are often threatened by cultural perception. The extent to which patients will apply health education to their disease states is affected by how culturally relevant they perceive it to be. Thus, the perception of cultural relevance will certainly affect patients’ reception of information provided and willingness to use it appropriately (Euromed, 2011).

Furthermore, this study is highly significant because it laid a foundation for research on defining the concept of dementia and understanding the perception of this disease across and within cultures. According to Campinha-Bacote (1998; 2007), cultural competence is a journey, not a destination, and we must not only recognize differences, but also build on similarities. The expected outcome of this study is to understand the meanings and perceptions of dementia by each represented culture, identify similarities and

differences that may exist between these cultures, and use the information gathered to further research on this rapidly growing disease. Although there have been many studies on culture and healthcare addressing both compliance and cost, there have been fewer studies on perceptions of dementia cross-culturally. One of such studies was a research by the Alzheimer Association in Australia titled “Perceptions of dementia in Ethnic Communities” which included 12 CALD groups. The ethnic groups included in this Australian study were: Arabic-speaking community, Croatian, Chinese, Greek, Italian, Macedonian, Polish, Russian, Serbian, Spanish-speaking community, Turkish, and Vietnamese.

The process of phenomenology is utilized in the study presented in this dissertation. A phenomenological study describes the common meaning of several individuals and their lived experiences of a concept or phenomenon. The focus of a phenomenological study is on describing what all the participants have in common as they experience a phenomenon, in this case, defining or expressing perceptions of dementia and their journey from diagnosis to nursing home admission (Creswell, 2007). The ethnic groups that were included in this study were African Americans, Asians, Caucasians and Hispanics.

Phenomenology has its roots in philosophy and psychology. It was popularized in the 20<sup>th</sup> century by the philosopher Edmund Husserl and was later developed by Heidegger. It broadly deals with understanding the perception of a person or group of persons on the meaning of an event, how they interpret the experience. In this study, phenomenology was used to answer the question: “What is the journey through dementia with your loved one?” or “What is your lived experience with dementia from diagnosis to admission to the nursing home for your loved one?”

As earlier stated, cultural sensitivity is an awareness of how culture shapes another person's beliefs and worldviews, with not only an acknowledgment that personal differences exist but also a respect for these differences (Administration on Aging, 2001).

#### **TERMINOLOGICAL CLARIFICATION**

The terms "Black" / "Blacks" and "African American" / "African Americans" are used interchangeably in this study.

The terms "White" / "Whites" and "Caucasian" / "Caucasians" are used interchangeably in this study.

The words "Latino" / "Latina," "Latinos" / "Latinas" and "Hispanic" / "Hispanics" are used interchangeably in this study.

#### **PLAN OF THE REMAINING CHAPTERS**

Chapter 1 has presented an introduction and background to the phenomenon of interest, "perceptions of dementia across cultures". The research question focused on the similarities and differences of lived experiences of family members of residents diagnosed with dementia who live in nursing homes. The theoretical framework utilized in this study is the process of cultural competence in the delivery of healthcare services by Campinha-Bacote (1991, 1998, 2002, 2011). Chapter 2 will review in depth the literature related to this very important area of study. Chapter 2 will also cover the gaps in the literature, the rationale for the study, synthesis of the literature, and its relationship to the research question and aim of the study. Chapter 3 will cover methodological techniques and strategies used for data gathering and analysis in this study. Chapter 3 will also cover the setting of the study, sample and sampling technique, protection of human subjects, validity

and reliability considerations, explanation of data collection, and identification of limitations. Chapter 4 will discuss in detail the findings of the research. It will also compare similarities and differences between cultures, including similarities and differences within cultures. The final chapter, Chapter 5, will cover the conclusions, discussion and recommendations of the study.



## **Chapter 2: Review of Literature**

### **INTRODUCTION/PREVIEW OF THE CHAPTER**

This literature review will cover the financial impact of dementia on society and the impact of the disease on Americans. It will also cover search strategies utilized in this study, discussions of literature related to cultural differences, definitions of different terms, cultural differences and how they affect healthcare decisions and reception, and where applicable, their consequences for health decisions. It will also cover phenomenology as a research process. This chapter will present the changing demographics of nursing homes, the significance of the changing demographics in nursing homes as they reflect the changing population of the United States, the history of nursing homes, the statistical incidence and prevalence of dementia, a review of literature related to this subject, gaps in the literature, and a summary of the literature.

### **WHY IS UNDERSTANDING CULTURE IMPORTANT?**

Health and illness are often perceived and defined from a cultural perspective. What one culture describes as illness, another culture may view as health or a deserved punishment, karma, spiritual attacks or repercussion, to name a few. Though the concepts of health and illness have an objective interpretation, they also have a strong subjective interpretation that often overrides the objective interpretation on a personal level. Cultural misunderstandings are therefore a common challenge between the nurse and patients that can in the long run affect the outcome of a patient's illness, if the nurse does not address the patient's need in a culturally sensitive manner.

There are many other reasons why understanding culture is important for healthcare providers. By 2050, no single racial or ethnic group will account for a majority of America. By 2043, the US is projected to become a majority-minority nation. Currently, one in four US residents are a member of a minority group, and this number is expected to grow rapidly in the coming years. Between 1980 and 1995, the Asian population grew by about 160%, the Hispanic population by 83%, the Native American population by 57%, the African American population by 24%, and the Caucasian population by only 12% (Pollard & O'Hare, 1999; US Census Bureau, 2012; Cohen, Bloom, Simpson, & Parsons, 1997).

Furthermore, the US census bureau has projected that, by 2050, there will be a decline in the percentage of the total population made up by Whites to about 47%, and increase in the Hispanic from 14% to 29% and Asians from 5% to 9%, with the Black population staying stable at about 13% (The American College of Obstetricians and Gynecologists, 2011; US Census Bureau, 2011; Passel & Cohn, 2008).

Another result of such changing US demographics requiring consideration is that the number of people self-identifying as bicultural is increasing. Being bicultural is not the same as being biracial or multiracial. One out of every four people residing in the US has lived in another country and internalized its culture. Furthermore, US-born descendants of immigrants often identify with both US culture and their ethnic minority culture that has been passed on from one generation to another (Shrestha & Heisler, 2011). According to Benet-Martinez and Haritatos (2005), biculturalism is often associated with feelings of pride, uniqueness and a rich sense of community and history. Unfortunately, however, it also brings with it identity confusion, dual expectations and clashes of values.

Given this demographic picture, it is inevitable that healthcare providers will encounter challenges in understanding and addressing cultural differences during delivery of care. Further, these challenges are likely to become more complex with every generation, especially with the use of the internet and the world becoming a global village. Besides ethnicity, other areas of diversity or cultural difference that are important to understand for effective healthcare delivery include religion, sexual orientation, culture, mental and physical disability, heritage, age, and gender. Other areas that are less recognized today, but which will likely be important in the future are level of education, use of internet to come up with a diagnosis before seeing a healthcare provider, and use of holistic medications such as herbs or vitamins. Also, the advanced healthcare of the United States also makes it a place of international interest for foreigners to come and seek medical care for their illnesses (Campinha-Bacote, 2003).

Cultural differences are inevitable in healthcare. It is important for healthcare providers to take these differences into consideration when providing or delivering care to patients. These cultural differences have given rise to an area of nursing called *Transcultural nursing*. Transcultural nursing focuses on the knowledge and understanding of these differences. It focuses on analysis of cultures and its application to nursing, health-illness practices, beliefs and values (Leininger, 1995).

#### **PURPOSE OF THE STUDY**

The purpose of this study was to explore the lived experiences of family members of residents diagnosed with dementia who live in nursing homes. The study compared the similarities and differences of these perspectives across and within four ethnic groups – African Americans, Asians, Caucasians and Hispanics. It also explored the already existing

literature related to this study which mainly looked at cultural, ethnic and racial perspectives of caregiving in dementia. It is expected that the findings of this study can be expanded upon and influence the delivery of care among nursing home patients to reduce cost, reduce waste, improve compliance, and treat residents with respect and dignity.

### **SIGNIFICANCE OF THE STUDY**

The significance of this study cannot be overestimated. According to the Administration on Aging (2001), cultural sensitivity is an awareness of how culture shapes another person's beliefs and worldviews, both acknowledging that personal differences exist and demonstrating a respect for these differences. The healthcare system in the US continues to place emphasis on compliance, detection, treatment, education and management of many disease states, which are often threatened by cultural perception. The extent to which patients will apply health education to their disease states is affected by how culturally relevant they perceive the teaching to be. Thus, the perception of cultural relevance will certainly affect reception of information provided and the willingness of the patient to use it appropriately (Euromed, 2011).

### **OVERVIEW OF THE PHILOSOPHICAL FOUNDATIONS AND METHODS**

This qualitative study utilized phenomenology. Phenomenology is a qualitative method of conducting research and was first described by Edmond Husserl in the 1800s. Since that time, the concept has grown into multiple schools of thought using qualitative approaches to study phenomena. Merleau-Ponty (1962) identified four qualities that are considered as characteristics common to different schools of phenomenology. These qualities are description, reduction, essences and intentionality. In this section, multiple

definitions of this concept were examined to shed light and understanding on this method of doing research (Kafle, 2011; Merleau-Ponty, 1962).

Phenomenology broadly deals with understanding an individual's or group's perception of the meaning of an event and how they interpret the experience. A phenomenological study describes the common meaning of several individuals and their lived experiences of a concept or phenomenon. It focuses on describing what all the participants have in common as they experience a phenomenon, as in this case, defining or expressing perceptions of dementia (Creswell, 2007). In this study, phenomenology will be applied to answer the questions "What is your experience with dementia with your loved one?" and "Describe your journey through dementia".

According to Lavery (2003), phenomenology is the study of lived experience, and how the phenomenon appears to the consciousness (Moustakas, 1994). It is important to note that phenomenology focuses on ontology – what it means to be (Hawes, 1997). Phenomenology is a research methodology that relies on spoken accounts of personal experience, or transcripts of these, and isolating all these accounts into themes. These themes become written interpretations of lived experience. The PI using phenomenology is required to examine texts and reflect on the content of the texts to discover something that is telling, meaningful, or thematic (Van Manen, 1997).

Van Manen and Adams (2014) summarize phenomenology as:

- Begins with wonder at what gives itself and how something gives itself and can be pursued by surrendering to a state of wonder. Driven by fascination: being swept up in a spell of wonder, a fascination with meaning.

- Questions explore what is given in moments of pre-reflective, pre-predicative experience – experiences as they are lived.
- Aim is to grasp singular aspects, which includes the identity, essence and otherness of a phenomenon.
- The two most critical forms of reduction are epoche (bracketing) and the reduction proper.
- Reflection and analysis occur primarily in the attitude of epoche, the reduction and the vocative. (p. 614)

Phenomenology was used in guiding the PI in the exploration of lived experiences of family members of residents with dementia admitted to the nursing home. According to Van Manen (1997), “the aim of phenomenology is to transform the lived experience into a textual expression of its essence” (p. 36), giving those who listen to and read the reflexive account the opportunity to relive the experience as if it was their own. In summary, phenomenology has the potential to dig deep into the human experience and trace the essence of a phenomenon, to analyze it in its original form as experienced by individuals who are living the phenomenon.

#### **LITERATURE SEARCH STRATEGY**

To explore the cultural differences in the perceptions of dementia, an extensive search of electronic and hardcopy material using the internet and libraries was utilized. Search for articles was done using CINAHL, ProQuest, Cochrane database, Medline, Medscape and sociology databases. Internet searches using Google Scholar™ were also utilized. Electronic libraries such as Research Gate, SCRIBD and Academia.edu were also subscribed to. The key terms used included: *Cultural differences in healthcare, Perceptions*

*of Asians, Perceptions of African Americans, Perceptions of Caucasians, Perceptions of Hispanics, Diversity in healthcare, Cultural differences in dementia, Cultural differences in caregiving, Dementia, Defining dementia across cultures, Cultural awareness theoretical model, Nursing home utilization by race, Minorities and nursing home, Research on nursing home, Minorities in nursing homes, Nursing home utilization, Nursing home residents with dementia, Nursing home admission, Changing demographics of nursing home, Changing demographics of nursing homes, Why do people take their loved ones to nursing homes, Nursing home residents with dementia, Understanding dementia, Cross-cultural views of dementia, Nursing home population, Defining dementia, Dementia beyond the US.*

The research discovered on these topics by using these words either individually or in combination was extensive. There were no time limits on the materials that were used or researched, since culture is a timeless concept.

## **EXPERIENTIAL CONTEXT**

As a Nigerian immigrant, the concept of nursing homes was completely new to me until 2006 when I was sent on an assignment by a nursing agency. This visit opened my eyes to the primary use of nursing homes and the primary diagnosis of residents in nursing homes. I really do not know what I was expecting, but when I heard the word “home,” I assumed that residents were treated as if they were in their homes, but I quickly realized that this was not the case. That experience produced a lasting change in my life and led me to pursuing a degree as a geriatric nurse practitioner. I thought of my aging Nigerian parents in a nursing home in the US. Will they be on a pureed or regular diet, and will they be able to reduce showers to three times a week from their twice a day shower? Will they be able

to eat the food? Will they forget their long-acquired taste of carbohydrates, protein and spice and settle for something more balanced, like more vegetables and fruits, likely to be bland to them? Will they have a weight loss problem and waste resources trying to find the source of the weight loss, like malignancy or dysphagia, when the only problem is food choices? Will they be diagnosed with dementia with behaviors because of these major changes? I also wondered how many times I had also wasted resources without understanding a resident's culture. I had so many unanswered questions about the lack of personalization of care in the nursing home, not only with the diet but even with our plan of care.

I am faced with cultural challenges every day and I realize it is not about being human or reasonable. It cannot be expressed objectively. It is a subjective concept and what sounds like poor quality of life (QOL) to one culture, may very well be the definition of QOL to another. A case in point was a Jewish nursing home resident. Ms. BW had a longtime diagnosis of multiple sclerosis with dementia and had been my patient for about 6 years. Unfortunately, her health progressively declined, and I had very interesting conversations with her husband whenever I visited the facility. In my opinion, we had a very healthy practitioner-patient relationship. We worked through so many hoops and loops of the healthcare system together, including having one of her medications for multiple sclerosis approved by the insurance company. We shared all kinds of stories, and one of the significant ones was when he told me that he had read somewhere that spouses tend to make better decisions at the end of life than adult children. We both wondered why this was the case.



After a couple of years, his spouse started to decline medically, especially with multiple infections requiring hospitalizations, including intensive care unit (ICU) stays. So, I approached him and talked about palliative and hospice care after one of her readmissions in the facility and quickly realized that I had crossed the line. He told me “Jews fight to the end,” and to Jews hospice sounds not like fighting but giving up, and this put a dent on our relationship. He considered my suggestion insensitive and disrespectful. Among many Jews, palliative care and hospice are inconsistent with Jewish teaching against “*giving up on life.*” There is a strong sense in Judaism that life and health should be pursued with great vigor. This idea makes it difficult for some Jewish patients to consider hospice care. Classical Jewish law believes that when a person has a chance to live, even with a reduced “*quality of life,*” aggressive treatment with a proven, reasonable probability of success—called in Hebrew “*refuah bedoka*”—is obligatory unless the treatment itself introduces new medical risks at a level comparable to the disease itself (Popovsky, 2007 p. 21, 23). I soon realized that though my recommendation was appropriate, it reflected a lack of understanding of his culture and was perceived as being totally unacceptable, disrespectful and insensitive. Ms. BW died on an ICU bed two week after I recommended hospice.

## **HISTORY OF NURSING HOMES**

The history of nursing homes in the US dates as far back as the 17<sup>th</sup> century, with the US following an English pattern by establishing institutions for the poor in Philadelphia in 1722, New York City in 1734 and Charleston, South Carolina in 1735. These homes were also described as asylums or almshouses and were designed for elderly people who needed shelter because of incapacity, poverty or family isolation, and they shared the

homes with individuals with mental disorders (Watson, 2012; Zinn, 1999; Foundations Aiding the Elderly [FATE], n. d.; ElderWeb, 2017; Ralston Center, 2017; Haber, 1977).

By the 18<sup>th</sup> and 19<sup>th</sup> centuries, the concept of the homes for the aged poor grew. Churches and women's groups became involved because they were concerned that worthy individuals of their own ethnic or religious background would end up with those from the lowest socio-economic tiers. This led to the establishment of Boston's home for Aged Women in 1850 and Philadelphia's Indigent Widows' and Single Women's Society in 1823 (FATE, n.d.; ElderWeb, 2017; Ralston Center, 2017; Haber, 1977). Furthermore, in the 19<sup>th</sup> century, though it appeared that there was some growth in this concept, records show that in this home in Boston, there were only about 2,598 people in 1910.

In the 20<sup>th</sup> century, these homes had a bad reputation and were generally associated with failure and despair. They were described as places for the poor as well as places that delivered less than standard care for the inhabitants. In the 1930s, as a solution to this the government decided to intervene by providing pensions to the elderly so they could continue to stay in their homes independently. But they were quick to realize that this was not a solution. Advocates like Homer Folks argued that only about 15% of the residents in a home were there for strict financial need, while the majority were there because they were physically infirm, medically sick, and had many other ailments that made them dependent on others for care. This would imply that they required nursing and medical attention in an institution. This argument did not save these homes at the time, and the government was successful in closing many of them (FATE, n.d.; ElderWeb, 2017; Ralston Center, 2017; Haber, 1977).

As the US became a highly industrialized society, this brought with it unique challenges, therefore making the growth of nursing homes in the 20<sup>th</sup> century inevitable. The society noted that aging workers had fewer children to care for them, wages were too low for people to save for their old age, people were living longer, and increased healthcare needs increased the necessity for long-term care facilities. In 1965, the government, through Medicaid and Medicare, became more involved in nursing home funding, and between 1960 and 1976, the number of nursing homes rose by 140%, nursing home beds increased by over 300% and revenue also increased by more than 2,000%. And before long, close to 80% of these homes became a business for many Americans and nursing homes earned many descriptions. Many investigations concluded that these institutions provided substandard and dangerous care that lacked medical care, food and attendants and were labeled “warehouses” for the old and “junkyards” for the dying and halfway houses between society and the cemetery (Doty, 1996; Haber, 2017; FATE, n.d.)

According to the Centers for Disease Control and Prevention (CDC), there are about 15,600 registered nursing homes in the United States, licensed for a total of 1.7 million beds, with about 1.4 million beds occupied (CDC, 2017). In 2015, Texas had the second highest number of nursing homes (after California), with a total of 1,191, representing approximately 8% of the total number of nursing homes in the US (Kaiser Family Foundation, 2017; CDC, 2016). There are 145 licensed nursing homes in Houston metropolis, representing approximately 13% of the total number of nursing homes in Texas (US News and World Report, 2017).

## **CHANGING DEMOGRAPHICS OF NURSING HOMES**

The ethnic demographics of nursing homes has changed over the years and will continue to do so. The CDC estimated that there were about 1.4 million elderly residents living in nursing homes in 1995 and described the population as predominantly women. Most importantly, in terms of ethnic makeup, this population was 89% Whites (representing over 1.2 million people), 8.5% African Americans (representing about 118,000 people), 2.3% Hispanics (representing 32,300) and another group described as “other,” representing 5.6% (about 77,00 people) (Dey, 1997; CDC, 2016). More recent research looking at the changing demographics of nursing home use between 1999 and 2008 found that, in this time, the number of elderly Hispanics and Asians living in US nursing homes grew by 54.9% and 54.1%, respectively; the number of elderly Black residents increased by 10.8%; while the number of White nursing home residents declined by 10.2% (Feng, Fennell, Tyler, Clark, & Mor, 2011).

Feng et al. (2011) reveal that Latinos are utilizing nursing homes at a growing rate. The study summarized that between 1999 and 2008, the number of Hispanics living in nursing homes grew by over 54.9%, while Whites decreased by 10%. It is safe to conclude that because the Hispanic/Latino population is the fastest growing ethnic minority in the US, the study predicts that among all ethnic minority groups, this group is likely to grow most rapidly by 2028 in the utilization of nursing homes at a rate of 3.9% annually. The study concluded that the number of Asians using nursing homes also grew by 54.1%, and though the number of Black residents is growing, it is doing so at a slower pace (Feng et al., 2011).

There are various explanations for these changing demographics in nursing homes. According to the Center for Medicare Advocacy (2015), early nursing home placement was challenged by discrimination among ethnicities. The use of nursing homes may also be attributed to the life expectancy of minority groups. Today, the use of nursing homes has changed with an increase in its use by minority groups and decrease in use by Caucasians. Caucasians are utilizing assisted living facilities and private caregiving in their homes, enabling them to stay in their homes longer compared with their minority counterparts (Center for Medicare Advocacy, 2015).

### **WHY DEMENTIA?**

Dementia is a broad term that simply describes diseases that impair cognitive function. It stands in a class of its own as a number one leading cause of death in the US that cannot be prevented, slowed down or cured. It is a complex disease that affects language, memory, problem solving, and impairs the ability to perform Activities of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL). There are many types of dementia. The most common cause is Alzheimer's, accounting for about 60%–80% of all dementia cases. Other causes include vascular dementia, Dementia with Lewy Body (DLB), mixed dementia, fronto-temporal lobar degeneration (FTLD), Parkinson's disease, Creutzfeldt-Jakob disease, and Normal Pressure Hydrocephalus (NPH) (Guagler, James, Johnson, & Weuve, 2017; ).

There are many reasons why this disease cannot be ignored. One in eight Americans aged older than 65 is diagnosed with Alzheimer's, and an American is diagnosed with the disease every 69 seconds. If nothing is done, by 2050 an American will be diagnosed every 33 seconds. As of 2011, the financial burden of this disease on the State Medicaid and

Federal government was more than \$37 billion for the care of people diagnosed with this disease. Additionally, unpaid caregiver costs were valued at over \$200 billion, and 38 states had estimated unpaid caregiver costs of over \$1 billion each. Healthcare associations and healthcare experts also see this as a medical emergency and have included Alzheimer's disease in the "Healthy People 2020" initiative in the next decade (Gaugler et al., 2016; Alzheimer's Association, 2012).

According to Gaugler et al. (2016), over 5 million Americans suffer from Alzheimer's dementia and the number is likely to rise to greater than 15 million in 2050. It is ranked the sixth leading cause of death in the US, taking more lives than breast and prostate cancer combined. Furthermore, an American develops the disease every 66 seconds and it takes the lives of 1 in 3 seniors in the US. Over 15 million Americans provide free care to people suffering from dementia, with an estimated 18.2 billion hours combined and an estimated value of \$230 billion annually. It is predicted that this cost is likely to rise to \$259 billion in 2017 and to \$1.1 trillion by 2050 (Gaugler et al., 2016).

Alzheimer's dementia was ranked the sixth cause of death in the US in 2013 and 2014, accounting for 5.1% of the total number of deaths in the US (Kenneth, Kochanek, Sherry, Murphy, Xu, & Tejada-Vera, 2016). According to the Alzheimer's Association (2017), it is described as the most under-recognized public health crisis of the 21<sup>st</sup> century. The Alzheimer's Association further concludes that if nothing is done, nursing homes will be overloaded, long-term care workers overworked, healthcare system will be overwhelmed, and the federal and state budget will be over-taxed.

According to Alzheimer Disease International (2015), there were 46.8 million people diagnosed with dementia in 2015, and it is predicted that this figure will rise to

about 131.5 million by 2050. They also estimated the total current cost of dementia at \$818 billion. If dementia were a country, the number of people diagnosed with this disease worldwide will make it the world's 18<sup>th</sup> largest economy.

### **PREVALENCE OF DEMENTIA IN THE US**

According to the Alzheimer Association (2017), currently one in every ten Americans aged 65 or older is diagnosed with dementia; and approximately 200,000 young onset dementia cases (people aged 65 or younger) are diagnosed annually. The Association concludes that the frequency of diagnosis of dementia increases with age. This is also supported by the study by Hebert et al. (2013), which summarizes that less than 4% of those aged 65 years are diagnosed with dementia, 16% of those 65–74years, 44% of those 75–84 years, and 38% of those 85 years and older. It is estimated that by 2050 the population of Americans aged 65 years or older will increase from 44 million to 88 million, which means that there will be a corresponding increase in people diagnosed with this irreversible condition. Many studies that presented the prevalence of the disease concentrated on prevalence by age using two popular studies – the Census and the Chicago Health and Aging Project (CHAP) and the Aging, Demographics, and Memory Study (ADAMS). The Alzheimer Association (2017) states that more women are diagnosed with dementia than men, and this could be because women live longer than men and the chances of dementia increase as age advances.

Some studies have also attempted to address the prevalence of dementia across ethnicities, with non-Hispanic Whites, Hispanics and Blacks being the primary population included. These studies have reached multiple conclusions, primarily that AA are more likely to have dementia than other races (Dilworth-Anderson et al., 2008; Manly &

Mayeux, 2004; Demirovic et al., 2003; Harwood & Ownby, 2000; Perkins et al., 2000). A review of studies by Potter et al. (2009) and Gurland et al. (1999) concluded that AA are twice as likely as their White counterparts to have dementia; and Hispanics one and half times as likely. Another study in California by Mayeda, Glymour, Quesenberry, and Whitmer (2012) also supports these findings on AA. This study, which assessed the electronic medical records of a large health plan in California, showed that prevalence of dementia was highest in African Americans, intermediate in Hispanics and Whites, and lowest among Asian Americans.

The prevalence and incidence of dementia as a growing epidemic in the US makes it important to study the disease.

#### **DEMENTIA IN NURSING HOMES**

Dementia can be described as a worldwide problem, affecting about 47.5 million people, with close to 8 million people diagnosed annually. Alzheimer's dementia makes up 60%–70% of all dementias, affecting seven to eight out of every 10 people with dementia. It is a disabling condition in which one loses one's independence and requires the support of others. It has physical, psychological, social and economic consequences on the caregivers, families and society (WHO, 2017).

It is not clear how many residents in nursing homes are diagnosed with dementia. However, according to multiple sources, more than half of all nursing home residents have a diagnosis of dementia (US Congress, Office of Technology Assessment, 1992; CDC, 2014). This is not debatable, because as the US population continues to age, the number of individuals with dementia is also rapidly growing. Because dementia is a progressive medical condition that is irreversible, individuals with dementia are likely to progress in



their disease to the point of being totally dependent on others for all Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). ADL includes activities such as bathing, dressing, using the toilet, moving independently, and feeding oneself. It is therefore likely that at some point in the disease process, individuals with dementia are likely to transition to a nursing home. IADL includes the following abilities: ability to use a telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for one's own medication, and ability to handle finances (Wiener, Hanley, Clark, & Nostrand, 1990; The Hartford Institute of Geriatric Medicine, 2007; Magaziner, Zimmerman, Fox, & Burns, 1998; Alvarado-Esquivel, Hernández-Alvarado, Tapia-Rodríguez, Guerrero-Itube, Rodríguez-Corral, & Estrada-Martinez, 2004; Reeves et al., 2011).

## **THEORETICAL FRAMEWORK**

Lately, cultural competence has attracted attention in healthcare because of the changing demographics of the US and health disparities in the US healthcare system that arrange themselves on ethnic, racial and cultural lines. Cohen and Goode (1999) argue that cultural competence is important in healthcare to improve quality of services and outcomes; to meet legislative, regulatory, and accreditation mandates; to gain a competitive edge in the market; and to decrease the likelihood of liability and malpractice claims. This study utilized the work of Josepha Campinha-Bacote (1991, 1998, 2002, 2011), "The model of cultural competency."

Nurses have over the years recognized the importance of understanding cultural diversity and they continue to work on delivering culturally sensitive care. According to nursing theorists involved in the concept of cultural-specific care, the desire to provide

appropriate care is based primarily on the knowledge that people belong to different cultures and this affects their expression, demands and needs in terms of health and illness. These differences must be respected, and healthcare provided must strive to be inclusive of this cultural difference. Theorists who have contributed significantly to understanding cultural differences include Leininger (1991), Purnel and Paulanka (1998), Giger and Davidhizer (2004), Campinha-Bacote (2007), and Dayer-Berenson, 2014).

Cultural competence is defined as a “process in which the nurse continuously strives to achieve the ability and availability to effectively work within the cultural context of a client which includes the individual (patient), family and/or community” (Medscape, 2005). The model of cultural competence by Campinha-Bacote (1991, 1998, 2002, 2011) was influenced by the work of other renowned authors in this field, namely Madeleine Leininger (1991, 1995), Arthur Kleinman (1981), Paul Pederson (1999) and Eric Law (n.d.). Campinha-Bacote identified assumptions of her theory as follows:

- Cultural competence is a process, not an event; a journey, not a destination; dynamic not static; and involves the paradox of knowing
- There is more variation within ethnic groups than across ethnic groups
- All encounters are cultural encounters
- Cultural competence is an essential component in providing effective and culturally responsive nursing care to all clients
- There is a direct relationship between the level of competence and the ability to provide culturally responsive healthcare services by healthcare provider
- The process of cultural competence consists of five interrelated constructs: cultural desire, cultural awareness, cultural knowledge, cultural skill, and

cultural encounters; the key pivotal construct is cultural desire. (Campinha-Bacote, 2002, p. 181)

These five interrelated constructs as identified by Campinha-Bacote (2002) are explained as follows:

1. Cultural awareness – this involves in-depth self-examination of one’s cultural and professional background. This step is very important in this study as it makes sure that one’s personal knowledge of the subject does not interfere with data collection or interpretation.
2. Cultural knowledge – this involves seeking and obtaining information on different cultural and ethnic groups.
3. Cultural skill – this involves the nurse’s ability to collect relevant cultural data and using that as a basis for cultural-specific assessment. During the study, the PI took into consideration different cultures and their practices. Asians, for example, accounted for most participants that wanted to be interviewed away from their loved ones, as it was disrespectful to be visiting and talking to someone else at the same time.
4. Cultural encounter – this process is defined as the process that encourages nurses to directly engage in cross-cultural interactions with patients from culturally diverse backgrounds.
5. Cultural desire – Described as the most important construct, it simply means that there is a motivation to be culturally aware and to seek cultural encounters. This process involves the willingness to be open, to accept and respect cultural differences and the willingness to learn from other cultures.

This was the primary goal of the study: to understand that there are cultural differences, and that interventions and communication styles used in managing residents in nursing homes and their families should be based primarily on ethnicity (Campinha-Bacote, 2002, p. 183).

## **REVIEW OF RELEVANT RESEARCH AND SYNTHESIS**

Between 1900 and 2000, the population of those older than 65 in the US increased dramatically from 3.1 million to 35 million (Humes, 2005). In 2012, the population was estimated to be about 43 million (Ortman et al., 2014). It is projected that the population in the US of those aged older than 65 will be about 80 million by 2050, or nearly one out of every five people, with a considerable percentage being immigrants (Ortman et al., 2014). Healthcare providers and others involved in the management of chronic diseases must be prepared for this growth. Dementia is an important disease to discuss because it leads to loss of independent function; has emotional and physical effects on the individual, their family members, and the healthcare system; has negative effects on healthcare costs; and it primarily occurs among elderly people. It is important to understand the cross-cultural perspectives of this disease because we can only effectively address diseases if we understand our patients. It is also important to note that the staggering costs of dementia directly affect social security, Medicare, Medicaid and other health insurance carriers (Plassman et. al., 2007; United States Census Bureau, 2005). The aging of larger numbers of Americans will require significant increases in financial and human resources for healthcare support and other social service to manage this disease (Leutz, 2007).

Culture is defined as the dynamic and multidimensional aspect of an individual's life which includes gender, sexual orientation, profession, tastes, age, socio-economic

status, disability, ethnicity and race (Wells, 2000). Being culturally aware and sensitive to these differences ensures that healthcare of any kind is delivered in the most effective and efficient manner. Cultural awareness and sensitivity can be described as the knowledge and interpersonal skills that allow healthcare providers to understand, appreciate and work effectively with individuals of cultures other than their own, to be accepting of cultural differences, and to have self-awareness, knowledge of a patient's culture, and adaptation of skills (Fleming & Towey, 2001; Wells, 2000, pp. 188–90). Leininger (1988) explained that clinical relevance is recognizing that culture is a holistic concept and it is the missing link in nursing knowledge and practice. It can be acquired through a reactive process of concept explication, reformulation, and synthesis. Galanti (2000) also summarized that there is no doubt that some knowledge of cultural customs can help avoid misunderstandings and enable practitioners to provide better care (O'Connell, Korner, Rickles, & Sias, 2007).

Research shows that many groups in the US tend to be at risk in the healthcare community due to being underserved for many reasons. Such groups include gay and lesbian individuals, individuals with disabilities, people of faith groups unfamiliar to the healthcare provider, people of a low or lower socio-economic class, ethnic minorities such as African Americans and Hispanics, and immigrant groups. One such reason that this study takes into consideration is lack of cultural understanding (American College of Obstetricians and Gynecologists [ACOG], 2013).

It is increasingly important that healthcare providers understand the impact of culture on the perception of health and illness because of the increasing racial and ethnic diversity of the US and the compelling evidence of racial and ethnic health disparities

(American College of Physicians [ACP], 2010). These racial and ethnic differences are the driving forces for incorporating cultural perspectives into healthcare delivery from birth to death. There is extensive evidence that providing culturally specific care reduces waste, increases compliance and increases patient satisfaction. The importance of understanding how culture affects the perception of health and illness is not only good for the patient, but also good practice for the healthcare provider (Smedley, Stith, & Nelson, 2002).

There are many examples of the cultural misunderstandings of many cultures in the US that have led to inappropriate referrals and sometimes undeserved punishment. One common example is the practice of “coining” among Asians (Tan & Mallika, 2011). The process of coining involves rubbing a coin which may or may not be heated or oiled on a patient’s back until welts appear. East Asian medical thinking is that this process draws the illness out of the patient’s body, and the red welts simply indicate that the process was successful. Healthcare providers who are not aware of this old traditional practice simply describe it as physical abuse. Hispanics also practice treatments by “*curanderos*” and “*santeros*.” Such practitioners use massages, herbs, spiritual counseling (called “*facultades*”) and cleanings (called “*lipias*”), lighting of candles for saints, and burning of incense. Hispanics further believe that these items, if needed, should be purchased in a spiritual pharmacy usually called a “*botanica*.” These traditional healers are very popular for the “healing” of stomach pains and cramps, which is referred to as “*empacho*.” They believe that abdominal pain is caused by lumps of food clinging to the wall of the abdomen and that strong massage over the stomach can heal this pain. Though there have been reports of these massages being effective, there have also been reports of their application in cases of more serious abdominal problems such as appendicitis, where the massage has

delayed medical care and usually led to life-threatening conditions (Galarraga, 2007; Galanti, 2000; Juckett, 2005; Tan & Mallika, 2011).

According to Leininger (1995), the role of effective nursing must be transcultural. Transcultural nursing can be defined as

“a substantive area of study and practice focused on comparative cultural care (caring) values, beliefs, and practices of individuals or groups of similar or different cultures with the goal of providing culture-specific and universal nursing care practices in promoting health or well-being or to help people to face unfavorable human conditions, illness, or death in culturally meaningful ways. (Leininger, as cited in Sitzman & Eichelberger, 2011, p. 101)

The importance of transcultural nursing cannot be overemphasized considering the rapidly changing demographics of the US population. Effective nursing must emphasize the understanding, respect, and appreciate the individuality of our patients and the diversity in the beliefs, values and culture that they possess.

According to Schulz et al. (2002), multiple studies exist in the literature on dementia looking at the personal, social, and health impacts of dementia caregiving. There have also been studies on the cultural influence on the diagnosis of dementia. These studies focused on the rate of dementia between ethnic groups in the US comparing rates of dementia among AAs and HIS to rates among Whites (Manly & Mayeux, 2004). Studies related to perceptions/lived experiences of loved ones or caregivers on the journey before, during and after diagnosis of residents who live in the nursing homes are scarce. Studies that do exist in the literature compare two ethnicities, and few compare more ethnicities and are mainly focused on the caregiver burden across these cultures and few on

understanding of the disease across and within cultures. Movies and documentaries have been produced on this irreversible disease as it affects people, affects their relationship with others, and as the disease affects our humanity (Manly & Mayeux, 2004; Schulz et al., 2002; Programs for the Elderly, 2017).

Hillman and Latimer (2017) suggest that there are culturally specific meanings attached to dementia within societies. Summarizing these meanings of dementia are interpreted, embodied, or resisted by people in their social contexts. These processes are shaped by individuals' social location and their individual biography, and dementia itself is a culturally determined phenomena (Hillman and Latimer, 2017, p. 1). This view is supported by Cohen (1998). Cohen (1998) described a before and after effect of acculturation on dementia understanding in India. In this study, the group of people who were studied before acculturation did not see dementia as a disease that needed medical intervention, but their views changed over time with the growth in the number of clinical specialists and geriatricians, global media, and lifestyle interventions directed to the elderly in India.

The Alzheimer Association (2012) compared African Americans, Hispanics and Asians in a study. The Alzheimer Association study described beliefs of each culture on dementia and caregiver role. The study stated that AAs are the largest minority group over the age of 65 in the US, and they are dependent on informal support and spirituality in their journey with dementia. Many AAs attribute dementia symptoms to normal aging and may sometimes not seek healthcare interventions until it is too late. Hispanics are the largest ethnic minority in the US. They have limited knowledge of dementia, limited knowledge of available resources, and high level of burden and stress among caregivers. Hispanics,



attribute dementia to the will of God or punishment for past sins, and the caregiver must bear the cross or *el mal de ojo* (evil eyes) or *nervos* (nerves) or normal aging. The study also revealed that Hispanics may see the disease as a stigma or as odd behaviors resulting from “*bad blood*.” They also sometimes keep it a family secret to avoid public shame and humiliation. The last category that was described in this study were the Asia and Pacific Islanders, described as APIA. This group included Japanese, Chinese, Koreans, Filipinos, South Asians, Pacific Islanders, Southeast Asians, Indonesians and Malaysians. Among this group stigma is a significant problem. Unfortunately, the shame extends to the family and beyond the person diagnosed with dementia. It is proposed that the symptoms are exacerbated by migration and culture shock (Alzheimer Association, 2012; Population Reference Bureau, 2017).

Understanding dementia or any other mental illness is clouded by cultural interpretations or influences. Mahoney, Cloutterbuck, Neary, and Zhan (2005), in a meta-synthesis conducted in Massachusetts, noted similarities and differences among cultural groups. All the cultural groups attributed the memory loss to normal aging and therefore felt it was not a medical condition that should be addressed and only got concerned when symptoms worsened. The authors identified the following differences based on cultural groups: Chinese were particularly concerned about the stigmatization of the disease. Latinos were concerned about acculturation and not stigmatization, with the fear that they would end up having to place their loved ones in an institution rather than home care. African Americans, on the other hand, had no problem with acculturation or stigmatization. They were most concerned about the response of the physicians. They perceived that there was lack of respect from healthcare practitioners on the memory loss of their loved one.

The authors also further explained that caregivers explained the disease in different words. The African Americans described it as “*Old timer’s disease*,” the Latinos as “*el loco*” (meaning “craziness”), and the Chinese as “*hu tu*” (meaning “forgetfulness in old age”).

Kyomen, Suzuki, Llorente, and Hargrave (2013) support the argument that culturally specific views of dementia affect the understanding of the disease and the caregiver burden. The authors concluded that that cultural views affect the etiology of dementia by the family or caregiver, recognition of symptoms and help-seeking behaviors. People who believe that the disease is a normal part of aging, an act of God or sin, or a punishment from God are likely not to seek medical help as they do not believe that it is amenable to medical attention. The authors also found that cultural views may also affect the level of burden that the carers or caregivers of dementia patients carry, and the levels of suffering. The authors concluded that culturally competent approaches to the care of these patients is necessary to help with seeking early interventions of the disease.

Lee, Lee, and Diwan (2009) published a study on Korean immigrants and their perspectives on dementia. The authors found that Korean immigrants had a strong stigma and interpret the disease as a form of insanity. They also considered memory loss and advanced dementia as a normal part of the aging process and lacked serious knowledge about the treatment, diagnosis and cause of advanced dementia. They concluded that there is a need to expand education about dementia to Korean immigrants in the US because of the belief in “stigmatization and normalization.” The authors believe that these perspectives pose a barrier to early detection, recognition and intervention of the disease and that further research should target symptom knowledge of the disease.

A study by Jang, Kim, and Chiriboga (2010) regarding Koreans obtained similar findings to the that by Mahoney et al. (2005) that Koreans believed that there was stigma and shame associated with the diagnosis of dementia in their loved one. Stigma and shame are very powerful barriers in seeking early medical intervention for the disease. Jang et al (2010) found that more than 14% of the study participants were convinced that no matter what they did, the disease would bring shame to their family forever. The authors concluded that greater knowledge of AD was directly related to higher levels of education and acculturation. This was because the feelings of shame were reported at higher percentages by family members with lower levels of education, acculturation and knowledge of AD. They also found that a previous experience with a family member that has had AD also helped with understanding the disease.

Another Study by Jang, Kim, and Chiriboga (2006) concluded that there is a cultural influence on the perception of depressive symptoms. Using data from 230 Korean Americans in Florida, the authors assessed how background variables (demographic information and acculturation), health constraints (chronic conditions and functional disability), and psychosocial factors (sense of mastery and filial satisfaction) were associated with health perception and depressive symptoms and whether health perception mediated the connections between health constraints and depressive symptoms. They conclude that positive perceptions of health and emotional states were higher for individuals with higher levels of acculturation, among other factors.

An extensive study by Alzheimer's Australia Vic (2008) focused on 12 ethnic groups that had migrated to Australia which resulted in the changing demographics of their healthcare system. This study was motivated by the major shift in the demographic profile,

decreasing birth-rates, and increasing ethnic diversity, which in turn were leading to a significant increase in the number of culturally and linguistically diverse (CALD) older Australians. According to the Australian Census Bureau (2008), in 2011 one in five people aged 80 years or over will be from a CALD background, and this number is likely to increase to one in four by 2026. These statistics are a replica of the US population when it comes to the aging of our population from an ethnic perspective. According to the US Census Bureau (1995), by 2050, two in 10 elderly Americans will be non-White and the Hispanic elderly population is expected to rise from 4% to 16%.

Alzheimer's Australia Vic (2008) collected information on perceptions of dementia, diagnosis and treatment, role of the family, attitudes towards community care, residential care and counseling, and role of religion in dementia care. This study included the Arabic-speaking community, Croatians, Chinese, Greek, Italian, Macedonian, Polish, Russian, Serbian, the Spanish-speaking community, Turkish, and Vietnamese (as shown in Table 2.1). Many similarities and differences were identified in this extensive research. Common themes were collated from the study after it was read and reread, among them mental illness, medical condition, normal aging, denial, unexplained causes, primarily negative connotation, perception affected by education, names by ethnicity, karma, and the difference between dementia and Alzheimer.

Italians were alone in their acceptance of dementia (Alzheimer's Australia Vic, 2008). They described dementia simply as a medical condition and, possibly, a mental illness. They did not demonstrate any stigmatization of those who had the disease, but they did not think it was normal aging and did not describe it as a mental illness. They were also the most likely to seek medical help and accept community assistance. The Arabic-

speaking community, Croatians, Chinese, Macedonians, Polish and Serbians were similar in their perceptions. To these ethnic groups, the disease was associated with significant stigmatization, and was described as a mental illness as well as normal aging. Arabic-speaking people evidence extensive denial when it came to the diagnosis of dementia and prayed to God to intervene as they viewed the diagnosis as primarily negative. Spanish-speaking people described it as normal aging. Some ethnicities – Arabic-speaking people, Greeks and Russians also of the thought that the disease was caused by unexplained causes such as stress, psychological problems, post-traumatic stress disorder, worry, depression, and anger. Greek people also saw the disease as having a very negative connotation in their communities, which led to the stigmatization and social isolation.

For some communities, education also played some role (Alzheimer's Australia Vic, 2008). That is, the higher an individual's level of education, the more accepting and/or understanding they were of it, and more willing they would be to accept community assistance. This was noted among the Croatians, Italians and Russians. The Macedonians and Serbians had a strong belief that this was because of some past sin and it was just karma. The Arabic-speaking people, Croatians and Turkish people strongly believe that there is a difference between Alzheimer's and dementia, believing that at the early stage it is referred to as Alzheimer's and in the advanced stages as dementia (Alzheimer's Australia Vic, 2008).

There were many names used ethnically to describe dementia (Alzheimer's Australia Vic, 2008). Arabic-speaking people called it "*kharat*" (meaning "lost one's mind" or "unraveled"), Italians, Macedonians and Polish referred to it as "sclerosis", Russians referred to it as "elderly imbecility," Serbians described is as "crazy" or

“*izhlapeo*” (meaning “evaporated mind”). Also, the Spanish-speaking people referred to people suffering from dementia as “*loco*” (meaning “crazy”), and Turkish people “*bunama*” (meaning “second childhood”). The Croatians, Turkish and Arabic-speaking people, believe that there is a difference between Alzheimer’s and dementia (Australia Alzheimer Association, 2008).

**Table 2.1. Perceptions of Dementia in Ethnic Communities**

<b>Ethnic Community</b>	<b>Perceptions of dementia</b>	<b>Diagnosis and treatment</b>	<b>Role of the family</b>	<b>Attitudes towards community and residential care</b>	<b>Religion and dementia</b>
Arabic-speaking community	Denial Stigma Normal aging but associated with mental illness	Medical care Modern Medicine	Children responsible for parents Nursing Home is a stigma	Gender matching is required Nursing home (NH) as a last resort	Islam – dementia is God’s will Catholics – Religion important for comfort
Croatian	Normal part of aging Dementia not different from forgetfulness Stigma	General practitioner Usually Croatian Modern medicine	Children responsible for parents, particularly females	Prefer female caregivers because they believe they are naturally nurturing NH usage is unacceptable	Predominantly Catholics and some are seventh-day Adventists and Jehovah’s witnesses
Chinese	Multi views – Mental illness Normal aging Social isolation	Prefer Chinese practitioners Diagnosis directly to the patient and family members if available Emphasis is on prevention – healthy eating, physical and mental exercise	Filial piety (Hsiao) Children are expected to take care of their elderly parents	Support groups and planned activities are valued Peer support They welcome community service, preferably in Chinese NH viewed negatively and usually a last resort Open to respite care in the home	Religion does not play a major role in dementia care
Greek	Symptomatic disease Heredity Shock, trauma or worrying about the same thing Stress or environmental factors such as pollution is causing it Negative	Seek diagnosis only when more serious symptoms like wandering starts to occur Does not seek help with memory loss alone Causes fear and denial Receptive to western medications and will sometimes combine with herbs	Second and third generation are losing the ability to speak the language making it difficult to keep family members at home Caring for family members at home is fading away	Will accept assistance for services that support staying at home Use of residential service seen as last resort They believe that the person deteriorates much quicker in a residential setting Spouses are primary care providers	Religion is important to Greeks but they only seek prayers for coping for the person caring for the person with the disease
					<i>Cont.</i>

Ethnic Communities	Perceptions of dementia	Diagnosis and treatment	Role of the family	Attitudes towards community and residential care	Religion and dementia
Italian	Affected by level of education and knowledge of English Seen as a normal part of aging Social isolation is a problem Caregivers feel guilty that the behaviors exhibited may be their fault	They would seek diagnosis later in the disease It is insensitive for healthcare providers to give diagnosis to the patient directly They will seek medical help	It is the primary responsibility of the spouse to take care of the patient	Community is family centered Community help may be sought for the carer instead of the patient Welcome in-home support Residential care not acceptable There is stigma on people that stay in nursing homes	Primarily Catholics Consult the Priest for advice or guidance on difficult family issues
Macedonian	Multiple views: Normal aging Mental illness Punishment for past sins or curse by someone else Seek spiritual guidance Stigma is a problem They also describe it as "sclerosis"	Diagnosed late because of denial of symptoms Prefer diagnosis to be given to family member because there is some fear among some that the patient may lose their will live and give up on possible treatment	Expect children to take care of parents Attitudes change with second generation who may find it difficult to meet this obligation because of work and their own family commitments Primary caregiver is the spouse	Open to community assistance preferably at home care Issues with personal care because it is embarrassing Residential care has a negative connotation and it is not accepted It is completely shameful to place loved one in a residential facility	Religion is separate from other aspects of life including illness and therefore may not play any role in the diagnosis or living with dementia journey
Polish	Memory loss seen as normal aging and more serious symptoms is described as mental illness Social isolation is common High prevalence of post-traumatic stress disorder Disease referred to as "sclerosis"	Late diagnosis because of denial Accept modern medicine Also use herbs, natural medicines and home remedies in conjunction with modern medicine	Family most important support Female members of the family are caregivers	Educated Russians from big cities will accept community assistance while those with less education and less command of English do not They do not want to be placed in residential facility because they believe they will lose their independence, freedom and will deteriorate quicker	Religion has no specific role except for pastoral care
					<i>Cont.</i>



Ethnic Communities	Perceptions of dementia	Diagnosis and treatment	Role of the family	Attitudes towards community and residential care	Religion and dementia
Russian	<p>Attributed to stress, trauma, lifestyle choices and other chronic conditions like high blood pressure</p> <p>To some Russians also a mental illness</p> <p>Also called “elderly imbecility”</p>	<p>Will talk to family doctor, family and close friends</p> <p>Seek delayed diagnosis</p>	<p>Spouse primary caregiver</p> <p>Care primarily by family.</p>	<p>Negative view of residential care</p> <p>Family primary care givers</p> <p>Fear and distrust of accepting community assistance</p> <p>If accepted requires explanation and convincing</p> <p>Services accepted late</p> <p>Fear of loss of independence and freedom prevents acceptance of care</p> <p>Residential care last resort.</p>	<p>No specific role</p> <p>Pastoral care</p>
Serbian	<p>Seen as mental illness and carries a stigma</p> <p>High prevalence of post-traumatic stress disorder, schizophrenia and depression makes it difficult to differentiate the diagnosis of dementia</p> <p>It is described simply as “crazy” and any other explanation appears to be an excuse</p>	<p>Late diagnosis because of stigma</p> <p>Lack of acceptance even when diagnosed</p>	<p>Spouse is the primary caregiver</p>	<p>Home care is accepted</p> <p>Residential care is unacceptable</p>	<p>Orthodox religion is important but no effect on dementia</p>
Spanish-speaking Community	<p>Normal part of aging</p>	<p>Seek medical help first</p>	<p>Family centered</p> <p>Spouse primary carer</p>	<p>Community care is well accepted especially from Spanish-speaking providers</p> <p>Residential care is not accepted: it is considered “end of line care”</p>	<p>Roman Catholic primary religion</p> <p>They believe in prayers</p>
					<i>Cont.</i>

<b>Ethnic Communities</b>	<b>Perceptions of dementia</b>	<b>Diagnosis and treatment</b>	<b>Role of the family</b>	<b>Attitudes towards community and residential care</b>	<b>Religion and dementia</b>
Vietnamese	Normal part of aging and will happen to everyone. Some also believe that excessive thinking and worrying can bring it on. Negatively perceived. Dementia is described as “lost in their mind”	Late diagnosis since it is perceived as normal part of aging. Rely on modern medicine	Family oriented. Children taking care of parents	Accept community care preferably by Vietnamese-speaking people	Primarily Buddhists and believe in karma

Note: Adapted from “Perceptions of Dementia” by The Alzheimer’s Australia Vic, 2008.

## SUMMARY OF LITERATURE REVIEW

The World Health Organization (WHO) (2017) described dementia as a public health priority. Dementia has no respect for boundaries of ethnicity, religion, language, cultural groups or any demographic differences. It does not respect the boundaries of ethnicity or culture and diverse groups adapt to the challenges of dementia uniquely. The attitudes, values, assistance and coping behaviors vary from one individual to another, and variations also exist among diverse ethnocultural groups. The World Health Assembly endorsed an action plan to curb the fast growth of this disease called the “*Global Action Plan on Health Response to Dementia 2017–2025.*” The Global Action Plan is a comprehensive blueprint for increase by international regional and national partners and the WHO in the awareness of the disease; establishing dementia friendly initiatives; reducing the risk of dementia; improving early diagnosis methods; treatment and care of dementia patients; research and innovation; and support for people that care for patients that have dementia (WHO, 2017; Brewer, 2016).

Studies support that culture affects the perceptions of dementia. This chapter outlined research to support the importance of understanding these cultural effects on the perception of the disease. Literature also reviewed in this chapter support that there are changing demographics in the US population and that these changing demographics affect healthcare delivery (from diagnosis to intervention) and successful education. There is a role that culture plays in the perception of dementia and its treatment interventions. Though this chapter is not exhaustive of the cultural perceptions, the review of extant literature supports that culture has a place in the way disease is perceived and managed.

## **Chapter 3: Methodology**

This chapter covers the research design, rationale for the design, and methods applied to this study to answer the research questions put forth in this phenomenological study. A discussion of the study design and associated methods, setting of the study, sample and sampling technique, protection of human subjects, data collection, data analysis and process of trustworthiness and rigor are presented.

### **RESEARCH AIMS AND SIGNIFICANCE OF THE STUDY**

This qualitative study explored the perceptions of dementia by family members of residents of a nursing home in the West-Northwest Houston area of Texas. Four major ethnic groups were included in the study to compare similarities and differences in the perceptions about dementia: African Americans, Asians, Caucasians and Hispanics. The methods and procedures employed in this phenomenology study addressed the following aims: 1) Explore how dementia is perceived differently across cultures; 2) Explore how dementia is perceived similarly across cultures; 3) Explore how dementia is perceived differently within cultures; and 4) Explore how dementia is perceived similarly within specific cultures.

This study is highly significant because it laid the foundation for research on defining the concept of dementia and understanding the perceptions of dementia across cultures, and what is similar within cultures among family members of nursing home residents.

## **STUDY DESIGN AND METHODS**

Strauss and Corbin (1998) defined qualitative research as research that produces findings not involving the use of statistical procedures or any other means of quantifying data. The Qualitative Research Consultants Association (QRCA) (2017) also describes qualitative research as research designed to reveal the behavior and/or perceptions of a target audience using in-depth studies of small groups of people to guide and support the construction of hypotheses. Phenomenology was selected for this study because it involves experiences, beliefs and perceptions. It broadly deals with understanding the perception of a person or group of persons about the meaning of an event and how they interpret the experience. In this study, it was applied in answering the question, “What is your experience or journey with dementia with your loved one?” (Davidsen, 2013).

## **SETTING OF THIS STUDY**

An analysis of census data of 1990, 2000 and 2010 indicates that the Houston region is the most ethnically diverse large metropolitan area in the US (Emerson, Bratter, Howell, Jeanty, & Cline, 2012). These findings made it appropriate to sample family members of residents in the Houston area. The facility chosen for this study is a 200-bed Medicaid-Medicare Facility located in the West-Northwest side of Houston. Its residents are 22% Asians, 20% Caucasians, 23% Hispanics, 28% African Americans, and 7% others. This population mix is reflective of the Houston area and the US (City of Houston Planning and Development Department, 2013, 2017). The PI made attempts to enroll all eligible participants until data saturation and redundancy were reached.

## **SAMPLE AND SAMPLING TECHNIQUE**

Phenomenology is a research method that strives to develop rich description of a phenomenon being investigated. It is therefore important that the selection of participants be purposeful to ensure that the PI selects from participants who are living or have lived the phenomenon under investigation. The PI in this study purposefully selected participants who were on a journey with dementia with their loved one who lived in a nursing home (Van Manen, 1997; Denzin & Lincoln, 2000).

The PI used purposive and snowball sampling techniques to recruit participants. Purposive sampling is choosing participants based on their experience with the study phenomenon. Snowball sampling is a method used with purposive sampling and involves a recruitment technique that uses one participant to assist in identifying other potential study participants. This type of sampling is committed to interviewing people who have lived a phenomenon of interest (Streubert & Carpenter, 2011).

The PI applied appropriateness and adequacy to guide in the sampling procedures. Appropriateness is described as the selection of sample participants who have knowledge or experience of the phenomena of interest and are willing to participate in the study. The intake questionnaire (Appendix B) specifically addressed the question of interest and willingness to participate. Adequacy, on the other hand, is described as the amount of data collected and not the number of subjects included in a study that will develop an appropriate description of the phenomena of interest. Adequacy is closely connected to saturation of the data, which means that no new meanings will emerge from any data collected during additional interviews (Burns & Grove, 2005; Denzin & Lincoln, 1998; Lincoln & Guba, 1985).

## **RECRUITING OF THE SAMPLE**

A purposive sample of 20 participants related to a resident of a 200-bed Medicare-Medicaid nursing home in the West-Northwest side of Houston who has a diagnosis of dementia was recruited for the study. All participants were from one of the ethnicities that were identified as inclusion criteria for the study – African American, Asian, Caucasian or Hispanic. The first step before recruiting the participants (PP) was obtaining approval from the Institutional Review Board (IRB) at the University of Texas Medical Branch (UTMB). After approval was obtained from the IRB, which included a letter from the administrator of the facility approving the use of the facility, recruitment began. Recruitment flyers that described the study and included information on how to contact the PI for inclusion or interest were posted in all approved areas of the nursing home, which included hallways, the front office, and the nursing units. The PI also discussed her dissertation with the nursing staff and requested that they make family members of their residents aware of the study. When the study started with the first participant, the snowball technique of sampling was initiated to recruit other possible participants.

All participants were required to fill out the demographic/intake questionnaire (Appendix B). This intake questionnaire included the purpose of the study and their willingness to participate and assured them that the information they shared would be kept completely confidential (Morse & Richard, 2007; Creswell, 2013). A complete description of the study sample is presented in Chapter 4.

## **PROTECTION OF HUMAN SUBJECTS**

Protection of human subjects was of utmost priority during this study. Approval from the UTMB IRB was obtained. A signed letter of approval from the nursing home administrator permitting the use of the facility for the study was also obtained.

All related study materials were coded to protect the identities of the participants. Codes were formulated using the ethnicity codes (EC) and a three-digit number that starts with 00. EC were AA for African American, AS for Asians, CAU for Caucasians and HIS for Hispanics. Codes were kept confidential and only known to the PI. All signed informed consent (IC) forms and intake questionnaires were locked in a cabinet in the home office of the PI. The recorded data was sent to the Collaborative Institutional Training Initiative (CITI) trained transcriptionist by electronically uploading to a safe website, and interviews were transcribed as PDF password encrypted files.

The study adhered to the elements of a proper IC as identified by Sims and Miracle (2002). These include disclosure of the study, comprehension by the participant, competence of the participant to make a rational decision, and voluntariness.

## **THE ROLE OF THE RESEARCHER IN DATA COLLECTION**

The researcher in this study is both an immigrant with a cultural view of dementia prior to being a nurse and a nurse practitioner in the facility that was used in this study. Being an insider helped to some extent to give the participants trust and confidence to participate in this research: even though their loved ones were not her residents, she was nevertheless a familiar face. This relationship with the facility facilitated a good rapport with the participants in the early stage of the data gathering process and through the entire process. The interviewer ensured that participants did not have their loved one directly



under her care to avoid any bias or unspoken expectations from participants. Only one of the 20 participants included had their loved one under the direct care of the interviewer. This one participant had her interview done outside the facility to avoid distraction and to separate both the participant and the interviewer from a familiar environment. All participants were told that there is no reward for participating in this study, and informed consent forms that included this information were signed by all participants.

## **DATA COLLECTION**

There were two main methods of data collection in this study: interviews and field notes. Interview as a data collection method serves two major purposes in phenomenology: a means of exploring and collecting stories of the lived experiences; and of developing a conversational relationship with the participant (Van Manen, 1997). According to Minichiello, Madison, Hays, Courtney, and St. John (as cited in Ajjawi & Higgs, 2007), interviews also allow participants to share their stories in their own words.

### **Interviews**

Informed consent was obtained prior to starting the interview. Polkinghorn (1989, as cited in Creswell, 2007), suggests that between five and 25 individuals who have experienced the phenomenon of interest should be interviewed. It is the most important data gathering technique in phenomenological studies because interviews explain and put into a larger context what the phenomenon means. Another advantage of interviews is that they require verbal interaction between the interviewer and the participant. Interviews also help to classify and organize an individual's perception of reality (Fetterman, 2010).

Semi-structured interviews (Appendix C) were the primary type of interview method used. According to Creswell (2013), semi-structured interviews are effective for finding answers to specific topics. Semi-structured interview has a set of prepared questions and has been demonstrated to be very effective because it encourages the interviewee/participant to answer questions at length and with vivid details. The study also answered the research questions (see Appendix C). Some of the interview questions that were asked included: 1) Tell me how did you feel when your loved one was starting to show some change in cognitive status? What did you think was going on? 2) Tell me about a time when you knew something was wrong? What did you think was going on when you first noticed these symptoms? 3) Tell me about hearing the news that your loved one has dementia? 4) At what point did you decide that you needed to move your loved one to a nursing home? What changed? 5) What was the driving emotion that was going through your mind when you made that decision? Whose decision was it? What was it like for you? The interview concluded with the open-ended question “Is there anything else you would like to share with me about your loved one and this journey through dementia?”

Data was recorded through digital recorders and intake questionnaires. Other data that are not included in the findings were documented in the PI’s personal journal and field notes. These included interactions or comments before interviews started or information that the participant said they did not want to be recorded. These included emotions like crying or just yelling from one of the participants.

### **Field notes**

There are three types of field notes: the transcript file, personal file, and analytical file. The transcript file contains the raw interview data that is recorded. The personal file

contains the detailed account and their settings. This included information like people present, setting of the interview and research experience. This information has its place in the reconstruction of conversations in the context in which it happened to create a rich text. The analytical file contained a detailed examination of the ideas that emerged in relation to the research questions as the research was progressing. This includes insights and reflections that sometimes will influence the direction of the interview (Minichiello et al., as cited in Ajjawi & Higgs, 2007).

#### **DATA ANALYSIS METHOD**

Van Manen (1990, 1997) suggests that data processing or analysis should be done by uncovering the thematic aspects of the phenomena and it is also used to find emergent themes in a study data, defining theme as a structure of experience. Data was analyzed using the following recommended guidelines based on a dynamic interplay of six research activities for a study of this nature: 1) commitment to an abiding concern/phenomenon of serious interest, 2) oriented stance toward the question, 3) self-reflection 4) investigating the experience as it is lived, 5) describing the phenomenon through writing and rewriting, and 6) consideration of parts and whole (Kafle, 2011, pp. 190–191; Van Manen, 1990, 1997).

During the analysis, the researcher also utilized the method identified by Van Manen (1997) described as the three-level approach in analyzing the transcripts. Van Manen described that the data, in this case the interview transcripts, must be examined using three approaches: 1) read the whole transcript multiple times, 2) reflection, and 3) meaningful narrative text. Van Manen advised that the transcripts must be read and reflected upon multiple times to capture the meaning of the lived experience. The PI did

an immersion of the data by listening to the recorded messages multiple times. A meaningful narrative is presented in Chapters 4 and 5.

### **TRUSTWORTHINESS OF THE STUDY**

Trustworthiness is an important concept in qualitative studies. It answers the question, “Are the findings of the study reliable?” For phenomenologists, the issue of reliability involves interpretive appropriateness, which tries to answer the question, “How can there be an accurate fit between experience and language, between what we know as individuals in our own lives versus how that knowledge can be accurately placed theoretically?” Von Eckartsberg (1998) explains this further:

How is it that we can say what we experience and yet always live more than we can say, so that we could always say more than we in fact do? How can we evaluate the adequacy or inadequacy of our expression in terms of its doing justice to the full lived quality of the experience described? (p.15)

There is no doubt that reliability in this kind of study cannot be subjected to a fixed set of rules based on some predefined scale, as it cannot be separated from the experience and understanding of the researcher. Giorgi (1970) espoused that reliability can only be had through “intersubjective corroboration,” which means that others are able to find their own life and experiences from what the phenomenologist has found in his or her work.

Thus, the chief point to be remembered with this kind of research is not so much whether another position with respect to the original descriptions could be adopted but whether a reader, adopting the same viewpoints as articulated by the researcher, can also see what the researcher saw, whether he agrees or does not agree with it.

That is the key criterion for qualitative research. (as cited in Churchill, Lowery, McNally, & Rao, 1998, p. 81)

According to phenomenologists, the most important thing to apply to a phenomenological study is the “rhetoric.” “Rhetoric” is defined as “the art of speaking and writing effectively” (Kafle, 2011 p. 196). The writing and reporting style in a phenomenology study is important in effectively analyzing the core essences experienced by the participants and this must not be done in everyday language. The study should therefore include formal and informal language, idiographic expressions, adages, verbatim sentences and other such expressions as they are considered appropriate in this kind of study (Kafle, 2011). According to Heidegger, we cannot establish the truth by distancing ourselves from those we want to study. Truth can only come by engagement with the world and subjectivity is as important as objectivity (as cited in Kafle, 2011).

The researcher presented findings in as simple language as possible using the direct words of the respondents when appropriate and available.

### **RIGOR OF THE STUDY**

Rigor in this study was established by using the work of Van Manen (1997). Van Manen enlists orientation, strength, richness and depth as the major quality concerns in the study of this method. Van Manen describes orientation as the involvement of the researcher in the world of the research participants and their stories. The PI is a geriatric nurse practitioner who works in nursing homes and understands the stories of dementia and, as an immigrant, understands that culture plays a role in the perception of the disease. Strength is defined as the convincing capacity of the text to represent the core intention of the

understanding of the inherent meanings as expressed by the research participants and their stories. The researcher will present the findings of this study in rich texts and use transcripts of interviews to identify important themes identified by the participants in the study. Richness is the aesthetic quality of the text that narrates the meanings as perceived by the participants. The PI will include non-verbal meanings, which include silence, emotional outbursts, body language, and other such factors that are observed during the interviews. Depth is the ability of the research text to penetrate down and express the best intentions of the participants (Van Manen, 1997). The written presentation of this study has a primary goal of bringing the readers close to the data and the participants. Multiple quotes taken directly from the participants are presented in Chapter 4 to ensure the authenticity of the study (Kafle, 2011; Van Manen, 1997).

## **SUMMARY**

This chapter covers the methodology used in this study to explore the lived experiences of family members of residents diagnosed with dementia and who live in a nursing home in the Houston area using phenomenological approach. Participants were recruited after approval by the UTMB IRB. The participants were recruited by purposive and snowball sampling techniques. Semi-structured interviews were used for data collection in addition to field notes. Semi-structured interviews provide greater breadth or richness of data compared with structured interviews and allow participants freedom to respond to questions and probes, and to narrate their experiences without being tied down to specific answers (Morse & Field, 1995). A further advantage over unstructured interviews is the ability to compare across interviews because some of the questions are standard (Minichiello et al., 1999). A list of the key questions asked during the interviews

is provided in Appendix C. The study also utilized the work of Van Manen (1997) for establishing rigor and data analysis.

## Chapter 4: Results and Discussion

The purpose of this phenomenological study is to explore the cultural perspectives of dementia across different cultures, comparing four cultures – African Americans (AA), Asians (AS), Caucasians (CAU) and Hispanics (HI). This study utilized interviews with family members of residents diagnosed with dementia and who lived in a nursing home in the West-Northwest side of Houston area. There was no consideration given to length of time in the nursing home when recruiting participants, the only inclusion criterion being that the resident had a diagnosis of dementia. Family members involved in the study could not be court appointed guardians or any other such person, but people who could describe the resident as a loved one.

As described in Chapter 3, the demographic/intake questionnaire and interview data were collected during the interviews with the PI. Interviews were guided by semi-structured questions and lasted between 45 and 60 minutes. All interviews were audio-taped and transcribed by a CITI certified transcriptionist. Transcripts were read and reread by the PI, and the PI was responsible for filling blank spaces. Each interview was coded to protect the identities of each participant. Participants were recruited using purposive and snowball sampling techniques, and 20 participants were included in the results discussed in this chapter. Data analysis utilized the work of Van Manen (1990, 1997).

The presentation of the findings of this study are presented in this chapter, guided by the aims of the study and the research questions. The aims of the study are identified below and the research questions in Appendix C.

Aim 1: Explore how dementia is perceived differently across cultures.

Aim 2: Explore how dementia is perceived similarly across cultures.



Aim 3: Explore how dementia is perceived differently within cultures.

Aim 4: Explore how dementia is perceived similarly within specific cultures.

Ten themes were deduced from the analysis of the interviews. Further reading, re-reading and abstraction helped in classifying and unifying related meanings from these ten themes. Finally, four major themes and seven sub-themes were identified. Figure 4.1 provides a preview of these findings. These are presented in detail in this chapter.

### **DESCRIPTION OF PARTICIPANTS**

A total of 23 respondents were recruited for this study, and 20 of the respondents completed the interviews. There were six African Americans, four Asians (all Koreans), five Caucasians and five Hispanics. According to Cohen, Phillips, and Palos (2001) (as cited in Streubert & Carpenter, 2011, pg. 29), there is great value in including cultural minorities in qualitative research studies. According to these authors, not only is their contribution valuable but it is also mandated by the National Institute of Health (NIH). The Hispanics included in this study were people of Mexican origin because of the possibility of different practices or beliefs that may exist among various Hispanic groups (Juckett, 2013).

Four of the participants in the study were identified as spouses. Two of the spouses were Caucasians and the other two were African Americans. All the participants for the Asians and Hispanics were adult children. Two of the four Asian participants were males and one Hispanic participant was a male. The three other participants for the Caucasians were children while the remaining four for the African Americans were a mix of female children and siblings. These findings are supported by extant literature.

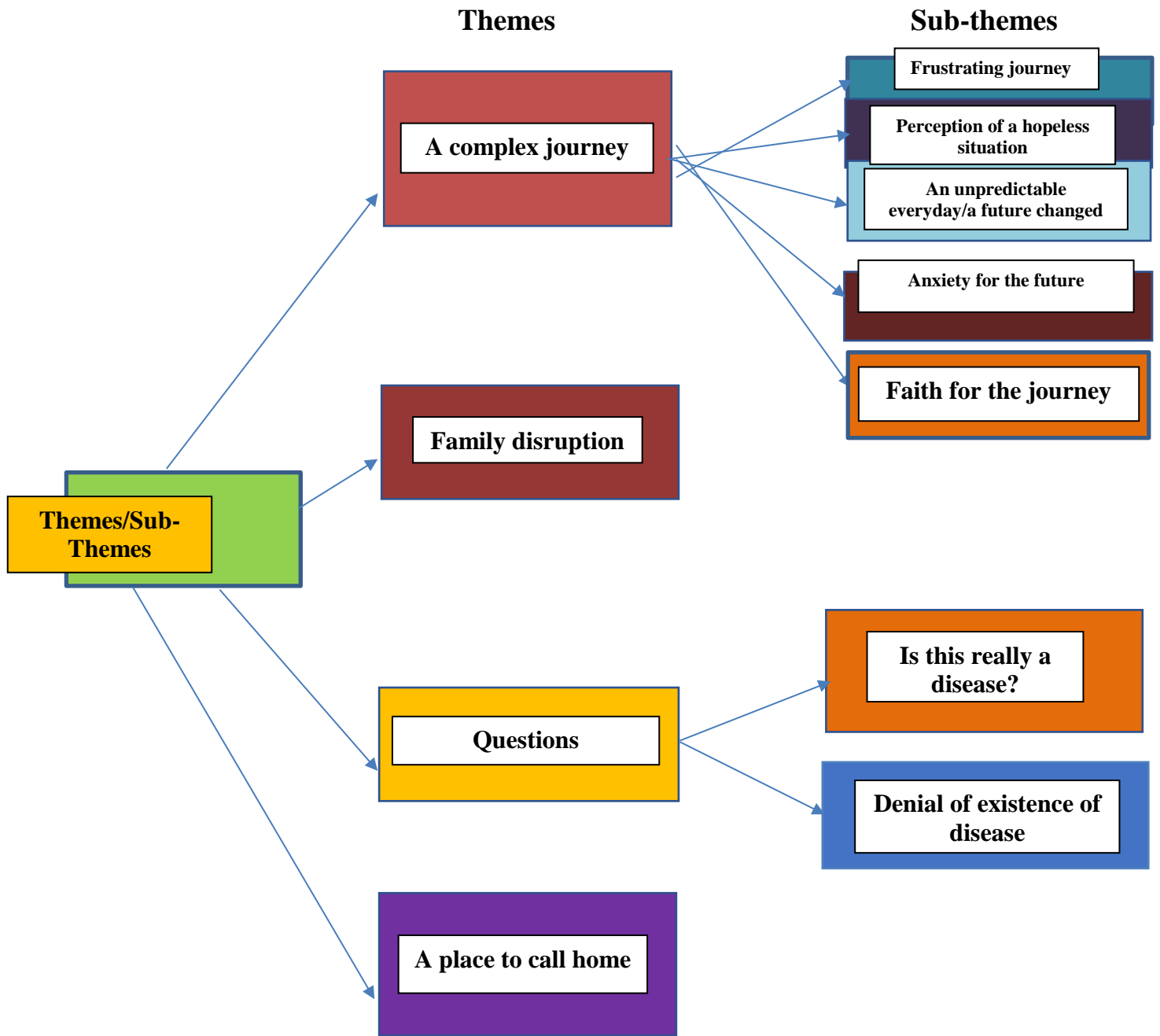


Figure 4.1. Preview of findings.

Pinquart and Sorenson (2004) in their meta-analysis of 116 studies found that 71% of caregivers were women, 46% were adult children and 38% spouses. The study also found that Caucasians were more likely to have spouses as caregivers than minority groups. These findings mirror this study, in which 85% of participants were females and 20% were spouses. However, it does not mirror the percentage of adult children acting as primary caregivers, which for this study was 70%. This study also found that 40% of the Caucasian participants were spouses and 33% of the African American participants were spouses which mirrors the findings of the study. There were no spousal participants for Hispanics and Asians.

#### **SETTING OF THE STUDY**

The researcher allowed the participant to choose a location that was convenient for them but also safe enough for the researcher. The opportunity to select an interview location was granted to the participant during the intake interview to ensure that the researcher could meet the needs of the participant and vice versa. The intake form was administered prior to the interview to ensure that the participant met the inclusion criteria and was willing to participate. The PI made attempts to enroll all eligible participants until data saturation and redundancy were reached.

All the participants had their interviews in the nursing home except one, who chose to have the interview in her home. Eighty percent of the participants chose specifically to do the interview with their loved one present as they felt that the interview would not make any difference to their quality of life, and leaving the side of their loved one would only

take away from their visit time. No participants were under the direct care of the PI as a healthcare practitioner.

## **DATA COLLECTION**

Verbal and written explanations of the study were given to all participants and they were required to sign an informed consent form before participating in the study. The interview started with some initial guiding questions (semi-structured) or core concepts. The PI gave the participant an opportunity to drift away from the primary topic and listened attentively to information given even when it was not in line with the guided questions.

All interviews were audio-taped and transcribed by a professional transcriptionist. Transcripts had to be reviewed by the PI while listening to the recorded interviews to check for accuracy. Study materials were coded to protect the identities of the participants. Codes were formulated using the ethnicity codes and a three-digit number that starts with 00. All signed consent forms and intake questionnaires were locked in a cabinet in the home office of the PI.

All data collected were coded and similar themes were collated together. As part of the data analysis, rigorous interpretation was done by collating themes by ethnicity and then comparing findings to identify similarities and differences among all ethnic groups. The themes and sub-themes identified are presented comprehensively under “Discussion of Findings.” Four themes were identified with seven sub-themes. No further interviews were conducted when similar themes began to re-occur within an ethnic group.

**Table 4.1. General Demographics**

<b>Characteristics</b>	<b>Frequency</b>	<b>Percentage</b>
<b>GENDER OF RESIDENT</b>		
• Male	11	55%
• Female	9	45%
<b>GENDER OF PARTICIPANT</b>		
• MALE	3	15%
• FEMALE	17	85%
<b>AGE</b>		
• 18–29	0	0
• 30–39	3	15%
• 40–49	6	30%
• 50–59	6	30%
• 60–69	3	15%
• 70–79	2	10%
<b>Education Level</b>		
• Less than High school	0	0%
• Some High School	1	5%
• Completed high School	4	20%
• Some College	6	30%
• Completed College	7	35%
• Masters	2	10%
• Post Masters	0	0%
• Other		
<b>RELATIONSHIP</b>		
• Spouse	4	20%
• Daughter	11	55%
• Son	3	15%
• Sibling	2	10%
<b>Ethnicity</b>		
• African American (AA)	6	30%
• Asian (AS)	4	20%
• Caucasians (CAU)	5	25%
• Hispanics (HIS)	5	25%

**Table 4.2. Demographics by Ethnicity**

<b>CHARACTERISTICS</b>	<b>AA</b>	<b>AS</b>	<b>CAU</b>	<b>HIS</b>
<b>GENDER OF RESIDENT</b>				
• Male	4	1	4	0
• Female	2	3	1	5
<b>GENDER OF PARTICIPANT</b>				
• Male	0	2	0	1
• Female	6	2	5	4
<b>Age</b>				
• 18–29	0	0	0	0
• 30–39	2	0	0	1
• 40–49	1	2	1	2
• 50–59	1	2	1	2
• 60–69	2	0	1	0
• 70–79	0	0	2	0
<b>Educational Level</b>				
• Less than High school	0	0	0	0
• Some High School	0	1	0	0
• Completed High School	1	0	1	2
• Some College	2	1	1	2
• Completed College	2	2	1	1
• Masters	0	0	1	0
• Post Masters	1	0	1	0
• Other	0	0	0	0
<b>RELATIONSHIP</b>				
• Spouse	2	0	2	0
• Daughter	2	2	3	4
• Son	0	2	0	1
• Sibling	2	0	0	0

**Table 4.3. Intake Questionnaire**

	<b>When was the loved one diagnosed with dementia?</b>	<b>When did loved one move to the nursing home?</b>	<b>Are you willing to participate in the study?</b>	<b>Are you willing to meet between 1–3 times for this study?</b>
AA001	Not sure	2013	Yes	Yes
AA002	2012	2012	Yes	Yes
AA003	2014	2015	Yes	Yes
AA004	2011	2012	Yes	Yes
AA005	Maybe 5- 6 years ago	2011	Yes	Yes
AA006	2011	2011	Yes	Yes
AS001	Denies dementia	2014	Yes	Yes
AS002	Denies dementia	2012	Yes	Yes
AS003	Denies dementia	2015	Yes	Yes
AS004	Denies dementia	2015	Yes	Yes
CAU001	2012	2013	Yes	Yes
CAU002	2009	2010	Yes	Yes
CAU003	2011	2013	Yes	Yes
CAU004	2013	2013	Yes	Yes
CAU005	2012	2012	Yes	Yes
HIS001	2013	2013	Yes	Yes
HIS002	2015	2015	Yes	Yes
HIS003	2014	2015	Yes	Yes
HIS004	2012	2012	Yes	Yes
HIS005	2011	2011	Yes	Yes

**PRESENTATION OF THE FINDINGS**

The purpose of this study is to understand the lived experience of having a close family member diagnosed with dementia and to culturally define the concept of dementia. Four major themes were identified in the analysis and seven sub-themes after reading and re-reading the transcripts and listening and re-listening to the interviews.

The first theme was “*A complex journey,*” with five sub-themes: 1a) *Frustrating journey,* 1b) *Perception of a hopeless situation,* 1c) *Faith for the journey,* 1d) *An*

*unpredictable everyday/A future changed forever*, and 1e) *Anxiety for the future*. The second theme was identified as “*Family disruption*.” The third theme was “*Questions unanswered*,” and it had two sub-themes: 3a) *Is this really a disease?* and 3b) *Denial of existence of disease*. The fourth theme was “*A place to call home*.” (Themes and sub-themes can be seen in Figure 4.1.) Some of the themes identified show similarities within and across cultures. However, the ones that showed similarities across cultures were perceived differently across cultures.

The themes identified during the study illustrate that there are similarities and differences between and among cultures when it comes to the perception of dementia or journey through dementia. Though the interview followed a semi-structured interview question guide, the participants did not answer questions chronologically or did not answer some questions at all. While analysis will include themes from the interview data, it will also include a tabular presentation for each research question and the similarities and differences among and within cultures based on these questions (Appendix E). It is important to note that names will not be included in these findings because phenomenology focuses on the common elements of a phenomenon and not on individuals.

#### **THEME 1: A COMPLEX JOURNEY**

Theme 1, “*A complex journey*,” represents a barrage of emotions revealed during the interview about the diagnosis of dementia, decisions that had to be made for their loved ones, the changes noticed in the loved one and the adjustments they had to make to accommodate these changes.



### **SUB-THEME 1A: FRUSTRATING JOURNEY**

All participants expressed frustration with the disease at different stages. While some expressed frustration before the diagnosis, others revealed frustration before and after diagnosis. Some participants revealed that the frustration gave them the drive to find help, while some said the frustration kept them from finding help as they were attempting to take care of their loved one at home by themselves. One participant revealed that when he was hearing that his mother was not doing well and was forgetting to come home from work, he was so frustrated because she was all the way in San Francisco and he was in Texas. The participant revealed that when he called her, she sounded like everything was just fine. The participant said that it was when his mother twice missed her flight to Houston that he thought something may be wrong. He went to San Francisco to get her and she was different. The participant summarized his frustrations:

I can't explain whom I saw, but it was not my mom. She had so much junk in her apartment and she looked unkempt. I was screaming and crying at the same time. I asked her repeatedly, 'Mom what is going on?' She said nothing. As I looked through her apartment, I saw so many unpaid bills. I knew something was wrong but I did not know what it was. I was screaming in my brain but thought everyone could hear me. It took the police to assist me in getting her to the airport in San Francisco. And I strongly believed that when she moves to Houston with me, she will be just fine. I was wrong, she was worse—maybe not worse, but worse than I expected. We had the police come to our house three–five times a week because she was calling 911. My wife and I took turns to take care of her but we were not getting anywhere. She got up one day and she said she was going to kill me. She

was out of it. I had to call 911 and it took three policemen to take my mom to the hospital. They took her to a psychiatric hospital. My God, my mom in a psychiatric hospital? It seemed there was no solution. I could touch the frustration that was how tangible it was. I felt for everything I was trying to help her, there was a road block. (AS001)

Causes of frustration varied between the cultures. With one of the participants, she was frustrated that her stepchildren did not want her husband to be transferred to a nursing home even though he was leaving the house at odd hours and he had been returned home by the police once. She said her neighbors had also called the police for her husband because he drove their family car into the neighbor's fence. She said it was a tough decision placing him in a nursing home, not because she did not know that it was the right thing to do but because it was tearing the family apart and there was nothing she could do about it. She said at a point she began to think that her stepchildren were being difficult just to frustrate her. The participant said:

I don't know what my stepchildren need to see happen to their dad. He has hurt himself and hurt others, he has been returned home by the police and they are still resistant to having me placing him in a nursing home, but they don't want to stay with him. He needs 24-hour caregivers that we cannot afford and I can't afford to stay at home. God knows I wish I could but it's not a luxury I can afford. I think they are doing this to frustrate me for marrying their dad. (CAU002)

Another participant expressed her frustration in the process of finding a nursing home for her loved one.

I have never known people being described in so many terms. I had to find my husband a place from the hospital. It was tough. Really tough [shaking her head, shrugged and appeared to have wiped a tear from the corner of her eyes]. I have never felt so rejected. One nursing home did not have a male bed. Another one did not take Medicaid pending. Another one did not take the kind of Medicare we had. One said they had no secure unit. I was losing my mind. I had no clue what all these meant. All I knew was that my husband was not wanted. I was not looking for a secure unit, I was looking for a nursing home. He stayed in the hospital for another two weeks, tied down in restraints and confused as hell (sorry I cussed) just because we had to find a home that would take him. I never knew it was that difficult and pray I don't have to ever go through that again. Of everything I went through this period from the diagnosis to this hospitalization when I was told I could not take him home, finding a place that would accept him was the toughest. No one cared about this man, all they cared about was a requirement in a book that he seemed not to be meeting. I cared about him and he did not have to meet a or any requirement or criteria between me and my three girls. He has met all our criteria and we would take care of him, but he was considered unsafe and has to move into a home. [Crying] (AA002)

Frustration was a journey they live with throughout the process from start to finish, and the frustrations varied on different issues even while they were admitted to the nursing home. They stayed frustrated on weight loss, unavoidable falls, missing personal items, strangers in their loved one's rooms and sometimes beds without sheets. As one participant summarized it,

losing one's mind must be frustrating, maybe that's why my husband has been so mean, this is not like him at all. He has suddenly become so ugly and mean to everyone including me, I will take any disease but not dementia. (CAU003)

Another said,

I think it's harder for her because she had a stroke combined with the dementia which left her unable to talk. And I think with just dementia, which is sad by itself, if you can talk, I think people can at least understand if you're hurting or if you want something, whereas in her case, she can't so it's a combination of the dementia and the stroke which makes it much more difficult for her. And she gets frustrated. (CAU001)

#### **SUB-THEME 1B: PERCEPTION OF HOPELESSNESS**

Hopelessness was an emotion that was shared among the AA and HIS. Both the AA and HIS participants verbalized difficulty finding a place for their loved ones for placement even after they were advised from the hospital that they could no longer take their loved one home. One of the participants even said their case was referred to Adult Protective Services (APS) because they insisted on taking their mother home as it was just hard for them to see her in a nursing home. They said they strongly believed that their mother was going to die if she moved to a nursing home. The participant said that, though they had APS involved in their case, that did not help them find a place. The participant said the case just looked hopeless and everywhere they turned, it seemed like their mother was not going to find a place, and even when she did, it would not be a place they like but a place that would accept her. One of the HIS participants said:

Finding a place for my mom was hard. The social worker gave us a list of nursing homes and asked us to go and see them and select one. I don't know if she was trying to keep us busy or she was really trying to help. If I remember correctly, we went to over half of the places on the list and she must have had about 40 or more on that list in no particular order. [sighing] It's been more than 4 years. We did not know what to look for or what to ask when we go there. It was just a list and we drove from one end of Houston to another and the answer over and over was "No." This was just a horrible situation. No light at the end of the tunnel. We had to go back to the hospital and asked, "What next? Since we can't find a place for our mama." (HIS 004)

They need a cure for dementia. They need to look for something. I mean, there are certain diseases that—and this is just my thinking and it may not be absolutely true—but certain diseases I think, because they are money makers—that they don't find cures for like cancer and dementia. I've had cancer and I've had stage IV cancer and—they—I had cancer 30 years ago and then it came back stage IV 5 years ago. So, in 30 years nobody could find a cure? I mean—and sometimes I know it takes a long time. But people are still dying from cancer every day. (AA005)

It's a terrible, mentally debilitating disease for anybody that has it and for the people that care for them. I mean, for family members it is just—it's devastating. It's very, very devastating and hurting. And then you have to watch them go down to nothing. (AA004)

### **SUB-THEME 1C: FAITH FOR THE JOURNEY**

A trust in God or faith was mentioned by all six AA participants. They described faith as a strong belief or trust in God or higher powers, and He was mentioned by all six AA participants as the source of their being here at this moment. They believed it could only be God that could make any family member go through such a cruel disease. One participant said:

I don't know what would have happened to my brother if he was not a Christian because he lived by himself before we all knew that he had the disease. He could have burnt himself alive or walked onto the road or killed someone else. (AA005)

One of the Asian participants (AS002) also mentioned that his faith has become stronger since his father was diagnosed with "being sick." He did not accept that his father had dementia, but he did say his father has some medical problems that makes people think he has dementia. He identified one of the medical problems as his father's inability to swallow, which led to the placement of a feeding tube. This participant said he was aware of dementia as a disease but denied that his father has it.

My dad does not have dementia. He is a sick man and has been sick for many years. He forgets things and could no longer take care of my mom. He forgot how to eat, they said, and he lost so much weight and he had to end up with a feeding tube. I think that is what is wrong with him. This condition has made me see life very differently. As a Christian, I have decided I am not going to acquire so much. I need the bare minimum and my wife agrees since eventually I will not remember all I have acquired. I am going to go around the US preaching the word of God to people because it gives hope for a future knowing that when you die in Christ you will be

in heaven, and we are all going to die. That is what encourages me to face every day with my dad that someday I will see my dad again, because this man with the tube and the forgetfulness is not my dad, and I am also encouraged that he does not have dementia because that will be devastating. (AS002)

One HIS participant mentioned faith or religion in their interview and stated that one thing that gives me joy is that she can still recite some of her prayers and she twists the rosary in her hands when you give it to her even though she does not know my name or the grandchildren's names. (HIS002)

#### **SUB-THEME 1D: AN UNPREDICTABLE EVERYDAY/A FUTURE CHANGED FOREVER**

The participants expressed that the unpredictable nature of the disease makes it tough to keep your loved one at home with you and makes the journey with the disease more difficult to navigate. All cultural groups in the study described different situations to reveal the unpredictability of the disease. These primarily focused on the period before transferring them to the acute care setting or to the nursing home.

One Asian participant described his mother's behavior as completely erratic and unpredictable. He said he and his wife could hardly predict what each day would have in store for them: while on some days she was extremely aggressive, there were days that were very quiet. He wonders if she was more stressed on her aggressive days or what could be causing it. He said they had to send his mother to the hospital when the behavior started affecting their neighbors.

Another participant described her unpredictable journey as follows:

Well I knew things were starting to go down because she had trouble. She couldn't control the TV, she couldn't use the remote control, she microwaved her glasses

and they melted and so, the whole microwave was smoking and she did actually finally unplug it but, she didn't know how to turn it off. She went from independent living in an apartment to assisted living where she had help with medications and things and from the assisted living, at that point also, she wasn't bathing and so, I had to make—come in and kind of force her to bathe and then get to her where she would let one of the attendants bathe her. And from there, I knew she needed memory care at that point. (CAU003)

Dementia is a terminal condition that affects the life of the patient and the life of the loved ones who support them or are involved in their care. The disease gets progressively worse over time and people who suffer from this disease lose functional and cognitive status. They lose the ability to even remember the names of their loved ones or know who they are. Some who suffer from the disease will begin to call their children “mom,” “dad” or someone else entirely. There is no reversal of this condition with medication or therapy (Ferrell, 2014). It is expected to get worse. For many loved ones this is a tough time and painful emotionally, and this is the new future and one that is not going to change regardless of the intervention. Many participants expressed this in their interviews. Some of the participants said:

He doesn't remember his kids. I mean, he sees them and he sees his grandkids and I think there's somewhere back in the foreparts of his mind he knows that they belong to him. But their name and stuff like that he does not really know. Just lost in his own mind. He even calls me “mom.” (AA005)



I can't physically lift him. I can't—I mean I've had to bathe him and I've had to take care of him but, I can't do it 24 hours and work too. It is just not possible and it's going to get worse. I am old too [laughing]. (CAU005)

Forcefully expressing the difficulty of watching their loved one living with dementia, one participant said, "I'd rather lose my legs. I'd rather lose my legs ... just to let him not have Alzheimer's. Again, I was ready to die. I still am, you know" (AA002).

### **SUB-THEME 1E: ANXIETY FOR THE FUTURE**

Anxiety was an emotion that was expressed by almost all participants, particularly for the future. One of the participants said that she knew her mother was going to end up with dementia because all the women in her family have the disease, but the question that she pondered on every day was, "When? Until it finally happened in 2010, and I thought to myself what am I going to do now?" She is a Caucasian but married to a Hispanic and their goal is to one day move to Panama. So, she has a lot of unanswered questions. What is she going to do with her mother then? How long will she live with the disease? Is she going to suffer? She further stated that,

some of the questions have been answered but I still have so many unanswered questions and will just have to take one day at a time. That is all you can do with this disease. Your mom becomes your child and you must let her live in a place that you would hate to see her live but be thankful that those places exist. It's a roller coaster. (CAU001)

Anxiety was expressed even by the participants who did not believe that their loved ones had a diagnosis of dementia. They wondered how the memory loss will progress and if they will eventually have dementia. One participant said, "My mom is good now. She

can't remember because her memory is bad but she does not have dementia yet. I don't want her to live to have dementia. I scared of that, very scared of that" (AS002). When I asked her what she would expect to see differently between what her mother has now and dementia, she was not able to explain. She just believes she will be worse.

## **THEME 2: FAMILY DISRUPTION/IMPAIRED FAMILY RELATIONSHIPS**

Family disruption was a theme that came up among all ethnicities. Most of the disruption resulted in some temporarily or permanently strained relationships among the children, siblings or spouse and children or stepchildren of the patient diagnosed with dementia. Most were upset with the person who decided to send the resident to the nursing home. A nursing home was not a place all the participants wanted their loved one to end up in. Their preference would rather be to take care of them at home, but it was not feasible in all the cases, primarily because of behaviors and safety. The decision to send the loved one to a nursing home was a mixed decision among all cultures. For some it was the spouse, for some the children and for the Hispanics, Asians and African Americans it was primarily a recommendation by a healthcare provider after hospitalization. Some of the participants had the following to say about family disruption/impaired family relationships:

And that helped for a while but then another situation happened in his life—someone else—his ex-wife came back into his life. And then he didn't want me around anymore and they were trying to, you know. So, I kind of stepped back for a moment but then I realized she wasn't taking care of him. And he was worse, so I told her, "You've got to go. You're not taking care of him." (AA006)

He was alone for two weeks and I didn't know, with no medication and that's when he really started getting really bad. I'm thinking she was still there and she wasn't. And he wouldn't tell me she wasn't, and she didn't really like for me to come around. So, in order for him not to go through issues with her I just kind of talked to him on the phone and stuff. And finally, one day he started telling me that there were people coming in the house and that they were sitting on the couch looking at them. I'm like, no. So, I just went there and found out she wasn't there anymore and started taking care of him. So, he kind of went down really bad. I know that dementia is not totally caused from depression but depression is a big factor in it. (AA005)

...to move her to a nursing home? Well, I was a little bit angry with some [appears to cuss under her breath]—my brothers and sisters because they weren't helping with anything. And with the finances in particular because I thought if we could all pull together, that we could still keep her in a private facility. And so, there was some anger because they didn't and was kind of like it was on me. And I couldn't do it on my own. So that's when I had to look for a Medicaid facility. (CAU001)

Another participant said he had no family problems when his mother started exhibiting memory changes and being the oldest in the Hispanic culture, he had to step in and bring her to his house with his family as she could no longer live alone. Unfortunately, over the years, she progressively got worse and after four years, there was no way he and his wife could keep her in their home anymore because she was totally unsafe, and she once tried to set their house on fire. At that point he made up his mind to place her in a

nursing home. His siblings were so upset and outraged they called him all kinds of names, and this led to a big family divide and dysfunction which persists after three years. The participant said they have two teams in their household: “my team,” which is his family, and “their team,” which is the other six siblings and their families. The participant said that what amazes him is that he has repeatedly asked his siblings to take her to their house if they want to, but they have not done so. Nevertheless, they remain extremely upset that he is not keeping her in his house.

### **THEME 3: QUESTIONS UNANSWERED**

*Questions unanswered* was identified as theme three and it had two sub-themes. Many of the participants had questions unanswered. One of the Caucasian participants had questions related to what would happen to her mother if she had to move out of the US and the disease lingered on. She was not in denial of the nature of the disease, and taking mother with her out of the US was also not an option. She said that, based on her research, she knew that people diagnosed with dementia can live up to 10 years in the condition and just move from one phase of the disease to another. She said she is more anxious wondering what she would do if her mother happened to be one of those in that category.

#### **SUB-THEME 3A: IS THIS REALLY A DISEASE?**

AA described it generally as a horrible cruel disease that steals the life of your loved one and as “*old timers*.” I asked one of the participants (AA003) if she called it *old timers* because it was common in old people, but she said, “No I called it that because I thought that was the name of the disease and I thought it was called that because it was

common in old people.” She said she had no idea how to spell Alzheimer’s, and even when people call the name,

like you just did now [pointing to me], I used to wonder why they are putting a z in it, so I guess I was the wrong person the whole time [interviewee and interviewer both laugh]. I will keep calling it *old timers* anyway, I just can’t pronounce the other word, and everyone knows what I am talking about when I say *old timers*.

Another AA said she thought it was called old timers because, “When you get old you can’t remember” (AA004). AAs and CAUs were consistent in describing it as a disease. One participant said:

Because I did a lot of research on it when my mom first started getting it. It was in the ‘80s. Like ‘85 and nobody could tell us what it was. She was living in another town and I brought her here and sent her to all kinds of medical centers and stuff and they didn’t know at that— Yeah, at that point they thought it was an old person’s disease. And like I said, she was 55 and so they were like, well—they didn’t even think of that. So, we went through a long time—maybe a year with her just being diagnosed with mental illness and depression. And that’s not what it was. It was dementia the whole time. Early onset [crying]. I lost my mom five years before she died so young. (AA006)

I was very familiar with what he was going through. My mom had it and she had it for a long time. She died at a very young age. So, I knew what it was and I kept talking to him about it trying to get him to go and see a doctor. He didn’t because he felt like it was the disease that my mom had and he did not want to face the truth

about it. So eventually—he was still working and he had someone living with him at the time. So, she took care of him until she finally left and then I took over his healthcare and at that point, had to stop working. He was a truck driver. He could not remember how to get to places he'd been to over and over. So eventually they fired him from his job and once they fired him from his job—I said, “You must start seeing somebody about it.” So, I took him to—I looked for a specialist and I found a specialist that does research work on it at the University of Texas Medical Center. (AA002)

I started getting him professional help right after I knew something was wrong with him. Like I said, I took him to the doctor. They prescribed medication for him. Once they knew it was dementia they started prescribing medication. So, he was on Namenda and got that for a while. (AA006)

Other participants simply described it as “Vicious, ugly disease. Vicious, ugly, hateful” (AA002) and “It’s terrible. It’s a terrible disease. And as family—we watch our family just deteriorate” (AA001).

Reflections on the nature of dementia as a specific disease were also frequent:

And we—we fully realized that, you know, and his mother had had it as well. And so, his family was kind of aware, you know, of different things to look for but they, you know, we’ve realized immediately—it was a disease, it wasn’t any kind of they do or kind of curse or the Black thing.... Yeah [laughs]. It’s clearly a disease [inaudible, laughs] no, no. So [sighs] it’s— you don’t have to be in the medical community to recognize that this is a disease process. (CAU002)

No, I guess we more look at it as true disease in that part of the brain and I want to find a way to where it's not going to happen to me. But, you know, it's medical. Look at it, completely medical. Now there is a difference, and I see different cultures because my husband is of a different culture. (CAU001)

Asians generally agree that as you get older you may be forgetful, but this is a normal part of aging, but that dementia is a very serious disease and it is beyond what their loved ones have. However, they are not able to tell me the difference between what their loved ones have now and dementia. One participant said,

My mom does not have dementia, I think its stress that is bothering her. If I had known I would have sent her to Korea long time ago and she would have been okay. I think she is missing her siblings since she is the only one in America, but she can't travel anymore. (AS 004)

Hispanics also described it as somewhat a disease but still with many questions to be answered. It is a sickness, but not like hypertension one of the participants said (HIS 003). Another participant said:

Everything for the disease is not going to cure it and it is not even given to have a hope to cure. Unlike other medications, you give it because you think it will cure a disease and some people will be cured while some others may not benefit from the medication. Dementia is not like that. There is no cure and if you are lucky the medication will slow down how fast only but you will continue to lose a part of yourself. It is crazy, very crazy [putting his fingers to his temples and shaking his head]. (HIS 002)

AA and CAU also believed that it was not just a disease, but that it was highly genetic, passing on from one generation to another. Participants frequently claimed that this had been seen over and over. One participant said, “And we—we fully realized that, you know, and actually his mother had had it as well” (CAU003), while another said,

I already knew. I knew what it was from experience with my mom, my cousin had it, my dad didn’t have it so bad. I mean, he could still remember stuff. He only had it for a short period, he just died in September. So he only had it for a little while before he passed away. But my mom had it at age 55 and lived with it for 5 years. Five horrible years. (AA002)

### **SUB-THEME 3B: DENIAL OF EXISTENCE OF DISEASE**

Denial was common among the four Asian participants. They were in denial that anything was wrong with their loved one: even though they were not acting right and had significant memory problems, they claimed that their problem was either stress-related or just simple aging. One participant explained it this way:

I just feel like she’s getting old. I’m forgetful too, but she’s getting worse. Then when she says something, the word, the same thing over and over, she forgets what she said, then she doesn’t remember what she said before that. She forgets. And she has such short memory. That’s about all. So, she’s good. She’s fine. She [looking at her mother] right now, she [shrugging her shoulders] has a regular routine, she’s pretty good. Other than when she goes to the bathroom, she forgets what to do or what she went there for, but I think that is normal. That’s about it for my mom. She’s not really having any part of dementia —just a memory problem that we all have. (AS003)



Yeah, she's getting older. And also, she's—she conversation. She talks, but she forgets what she says. When you talk to her, she's normal. And then she forgets all that. And that's about it because she remembers it. When you talk to her, she remembers a while back. She remembers peoples' names, all that. She's not really that bad case. I think she's kind of just old and just kind how old people get like this, lose their memories. So that's about it for my mom. (AS001)

Yeah, just slowly. She didn't have like that—some people, like you say, they just go out and they cannot find their way home. It's not like that. She never did that. She lived by herself. She's fine. Just we had problems with her. She can't really take care of herself. This was a really—we bring her here. But that's about it. She didn't have any dementia that was that bad dementia. (AS002)

#### **THEME 4: A PLACE TO CALL HOME**

In 2006, the Houston Public Media interviewed some physicians and nurses who work in nursing homes, asking them to describe nursing homes in their own words. One physician described nursing homes as an institution where people lose their personal identity and must give up their individualism to live in a group setting. Another physician described some of the processes in the nursing homes as “dehumanizing.” One nurse described it in the words of others as “a place you go to die.” Unfortunately, nursing homes leave a bad taste in the mouth of most Americans because of the care they perceive to be provided and the stories that are passed on from one person to another (Houston Public Media, 2006). Staffing ratios in nursing homes, especially those that are described as “Medicaid facilities,” often appear to be providing substandard care that most families want

to avoid for their loved ones. Placing a loved one in a nursing home is a tough and emotional decision for most families, and unfortunately this decision is often made quickly and impromptu. For 90% of the participants in this study, residents were transferred to the hospital and they were deemed not to be able to discharge home anymore with family primarily for safety reasons. Over the years, all participants regardless of ethnicity said they were very grateful for the nursing home and that their loved ones have come to call it home. In the words of one participant:

It was [pause] not a terrible difficult decision to make, but bothersome, how can— how do you live at home? He did not suffer I think and I had to worry about his safety as well as my own and the safety of others and that was, you know, the main thing that we took into consideration was that he needed—he needed to be cared for and it was something that we could not do at home. And we had to keep him safe and he had to be where he could be cared for medically because he refused to take his medication at home. (CAU003)

Another participant said bringing her husband to the nursing home was the toughest part of the journey for her. She is grateful he is here, but that is not enough to help take away the guilt. She described the emotion that was going through her when she decided to bring him to the nursing home as “sadness.” She further said

Yeah. Well, you can't show that to anyone because I'm traveling by bus now. So here—when I'm here [pointing to the restroom and she started crying again], I have my time I can go in there and I can cry but he knows because he'll do this. He has been here 4 years and I still cry.... But I couldn't stand—and the first time I took him to the nursing home—I don't know. I probably got down to about 119 pounds

from 220 pounds in a few months because I couldn't eat. Couldn't eat. I had to watch him. I had to watch him [crying]. (AA002)

## **SUMMARY**

This phenomenological study explored the lived experiences of the journey through dementia of family members of residents admitted to nursing homes. The study compared the views of four ethnic groups – African Americans (AA), Asians (AS), Caucasians (CAU) and Hispanics (HIS) utilizing semi-structured interview questions. The methods described by Max Van Manen (1990, 1997) were applied in analyzing the narratives. This data analysis method revealed four themes and seven sub-themes revealing the experiences and/or emotions during the journey of dementia. The findings may have a role to play for healthcare providers to assist the family members of patients with dementia in finding a place for their loved one to reduce the frustration that people face in finding appropriate placement. Healthcare providers including nurse practitioners, nurses, physician assistants, medical doctors and social workers to name a few must also realize that we must intentionally teach the family members about the disease and the expectations of the disease and its progression. It is important to note that though the journey with dementia started with frustration and was faced with many obstructions, finding nursing homes and the help they receive there was considered a blessing among all cultures. The findings of this study also show that there is a problem in the acceptance of dementia as a disease among some cultures. Though the diagnosis remains a disease that changes the future forever for the patient and the participant, the emotions along the way such as anxiety and frustration, and sometimes the perception of hopelessness which some of the participants expressed, led all their loved ones to a place that they eventually called home. The findings

of this study have answered the research questions that were posed in this study as the study permitted.

## **Chapter Five: Conclusions, Recommendations and future research**

The purpose of this chapter is to present the findings of this study that covered the cultural perceptions of dementia across cultures: a focus on African Americans, Asians, Caucasians and Hispanics. This study utilized semi-structured interviews involving 20 participants. The findings of this study take into consideration extant literature that covers culture and its influence on health decisions for healthcare and caregiving. The interviews carried out in this study support the view that there are culturally specific perceptions of dementia and the journey through dementia, and that these perceptions are more similar within cultures than across cultures. This chapter will also cover a summary of findings, limitations of the study and recommendations for further study.

The review of the literature provided in Chapter 2 reveals that culture plays an important role in healthcare compliance, decisions and management. Diseases like dementia are no exception to cultural influences. Findings from this study revealed that there are cultural differences in the perception of dementia or the journey through dementia for loved ones of patients diagnosed with dementia that live in a nursing home.

This chapter will also cover what is known about cultural perceptions of healthcare, what the study adds, how the findings can be used in practice, and limitations of the study. The interviews with some of the participants will also be used in this chapter to support the findings. The importance of culturally sensitive healthcare cannot be emphasized enough to ensure compliance and benefits to nursing and healthcare intervention. This chapter will also include conclusions about the findings, interpretation of the data collected, recommendations for further study and future research.

The purpose of the current phenomenological study was to explore the lived experience of having a close family member diagnosed with dementia and to culturally define the concept of dementia. The demographics of the population of nursing home residents has changed over the decades. While in the past nursing homes were utilized primarily by Caucasians, today that is not the case. There is a decline in the number of Caucasians that use nursing homes and a rise in the number of minority groups that currently use nursing homes (Feng et al., 2011; Dey, 1997). Ten semi-structured interview questions were utilized in this study. The goal of the semi-structured interview was to elicit responses from the participants that revealed their lived experiences on the study of interest and to frame the findings around the aims of the study. This study revealed the thoughts and perceptions of the participants.

#### **SIGNIFICANCE OF THE STUDY SAMPLE**

Given the current changing demographics of the US, which are predicted to continue to change over the years, studies related to culture and the delivery of healthcare are not only important but inevitable. Gregory Spencer, the chief of the US Census Bureau, summarized the changes in one sentence: the “US is getting bigger, older, and more diverse” (Shrestha & Heisler, 2011, p. 1). The country is getting bigger due to the interplay of increased births by some ethnicities, increased life expectancy and increased immigration. According to the US Census Bureau, there is an increasing population of people aged 65 years and older and an increase in the median age of the country. The country is more diverse because it is simply becoming more racially and ethnically diverse, primarily because of immigration, and this trend is not going to change. Furthermore, dementia has also been listed as the sixth leading cause of death in the US, affecting all

ethnicities (Shrestha & Heisler, 2011). The focus on African American, Asians, Caucasians and Hispanics in this study is a true reflection of the population of the country as these ethnicities represent the four largest ethnic groups in the US. According to the US Census Bureau (2016), the population continues to be more diverse showing the growth between July 1, 2015 and July 1, 2016 by race as most significant (see Table 5.1).

**Table 5.1. Population growth**

<b>Race</b>	<b>Population in millions</b>	<b>Percentage growth from 07/01/2015–07/01/2016</b>
<b>Hispanic</b>	57.5	2
<b>Asian</b>	21.4	3
<b>Native Hawaiian/Hawaiian/ other Pacific Islander</b>	1.5	2.1
<b>American Indian/Alaskan Native</b>	6.7	1.4
<b>Black/African American</b>	46.8	1.2
<b>White</b>	256	0.5

## **SUMMARY OF MAJOR FINDINGS**

The findings of this study are presented under four major themes and seven sub-themes which emerged from the participants’ descriptions of their lived experiences related to dementia before diagnosis, during diagnosis and admission to the nursing home. These themes represent patterns of commonality and differences across and within cultures that the participants of the study group expressed through their interviews. Overall, the findings show that there are emotions that family members of patients diagnosed with dementia go through during their journey with dementia. The major themes are: 1) *A complex journey*, 2) *Family disruption*, 3) *Questions unanswered* and 4) *A place to call home*. In their

narratives, the emotions described by study participants were placed under the major theme *A complex journey*. The emotions were used as the sub-themes and the sub-themes are described as 1a) *Frustrating journey*, 1b) *Perception of hopelessness*, 1c) *An unpredictable everyday*, 1d) *Anxiety for the future* and 1e) *Faith for the journey*. Based on narratives collected during the interview process, though some of these emotions or perceptions were common within and across cultures, the expressions were different across cultures but similar within cultures. What caused frustration in African Americans and Hispanics was similar within the participants of these ethnic groups but differed in Caucasians and Asians. The source of frustration in Asians was similar among all Asian participants, and this is also true for the Caucasian participants. *Hopelessness* was also noted to be similar and common in the AA and HIS groups, while the Asians reported low levels of hopelessness and CAU had no significant narrative supporting hopelessness. *Unpredictable everyday* was common among all the cultures and this reflects the nature of the disease as a disease that affects the behaviors, thoughts and functions of the individuals that are diagnosed with it. Anxiety for the future was also an emotion that was common among all cultures but the reason for the anxiety once again varied across cultures.

*Family disruption* was noted to be common among all cultures through the narratives collected. The way this was expressed was also similar within cultures and different across cultures. AA generally saw this as a family member missing though alive. One Caucasian participant (CAU002) expressed problems with her stepchildren. One Hispanic participant, HIS001, expressed that they have had family disruption with “one team against the other team” since he decided to place his mother in a care home. He expressed that the decision to place his mother in the NH was medically motivated when



his mom's dementia became worse, especially with her behaviors compromising safety in his house. He said that though he offered his other siblings the opportunity to house her in their homes if they had a problem with him transferring her to the NH, they declined. He said it has been four years and they still cannot bridge their differences. The Asians expressed no family disruption.

*Questions unanswered* was another major theme identified in reading and re-reading narratives and this theme had two sub-themes: 3a) *Is this really a disease?* and 3b) *Denial of a disease*. Caucasians and African Americans both agree that dementia is a medical condition. The Asians believe that it is a disease, but they describe it as being very serious and they denied that any of their loved ones truly had dementia. They were frustrated that their loved ones were diagnosed with dementia when in their opinions what they really had was memory impairment with behavioral impairments and the inability to live independently anymore. The Hispanics believed that dementia was somewhat a medical condition but said it was different from hypertension or cancer.

*A place to call home* was the last theme that was identified in the study. Caucasians and Asians had similar experiences in picking this NH as home for their loved ones, while the HIS and AA participants did not have any choice. AA and HIS participants agreed in their narratives that they were in this NH because that was the only place that would accept their loved ones. All cultures agreed that their loved ones being in a NH is helpful and they have come to see it as home.

Next, findings are compared to extant literature when available and appropriate for the primary purpose of finding a place in the literature for this study and identifying room for further studies for this phenomenon of interest.

## **DISCUSSION OF FINDINGS IN CONTEXT AND IN RELATIONSHIP TO EXTANT LITERATURE**

### **A COMPLEX JOURNEY**

*A complex journey* was identified as theme 1 with five sub-themes: *Frustrating journey*, *Perception of hopelessness*, *Faith for the journey*, *An unpredictable everyday/A future changed forever*, and *Anxiety for the future*.

New experiences can be complex, especially for terminal diseases like dementia. The participants in this study revealed through their narratives different challenges, emotions and decisions that had to be made before and after diagnosis of this life-changing diagnosis. Thompson (2015) described the complexities of dementia in four phases – pre-diagnosis, diagnosis, living with dementia and end of life and after death. According to Thompson, at the pre-diagnosis stage complexities include recognizing changes, comorbidities, and reducing risk factors. At the diagnosis stage, complexities include fear/stigma, comorbidities, different symptoms and types. Living with dementia is described as the most complex stage and this includes changes in function and behavior, changes in capacity, and impact of the disease on family and friends. The final stage includes decisions such as palliative care. The author also described the care of the patient and all the multiple levels of care and interventions that may be needed as “complexity within a complex system.” This system involves the movement of the patient with dementia through all the levels of healthcare, which include hospital, community care and care homes. The system also involves the number of providers that may be involved in the care of this patient including but not limited to general practitioners, neurologists, physical therapists, occupational therapists, speech pathologists, social workers, psychiatrists, dieticians and psychologists. The system also described supplies that may be needed, such

as oxygen, specialty beds, mobility aids such as walkers and wheel chairs, and incontinence supplies. The description of the complexities involved with dementia revealed by Thompson supports the complexities that the participants in this study revealed.

### **THE JOURNEY IS FRUSTRATING**

This sub-theme includes the perception of frustration among all races. One thing that was similar was that the participants all expressed frustration during or after the diagnosis of this disease. African Americans and Hispanics were most frustrated with the process of finding placement for their loved ones. They faced challenges that they did not know existed with finding placement when their loved ones were deemed to no longer be able to live in a regular home setting primarily because of safety. AA001 said it was so frustrating and upsetting, particularly with respect to how their loved ones were described. She said “they were described with anything but their names. They used their gender, disease process, behaviors and income to describe them.” The participant gave examples, saying that when they were rejected they heard answers such as “we don’t have a male bed,” “we don’t have a secure unit for his behaviors,” “we don’t take Social Security Income (SSI) pending,” or “we don’t take Medicaid pending.” This gave rise to the perception that the summary was “we just don’t want your husband,” and they “felt a sense of rejection and it’s a bad feeling.”

The Asians were frustrated with the way the diagnosis of dementia was thrown around as the explanation of their loved one’s symptoms. Though all the participants agreed that their loved ones had memory issues and could no longer live independently, they did not believe they had dementia, but considered that the behavior they were demonstrating was a normal expression of processes of aging. One of the Asian participants

(AS001), though he had to go to San Francisco to get his mother who had extensive and progressive memory issues and required the assistance of the police to get her to the airport, still believed that her diagnosis should be memory loss only, and it was not serious enough to be described as dementia. This same participant described his work through memory loss (dementia) with his mother as frustrating.

The feeling of frustration in all cultures, regardless of the reason that is leading or led to frustration, has already been identified in the extant literature, emphasizing that this is a feeling that is present in primary caregivers particularly and can sometimes be the reason why loved ones seek placement in the long-term care for their loved ones. Research shows that because of the severe multiple or health conditions and functional limitations among the elderly patients, they are likely to go from one level of care to another, including but not limited to emergency rooms and long-term care facilities, and as a result they are more vulnerable to fragmented care and “falling through the cracks” (Coleman, 2003). Rich, Lipson, Libersky, and Parchman (2012) stated that frustration is inevitable and evident, and the burden placed on the loved ones and family members of these frail elderly is enormous. They further concluded that even professionals who consider themselves experts in healthcare delivery find it hard to navigate the healthcare system (Rich et al., 2012; Thompson, 2015).

#### **PERCEPTION OF HOPELESSNESS**

A study by Hirsch, Visser, and Jeglic (2011) supports the emotion of hopelessness in a difficult diagnosis. In their study they compared Blacks and Whites, and discovered that while hope was a significant moderator for Whites, hopelessness operated as the main buffer for Blacks. They concluded that hope and hopelessness differ based on ethnicity.

Sub-theme 1b, *Perception of hopelessness*, was particularly evident in the African Americans and Hispanics. Respondents of these two cultures seemed to have the fear that when their loved ones are admitted to the nursing home, that is the beginning of their dying process. Their expectations of nursing home care were very low and distrustful. However, because the focus of the research was not on their nursing home care, this concern was not pursued. They also felt that it was a hopeless situation when they were trying to find their loved ones' placements, and they encountered multiple roadblocks in finding a place. Among the AA and HIS, the current nursing home where they placed their loved one was not a nursing home of choice but a nursing home that agreed to accept them. While some of them have come to accept it and to be thankful for the place, some of them still wished their loved ones were in a different facility. The Asians did not share this same feeling of hopelessness. They said their primary concern was finding a place that understood their culture: there are facilities in the Houston area that cater to their culture through meals and activities, one of which is the one in which this study was conducted. They all selected this one because of proximity to their home or work. They could not recollect any difficulty in finding a place.

Caucasians were more prepared about the disease. All except one chose to bring their loved one to the nursing home, with the single exception believing she could take care of her husband at home by herself. When she realized she could not, she decided to find an appropriate place for him. Though it was a difficult situation, as she felt she was betraying him or her behavior would look like she was not standing by her husband through sickness and health, she realized it was in their best interest. She summarized her thought thus:

I could not take care of him at home anymore. I am just as old, and he needs help with everything and after knee surgeries and joint pain, you just can't help anyone anymore. But you know when you make that commitment in sickness and in health, which I did about 50 years ago, you want to make sure you are not violating that promise because I did not make that commitment lightly and he is a good man, was a good husband and dad. (CAU003)

However, she was quick to say that she knew it was the right thing to do and did not see it as a hopeless situation since nursing homes are designed to take care of people with these kinds of diagnosis.

#### **FAITH FOR THE JOURNEY**

*Faith for the journey* is a sub-theme under *A complex journey*. This is just a belief in something or someone spiritual and greater than oneself, that there is something supernatural about our existence. All six AA participants talked about the role of God in making the diagnosis and journey bearable. Meng, McLaughlin, Pariera, and Murphy (2016) concluded that AA respondents showed a higher sense of religious belief and religious activity in handling illness and a higher sense of distrust in medical professionals when compared to Caucasians.

One Asian participant (AS002) had an extensive view about spirituality when it came to memory loss. This Asian male claimed, when considering dementia and a person's future, that the best thing anyone could do to prepare for this unfortunate end is to serve Christ when they can and serve him well. He further said he and his wife have decided to be local missionaries after this experience with his father. He said that though his father does not have dementia yet (even though his doctor says he does), he is on the way since

he now has a peg tube for feeding and he does not talk to them much. He said seeing his father going through the journey has made him more grounded in his walk with Jesus and enabled him to make some serious decisions concerning his future, since this may also be his end. One Hispanic mentioned her mother still using her rosary.

Caucasians and the majority of the Hispanics and Asians did not reflect on faith or spirituality in any way during this research. According to Mclaughlin and Braun (2008), many African Americans participate in a culture of family and church and the church being an important support system. This supports the fact that all AA participants referred to religion or their faith in the journey through dementia.

#### **A FUTURE CHANGED FOREVER**

Sub-theme 1d identified in this study was *A future changed forever*. According to Chenoweth et al. (2009), the progressive deterioration in cognition, function and behavior in dementia patients creates increased dependency. The needs that arise from the progression of the disease can become increasingly difficult for the caregivers to meet, leading to need-driven dementia compromised behaviors. These behaviors include but are not limited to disturbance of sleep-wake cycle, screaming, and crying. These behaviors lead to the placement of patients in residential facilities (Chenoweth et al., 2009). One of the Caucasian participants asked rhetorically during the interview,

Have you ever thought of someone being dead and alive at the same time? That is what happened to my husband. He is dead now because this is not him. He does not talk to me anymore. He talked to me just yesterday. He does not laugh anymore, he laughed yesterday. He shuffles instead of walks and sometimes even crawls, he walked yesterday. Everything happened so suddenly. I lost a little of him a day at a

time and every time I came to visit, I did not know which version I was going to get. He is dead because this is not him. (CAU001)

All participants expressed changes in their loved one that will never be reversed. For the Asians, memory loss was the emphasis. One of the Asian participants (AS003) said:

Little by little, every day the memory gets worse, maybe one day it will no longer be there. She doesn't ask me for my brother anymore. He lives in San Francisco. When I talk about him, she does not look like she remembers him. Do you think she remembers him or she has forgotten him? She calls me her sister or mother, what does that mean? (AS004)

One of the AA participants said:

My brother loved his family. Loved them so much. It's unbelievable he does not love us anymore. You ask after someone if you love them. You remember their birthdays and anniversaries. He does not even remember his own birthday. All that is gone forever. He was the family lover, showing everyone love on birthdays, anniversaries and family reunions. He is gone forever, this person you all met is just a patient or resident as you all call them. He is a chart and he is documented on. He did the documenting and he did it in a loving way. It's all gone [shrugging and quiet for a few minutes]. Sometimes I want to shake him and get him back, but I know that won't do anything. I have to get used to my new brother. (AA003)

One the Hispanic participants described her mother as a wonderful mother and said:

But somehow the wonderful and happy future she deserves has been stolen away from her. She cannot enjoy her grandchildren, they are scared of her and scared of



where she lives. They don't want to come and visit her in the nursing homes. They are afraid of the nursing home. (HIS 005)

### **ANXIETY FOR THE FUTURE**

*Anxiety for the future* is sub-theme 1e identified in the study. Two renowned long-term care experts Drs. Rosalie and Robert Kane, in a whitepaper prepared for the US department of Health and Human Services by Rich et al. (2012), stated that despite their experience in geriatrics and long-term care, "it is technically complex, emotionally taxing, there is not much help out there, and panic is the normal reaction. If Rosalie and I can't do it, what chance does the average person have?"

Anxiety was a common theme among all cultures. One common question regardless of culture centered around how long their loved one would have to live like this. One of the Caucasians (CAU001) was anxious about her mother outliving her resources, which is likely to make life difficult. She was also concerned about what would happen to her mother if she decided to relocate out of the US. She said she has plans of retiring to Panama with her spouse when she retires as a school teacher and it will be difficult for her to do that if her mother is still alive. One AA participant (AA002) was concerned about her husband going to the hospital and the facility refusing to take him back, and her having to go through the ordeal of looking for a place again. One HIS (HIS003) participant was concerned about her mother suddenly dying in the nursing home because she has had so many falls and skin tears and she receives a call for each incident. She said, "anytime I see the phone number to the nursing home, I get scared and wonder if one day I will be told my mom just passed away." The Asians had some anxiety about when their loved one would finally be diagnosed with dementia. When they were told that they had already been

diagnosed, they claimed that they believed it was a wrong diagnosis and all they have is memory loss. When they were asked what they think would be different when they are diagnosed with dementia, they could not tell say what they expected or what would be different.

## **FAMILY DISRUPTION**

*Family disruption* was identified as theme 2 when analyzing the interview data that was collected. The AA described a separation from their family members as family disruption. One AA summarized it in this way: “family reunion will never be the same, my brother can’t be there. Even if I took him there, he is not present. Our family will never be the same again” (AA006). One of the Caucasians talked about disruption with her siblings:

my mom has no memory to know what is going on, but my brother has not come to see her since she has been here, and he has no plans of coming. At first, he said he was upset I had transferred her to a nursing home, but he did not want to keep her either and now I wonder what his reason is. She has been living here for 5 years. He has not mailed her a Christmas or birthday card, he has not come to see her even during the holidays. This is his loss. (CAU005)

One other Caucasian participant described the difficulty that her stepchildren were giving her with the decision to transfer her husband to the nursing home.

They can’t keep him, and I can’t either. He needs 24-hour supervision. It’s not a luxury I can afford, and he does not have millions. The bills keep coming and they have to be paid somehow so I must keep working. I can’t afford the luxury of a full-time caregiver financially. I can afford it emotionally, but we will both be homeless. His children did not talk to me for years after I moved him to a nursing home, but

they are fine now. They come and see their dad, he does not know it, but I know he likes his kids so much, I am glad they do that. (CAU002)

### **QUESTIONS UNANSWERED**

*Questions unanswered* was identified as theme 3 in this study, and it had two sub-themes, sub-theme 3a, *Is this really a disease?* and sub-theme 3b, *Denial of existence of disease*. Sub-themes 3a and 3b are interrelated and were clustered into the theme *Questions unanswered*.

According to Kleinman (1981), it is important to obtain the explanation of an illness from the patient or their families, referring to this as the patient's explanatory model (EM). According to Kleinman, applying EM to the conceptualization of illness will shed light on how the illness is understood, recognized or interpreted by the patient or family members. Kleinman further states that illnesses can be understood from popular beliefs, folks and professional perspectives. When providers understand the views of the patient and/or family member, the care that will be delivered is likely be more effective and efficient.

Downs, Claire, and McKenzie (2006) in their research on applying EM, concluded that dementia is explained by family members or patients as normal aging, as a spiritual experience, as a neuropsychiatric condition, and as a dialectical process. Research supports the varying explanations of the disease by the participants of this phenomenological study. Caucasians and AA in the study describe it as a disease process, Asians described it as simply normal aging processes, and the Hispanics, though they thought it was a disease, felt that there were still many unanswered questions in thoroughly explaining the disease.

All the Asians in the study denied the existence of the diagnosis of dementia for their loved ones. They agreed that their loved ones had cognitive problems, but they did

not think they should be diagnosed with dementia. This denial is supported by the work of Lee, Lee, and Diwan (2009), on Korean immigrants. They concluded that memory loss and advanced dementia are a normal part of the aging process and lacked serious knowledge on the treatment, diagnosis and prognosis. They also described the disease as insanity and found that acculturation affected the views of dementia in Korean immigrants.

#### **A PLACE TO CALL HOME**

This was the last of the four themes identified in this study. All ethnicities revealed during the study that their loved ones have come to accept the nursing home as home. Some of the family members of the residents with dementia still struggled with this fact that this is home for their loved ones. Among the Asians and Caucasians, the acceptance of home was more prevalent because they all had an opportunity to pick the nursing home of their choice either based on proximity to their homes or the cultural attention they pay to their family members. The nursing home in this study has an established Asian program that provides meals and activities acceptable to their culture. Unfortunately for most of the AA and HIS in the study, this nursing home was not their choice, and their loved ones are there because that was the only place that will accept them when they were looking for placements for them. The reasons for this lack of choice centered primarily around economic status and behavioral problems. However, over the years, they have gradually come to see the nursing home as home for their loved ones.

A study by Mahoney et al. (2005) revealed that Latinos were most concerned about having to put their loved ones in a nursing home when diagnosed with dementia. Chinese people are concerned about stigmatization, which may be the reason for the denial of the disease. The findings of the study also support the descriptions found by the participants in

this study. In the study by Mahoney et al. (2005), African Americans described it as “*Old timer’s disease*,” which was also consistent with the description by AA in this study.

## CONCLUSIONS

The phenomenon of interest in this dissertation was the lived experience of having a close family member diagnosed with dementia living in a nursing home and to culturally define the concept of dementia. Semi-structured questions used in this study covered the journey before or at diagnosis, after diagnosis, and living in a nursing home. Four themes and seven sub-themes from the semi-structured interviews were identified. The themes identified are a representation of the patterns of common experiences about the perspectives of dementia that members of the study group revealed. Most of the themes revealed were experienced differently by ethnicity. Not all identified themes were similar across all races.

Banks, Banks, and McGee (1989) described culture as the values, symbols, interpretations, and perspectives that distinguish one group of people from another in modernized societies. Culture is not material objects and other tangible aspects of human societies. People within a culture usually interpret the meaning of symbols, artifacts, and behaviors in the same or in similar ways. These practices differentiate a group of people from another group, and include the following characteristics: ethnicity, language, religion and spiritual beliefs, gender, socio-economic class, age, sexual orientation, geographic region, group history, education, upbringing and life experience. Furthermore, culture is described as dynamic and evolving, learned and passed on from generation to generation, shared among those who agree on the way they name and understand reality, identified symbolically (for example through music or dress), and integrated into all aspects of any

individual's life (Banks, Banks, & McGee, 1989; Nova Scotia Department of Health, Primary Health Care Section, 2005). With this definition, it is expected that there will be differences in the perceptions of health, diagnosis, description or understanding of certain disease processes and decision-making related to some (if not all) diseases, and these variations among cultures are likely not to change, since culture is passed on from one generation to another. These studies support the differences in cultural perceptions of illness/disease.

There are extensive studies on different aspects of culture as it affects healthcare decisions or approaches. These studies are based on differences in language, race/ethnicity, level of education, religion, gender differences and orientation, sexual orientation, socio-economic status, professions, tastes, age and disability (ACOG, 2013). The findings of this study reveal that there are differences among cultures/ethnicities in the US in the perception of the lived experiences on the journey through dementia. This study revealed that while some themes may be common among all cultures in the study, the way it is perceived was similar among all members of the same culture and different across cultures.

Healthcare providers are faced with the challenge of understanding these cultures to provide effective and efficient care that is likely to change the lives of our patients. Nurses can be compared to teachers in the cultural challenges they have to conquer to make teaching happen. Teachers are only effective when their students learn regardless of their cultural differences. Nurses and other healthcare providers are only effective if we can improve the quality of life (QOL) of our residents in their illnesses regardless of their cultural background. Healthcare providers must see all patients as unique. According to Galanti (2000), "Knowledge of cultural customs can help avoid misunderstanding and

enable practitioners to provide better care” (p. 1). To emphasize this point, Galanti stated that while medical science in the US enables physicians to predict when patients may die, the Hmongs, regardless of their length of time in the US, strongly believe that only God knows when a person will die, and the only way a physician could possibly be able to tell is if the physician planned to kill the patient. Galanti also further stated that while American healthcare emphasizes the autonomy of patient’s right to know, this belief or attitude is not appreciated but frowned on by many other cultures in the US, such as Filipinos, Mexicans, Chinese and Iranians, where the emphasis is on telling family members first and they will in turn present the information to the patient in an appropriate manner. It would not be unusual for members of these ethnic groups to see the healthcare provider as insensitive when they break the news directly to the patient (Galanti, 2000).

Two landmark studies by the Institute of Medicine (IOM), *Crossing the quality chasm* (2001) and *Unequal treatment* (2003), are partly responsible for the emphasis on cultural competence (CC) and patient centered care (PCC) as being important in healthcare delivery. *Crossing the quality chasm* (2001) identified PCC as one of the six aims for high quality care, with the others being safety, effectiveness, timeliness, efficiency and equitableness. The other study, *Unequal treatment*, identified PCC as important for healthcare providers to avoid ethnic healthcare disparities. Culturally competent care refers to nursing care that is sensitive to issues regarding culture, race, gender, and sexual orientation, while cultural competence is the process of the nurse striving to achieve the ability to effectively work within the cultural context of an individual, family, or community from a diverse cultural/ethnic background (Euromed, 2011; Smedley et al., 2003; IOM, 2001, Betancourt, Green, Carrillo & Park, 2005).

This study was based on the theory of cultural competence by Campinha-Bacote (2002) that emphasizes cultural competence in the delivery of healthcare services. Because the onus falls on the healthcare provider to be culturally sensitive, every healthcare provider must be equipped to provide this kind of care. Campinha-Bacote (2002) defines CC as the ongoing process in which the healthcare provider continuously strives to achieve the ability to effectively work within the cultural context of the individual family or community (p. 181). According to Campinha-Bacote, this ongoing process for healthcare providers involves the integration of cultural desire, cultural awareness, cultural knowledge, cultural skill and cultural encounters. Cultural encounters cannot be avoided by many healthcare providers as the demographic of our patients will generally mirror the demographics of the US. This study revealed that differences exist among different cultures/ethnicities on their perception of care, thereby affecting their expectations and acceptance of healthcare advise.

#### **STRENGTHS AND LIMITATIONS**

Large numbers of elderly Americans continue to seek long-term care in nursing homes, and over the years the demographics of the population represented in them have changed significantly, from predominantly Caucasians to other ethnicities. The primary diagnosis for seeking admission to nursing homes is primarily dementia, accounting for more than 50% of nursing home admissions, and every ethnic group is now represented in nursing homes (CDC, 2016). There are currently limited studies exploring the lived experience of having a close family member diagnosed with dementia (from diagnosis to placement in an institution) and to culturally define the concept of dementia when compared to the financial and societal impact of the disease. This study focused on four



ethnicities—African Americans, Asians, Caucasians and Hispanics. This is identified as a strength of this study, as many studies compare two cultures, usually Blacks and Whites, and compare caregiving similarities and differences among cultures. Studies that cover the journey from home to the nursing home are few, and this study laid a foundation for further research in this area. Findings of this study conclude that perceptions of dementia are somewhat different across these cultures and more similar within the cultures.

Limitations of this study were related to the number of respondents included in the study and the restriction to one facility in the Houston area. The study was also limited by time: though the researcher had enough time, the participants did not have as much time to dedicate to the study and multiple meetings were not welcoming. One other significant limitation was the number of males included in the study. Only three males were included in this study, compared to 17 females.

### **IMPLICATIONS OF THE STUDY**

Future studies must also include what healthcare providers need to do to acquire the skills needed to provide culturally sensitive care and inclusion of cultural studies in healthcare curriculum at all levels. This supports the application of the theory of Campinha-Bacote for this study, which lays emphasis on the healthcare providers being CC and not on our patients. All levels of study should include CC as a core part of their curriculum. Healthcare providers must act like teachers and lawyers, teaching, defending and impacting lives regardless of cultural differences in an effective manner. Healthcare providers must consistently be aware of their biases and take inventory of their own cultural beliefs when caring for patients.

## **RECOMMENDATIONS FOR FURTHER RESEARCH**

More studies need to be done to explore perceptions of dementia among different cultures and perceptions of nursing home use. Further studies exploring expectations of nursing home, end of life choices and expectations, and providing culturally sensitive care are beneficial to long-term care and to the society in general. These recommendations for further study on these identified topics is because of responses and knowledge acquired during this study, and they are likely to reduce the financial burden of this fast-growing disease.

## **SUMMARY**

Findings from this study and those reported in the literature support that differences and similarities do exist across and within cultures in the perception of disease acceptance and treatment. The changing demographics of the US makes this a current urgency for healthcare providers to understand and deliver care in a culturally sensitive manner. A landmark study by the Institute of Medicine [IOM] (2003), *“Unequal treatment: Confronting racial and ethnic disparities in healthcare,”* shows evidence that bias, prejudice, and stereotyping on the part of healthcare providers may contribute to differences in care. These studies were a surprise to most healthcare providers. The studies found that education may be the most important intervention to eliminate these disparities and provide culturally sensitive care. The researchers in these landmark studies further concluded that cross-cultural education programs be provided for healthcare providers. This program can be divided into three conceptual approaches: 1) focus on attitudes and awareness, 2) multicultural approach focusing on knowledge, and 3) skills needed to

deliver this knowledge. Essentially understanding other cultures and delivering culturally sensitive care is not only beneficial to nursing but to the entire healthcare industry.

## **Appendix A: Research consent form**

### **RESEARCH CONSENT FORM**

You are being asked to participate as a subject in the research project entitled, Cross-Cultural View of Dementia, under the direction of Abiola E. Williams, RN, MSN, GNP-BC, PhD-C

#### **PURPOSE OF THE STUDY**

The purpose of this study is to understand the way different cultures see or understand dementia. You are being asked to participate because your family member has been diagnosed with dementia and they live in Spring Branch Transitional Care in Houston, TX.

#### **PROCEDURES RELATED ONLY TO THE RESEARCH**

The procedures related only to research include three interview sessions where you will be asked a set of semi-structured interview questions about your experiences related to having a family member diagnosed with dementia.

#### **PROCEDURES NOT RELATED TO THIS RESEARCH (i.e., standard of care)**

No procedures related to this research will be done that are not part of this research.

#### **RISKS OF PARTICIPATION**

The only potential risk from participation in the study is the risk of losing confidentiality that may arise from the information collected.

#### **NUMBER OF SUBJECTS PARTICIPATING AND THE DURATION OF YOUR PARTICIPATION**

The anticipated number of subjects involved in the study will be 6–10 subjects from each of four different cultures/ethnicities. There are no participants from UTMB in this study. Participants will have a family member admitted to Spring Branch Transitional Care Center in Houston who have been diagnosed with dementia.

#### **BENEFITS TO THE SUBJECT**

There is no benefit for participating in this study.

#### **BENEFITS TO SOCIETY**

This study will add to the knowledge of dementia across culture that already exists in literature.

#### **OTHER CHOICES (ALTERNATIVE TREATMENT)**

There is no alternative treatment or choices involved in this study. Your participation in the study is voluntary. The alternative is not to participate in the study

#### **SAFE WITHDRAWAL FROM THE STUDY**

There is no consequence for withdrawing from this study. You may choose to withdraw from the study at any time.

### **REIMBURSEMENT FOR EXPENSES**

There will be no reimbursement for participation in this study.

### **COMPENSATION FOR RESEARCH RELATED INJURY**

You will be responsible for paying any costs related to illnesses and medical events not associated

with being in this study. There are no plans to provide other forms of compensation.

However,

you are not waiving any of your legal rights by participating in this study. Questions about compensation may be directed to the principal investigator Abiola E. Williams, RN, MSN,

GNP-

BC, PhD-C

### **COSTS OF PARTICIPATION**

This study has no cost of participation.

### **USE AND DISCLOSURE OF YOUR HEALTH INFORMATION**

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provide safeguards for privacy, security, and authorized access of your records. These regulations require UTMB to obtain an authorization from you for the use and disclosure of your health information. By signing this consent form, you are authorizing the use and disclosure of your health information related to the research study. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB). For records disclosed outside of UTMB, you will be assigned a unique code number. The key to the code will be kept in a locked file in Abiola Williams, RN, MSN, GNP-BC, PhD-C home office.

As part of the study, Abiola Williams, RN, MSN, GNP-BC, PhD-C will report the results of your study to her PhD dissertation committee at UTMB School of Nursing.

If you sign this form, you are giving us permission to collect, use and share your health information. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. We cannot do the research if we cannot collect, use and share your health information. Whether or not you agree to the research project or give us permission to collect, use or share your health information will not affect the care you will be given at UTMB.

Your records may be reviewed in order to meet federal or state regulations. Reviewers may include, for example, the Food and Drug Administration, UTMB, and UTMB IRB. This

authorization for the use and disclosure of your health information as described above expires upon the conclusion of the research study except for FDA regulated studies. For FDA regulated studies, the study sponsor and government agencies, such as the FDA may review your records after the study ends.

If you change your mind later and do not want us to collect or share your health information, you need to contact the researcher listed on this consent form by telephone. You need to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it. The results of this study may be published in scientific journals without identifying you by name.

### **ADDITIONAL INFORMATION**

1. If you have any questions, concerns or complaints before, during or after the research study, or if you need to report a research related injury or adverse reaction (bad side effect), you should immediately contact Abiola Williams RN, MSN, GNP-BC, PhD-C at 713-253-1549 or, if after normal office hours, at 713-253-1549 or Dr. Carol Wiggs, my faculty advisor at 409-772-9284.
2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If there are significant new findings or we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.
3. If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information, you may contact the Institutional Review Board Office, at (409) 266-9475.

The purpose of this research study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by

notifying Abiola Williams at 713-253-1549. You will be given a copy of the consent form you have signed.

Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.

_____ Signature of Subject	_____ Date
_____	_____
_____	_____
_____	_____

_____ Date	_____ Signature of Person Obtaining Consent
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## Appendix B: Intake/Demographic Questionnaire

### Demographic Questionnaire

Internal Audit Number \_\_\_\_\_

Date of first encounter \_\_\_\_\_

Date of Second Encounter \_\_\_\_\_

Date of third encounter \_\_\_\_\_

Date of any other encounter \_\_\_\_\_

Name (initials only) \_\_\_\_\_

Facility \_\_\_\_\_

Gender of resident Male/Female

Gender of participant male / Female

Age of participant \_\_\_\_\_

Ethnicity Caucasian African American Hispanic Asian

Relationship to resident Spouse Daughter Son Other \_\_\_\_\_

When was resident Diagnosed with dementia \_\_\_\_\_

\_\_\_\_\_

When did your loved one move to the Nursing Home \_\_\_\_\_

Are you willing to participate in this study Yes No

Are you willing to meet about three times for this study at your convenience?

\_\_\_\_\_



## Appendix C: Semi- Structured Interview Questions

### Semi-Structured Interview Questions

How would you describe dementia, what do you understand this disease to be?

When was your loved one first diagnosed with dementia?

Prior to this diagnosis, did you observe any symptoms with memory or activities of daily living (like feeding herself/himself, incontinence, skipping meals, hoarding, forgetting to call you, not picking up her phone, not paying bills, etc.)

What has any healthcare provider told you about the disease?

What are you expecting life to be like in the next five years for your loved one with this disease? Do you think he/she will get better or get worse?

Do you believe this disease is reversible or progressive?

When did you move him/her to the nursing home? \_\_\_\_\_

What prompted you to move your loved one to the nursing home?

Among your ethnic group, how do you describe this disease?

Concluding questions?

Is there anything else you will like to share with me about your loved one and this journey through dementia?

## **Appendix D: Recruitment Flyer**

# **RECRUITMENT FLYER!!**

**ARE YOU INTERESTED IN SHARING YOUR PERCEPTIONS OF  
DEMENTIA?**

**Looking for volunteers to participate in a research study on cross**

**Cultural perceptions of dementia**

**Sharing your experiences is very valuable to providing care to people diagnosed  
with dementia.**

**You are eligible if your loved one lives in this Nursing Home**

**THERE IS NO COMPENSATION FOR PARTICIPATION**

**Please contact Abiola Williams (Abby), RN, MSN, P (Nursing PhD student)**

**aewillia@utmb.edu or 713-253-1549**

**\*\*Please share this information with other family members that may be interested in  
participating in this research study\*\***

## Appendix E: Interview findings by research questions

### Research Question 1

Research questions	Cultural findings
<p>Tell me how did you feel? What did you think about what was going on?</p>	<p><b><u>African Americans</u></b> – 2 of the participants said it was anger because history was repeating itself as they had family members that had it in the past. Blamed it on genes. 3 of the participants started with denial and eventually woke up to the new life that this was not going to go away because they were praying or because they were in denial. All AA participants said they knew it was dementia.</p> <p><b><u>Asians</u></b> - Denial by all Asians. They simply described it as aging and the loss of memory with behaviors was an expectation. They were not surprised or angry because it was an expectation in old age to lose one’s memory.</p> <p><b><u>Caucasians</u></b>- all participants knew what it was and it was not a shock to any of them. They struggled with the future. One of the participant was a spouse and she knew her husband may likely end up in the nursing home because he may become too hard for her to take care of him at home and she said that was the toughest part for her – planning for the future.</p> <p><b><u>Hispanics</u></b> –knew it was dementia. They said they were primarily frustrated because they did not want it to happen to any of their loved ones. Two of the participants said they struggled with denial but that emotion was not long lived.</p>

## Research Question 2

<b>Research Questions</b>	<b>Cultural findings</b>
<p>Tell me about a time when you knew something was wrong? What did you think was going on when you first noticed these symptoms?</p>	<p><b><u>African Americans</u></b> – varying stories of when the found out but they all agreed they knew something was wrong when they noticed their loved one with memory loss and bizarre behaviors. They all knew that it was dementia.</p> <p><b><u>Asians</u></b> – there was no clear timeline or description of symptoms as memory loss was considered a normal part of aging. They all agree when they first noticed the change they all knew that it was an aging problem and not dementia</p> <p><b><u>Caucasians</u></b> – they all knew their loved ones had dementia when they noticed memory changes thought their stories varied. One of the participants said at first, they thought it was side effect to a medication, but they soon realized that it was dementia. They all associated it to some familiarization with the disease based on a family member having it.</p> <p><b><u>Hispanics</u></b>- they all knew something was wrong when they noticed memory and behavior changes. They knew that it was dementia and they expect this comes naturally with aging. They were frustrated and had a lot of family disruption and impairment following the diagnosis.</p>

### Research Question 3

Research Questions	Cultural findings
<p>Did you talk to anyone about what was going on? Or did you try to figure this out by yourself by looking up resources like internet? Did this help you? How?</p>	<p><b><u>African Americans</u></b> – they talked to other family members and church members. Only one of the participants tried to find resources online. All participants sought medical help and guidance</p> <p><b><u>Asians</u></b> – they did not talk to anyone because of the stigma associated with the disease. It was hard to see their loved ones having memory loss and not making sense all the time. It was hard enough for the family and they did not need to share it with anyone else. They did not look for resources online because they were certain that it was part of aging.</p> <p><b><u>Caucasians</u></b> – they talked to family members. They looked for resources online to help with progression of the disease and what to plan for as the disease progresses. During the interview one of the participants asked what to expect next with the disease if everything goes the way it is going. They asked “shat stage of dementia is he at now?”</p> <p><b><u>Hispanics</u></b> – they talked to family and they did not look for online resources because they believe they know enough about the disease.</p>

**Research Question 4**

<b>Research Questions</b>	<b>Cultural findings</b>
<p>Tell me at what point did you think you needed professional help? What kind of professional help did you seek first (religious? Medical?)</p>	<p><b><u>African Americans</u></b> – All agreed that they needed professional help as soon as symptoms were noticed. They all took their loved one to a neurologist or their PCP. All AA also spoke to church members not particularly to get professional help but spiritual encouragement for the journey.</p> <p><b><u>Asians</u></b> - did not seek medical help when symptoms started because they were part of aging but as the memory impairment worsened with behavioral changes, they all ended up in the acute care setting.</p> <p><b><u>Caucasians</u></b> – all Caucasians sought medical help. They all took their loved one to their PCP or neurologists. These professional interventions happened as soon as they noted memory changes and felt that their loved ones have dementia.</p> <p><b><u>Hispanics</u></b> - they did not seek medical help by going to their PCP or neurologist. Their loved one ended up in the acute care setting for complications related to dementia like dehydration, falls with injuries aggressive behaviors and were then transferred to the Nursing home.</p>

### Research Question 5

<b>Research Questions</b>	<b>Cultural findings</b>
Tell me about hearing the news that your loved one had dementia?	<p><b><u>African Americans</u></b> – it was a feeling of history repeating itself and anxiety for the future. They expressed frustration and hopelessness transitioning from the acute care setting to the nursing home.</p> <p><b><u>Asians</u></b> – All participants deny that their loved one has dementia and still insist that they don't have dementia. The news was therefore irrelevant and unnecessary.</p> <p><b><u>Caucasians</u></b> – There was an expectation. Some expressed they had some anxiety planning for the future</p> <p><b><u>Hispanics</u></b> – they expressed disappointment, shock, hopelessness and in some cases frustration, making the transition from the hospital to a nursing home.</p>

## Research Question 6

Research Questions	Cultural findings
<p>Has any healthcare provider formally told you about this disease? If yes what have they told you?</p>	<p><b><u>African Americans</u></b> – All but one reported no formal discussion of dementia with any healthcare provider except the diagnosis. One of the participants reported a formal discussion on the disease and what to expect with multiple healthcare providers. The participant revealed that she was told that it is a terminal disease with no hope of improvement and there will be loss of functional status and loss of dependence as the disease progresses. The participants that had no formal discussion also knew that it was a terminal disease with no hope of cure but did not really know what to expect from day to day but have lived a difference in the behavior and memory of their loved ones from day to day.</p> <p><b><u>Asians</u></b> - all reported no formal discussion with a health provider. One participant said he vaguely remembers a conversation, but he was not interested or could not tell me what it was about because that was not his dad’s diagnosis.</p> <p><b><u>Caucasians</u></b> – all the participants reported that there was formal discussion about the disease with a healthcare provider. They all described it as a terminal condition with no cure and behavior, memory and functional status is likely to deteriorate over time. They also knew that they are usually involved in a lot of falls and other injuries because of their poor safety awareness. Four of the five participants said they wished their loved ones would not linger with the disease because they are aware that you can live with dementia for many years</p> <p><b><u>Hispanics</u></b> all reported no formal discussion with any healthcare provider related to the diagnosis of dementia. They understand that it is a terminal disease and there is no cure. They are not prepared for any worsening functional status that there loved one is already suffering.</p>



## Research Question 7

Research Questions	Cultural findings
<p>At what point, did you decide that you needed to move your loved one to a Nursing Home? What changed? What was the driving emotion that was going through your mind when you made that decision? Whose decision, was it? What was this like for you?</p>	<p><b><u>African Americans</u></b> – All the participants there loved one was moved to the nursing home when they became a danger to themselves and could no longer live by themselves. All were transferred from the hospital during and acute stay for either behavioral or medical problems. Frustration was a primary emotion because there were lots of challenges involved in finding a home that will accept their loved one. According to all participants, it was the decision of the healthcare provider in the hospital who deemed that the residents could no longer be discharged home except they had 24hour care giving. One of the participants reported that she already knew her brother could not be home but it was difficult just walking to a nursing home to be admitted if you don't have any money so she went through the police, who then took him to a behavioral hospital and he was then discharged to a nursing home.</p> <p><b><u>Asians</u></b> – they were all transferred from the hospital to the nursing home because their memory was getting old and they were forgetful. They all said they were sad but they knew it was the right thing to do for their loved ones.</p> <p><b><u>Caucasians</u></b> – two of the five participants said their loved one transferred here from a setting that could no longer meet the needs of their loved one as they progressed in the disease. They all stated the safety of their loved one as the primary reason for transferring them to the nursing home. One of the participant reported that the mother was getting low in funds to continue to stay in a private memory care facility and that was what brought them to this nursing home because they accepted Medicaid and it was also close to her house</p> <p><b><u>Hispanics</u></b> – one of the participants reported safety concerns was the driving singular force that prompted him to bring his home to a nursing home after she was stabilized in the hospital. The other participants said though they knew their loved ones were no longer safe to live at home without 24hour supervision but they had not reached a point of acceptance emotionally. They were all transferred from the acute care setting to the nursing facility. Primary emotion was frustration trying to understand the system or finding a place for their loved one.</p>

## Research Question 8

Research Questions	Cultural findings
<p>Among your ethnic group, how do you describe the disease? How did your loved one describe the disease before they were diagnosed? Did they tell you what they would want to happen to them if they ever were diagnosed with dementia?</p>	<p><b><u>African Americans</u></b> – they all agreed that it was a disease and said they believe among their ethnicity that is what it is. None of the participants had any recollection of their loved one describing what should happen to them if they were ever diagnosed. One said their mother that it at a very early age in her fifties but she cannot recollect if her brother ever describing it in any words but she remembers it being a very sad time for their family especially when they went to visit her in the nursing home and she did not know who they were.</p> <p><b><u>Asians</u></b> – All participants said among their ethnic group, dementia is seen as a very serious illness or disease. They all said their loved one never described or talked about the illness and so never described life after they were diagnosed.</p> <p><b><u>Caucasians</u></b> – one of the participants said her husband talked about the disease extensively because his mother suffered from it for a prolonged length of time and even at a point, it became difficult for him to visit her in the nursing home and he said multiple times that he would never want to live with a disease like this. Others said their loved ones mentioned it and described it as a horrible disease but never discussed what should happen to them if they were ever diagnosed with it. They all agreed that among Caucasians it is described and understood to be a progressive irreversible disease with no cure.</p> <p><b><u>Hispanics</u></b> - all participants described it as a “sad” disease. They said their loved ones never had a discussion about it before they were diagnosed and therefore had no plans or discussion for post diagnosis. Two of the five participants said they were sure that if their loved ones had said something, they would never have wanted to be like this and that is why they were both a Do Not Resuscitate Status in the nursing home. One of the described it as being worse than cancer. Which is like how one of the AA participants described it. She described it “as a cancer of the brain that just never stops”.</p>

**Research Question 9**

Research Questions	Cultural findings
<p>How do you describe dementia? What do you understand it to be?</p>	<p><b><u>African Americans</u></b> – one of the participants simply described it as “a disease that stole my husband away from me”. Another one described it as “cancer of the brain that just never stops”. One other participant said crying “it is a horrible disease that takes all you have from you, your sprit, soul and body how do you wake up every day and not even know you are up, you just keep going without direction?”</p> <p><b><u>Asians</u></b> - interestingly all Asians described it as a very serious disease that is completely different from memory loss.</p> <p><b><u>Caucasians</u></b> – one participant described it as “cruel disease”. Another participant described it as “terminal irreversible condition with no hope”. Another participant simply described it as “a disease that everyone has a chance of getting as they get older”.</p> <p><b><u>Hispanics</u></b> – one participant said it can simply be described as” madness” using her finger to show a twisting of the brain. She said sometimes her mother does not want to take a shower, walks around naked and does other strange things that is what mad people do. Other participants used the same words like sad, terrible and ugly to describe the disease.</p>

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## Vitae

Abiola E Williams was born in Lagos, Nigeria to Late Eugene Olatunde Akinosho and Tinuade Abike Adele-Akinosho. She immigrated to the United States in September 2001. She is married to Abiye S. Williams and blessed with two wonderful children, Omiete Jemima and Tekena David, and a wonderful four-legged friend called Nova. She is also blessed with one brother, four sister, aunties, uncles, cousins and wonderful friends.

She earned a Bachelor's degree in Business Administration and a Master's in Business Administration in her home country Nigeria before she relocated to the United States in 2001. She started her nursing education at Houston Community College in 2002, where she obtained her Associate Degree in Nursing in 2004. She obtained her Bachelor's degree in Nursing from Texas Tech University in Lubbock Texas in 2006. She later went to University of Texas Health Science Center in Houston for her Master's in Nursing as a nurse practitioner with a track in geriatrics in 2009.

She has more than 8 years' experience as a geriatric nurse practitioner in the Houston area, seeing residents in multiple nursing homes, skilled nursing facilities and assisted living facilities. Prior to being a nursing practitioner, she worked as a medical surgical nurse and charge nurse in some of the finest hospitals in the Texas Medical center: The Methodist hospital, St. Luke's Hospital and Memorial Hermann Hospital.

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### Education

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