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A Silent Epidemic with No Voice:
Alzheimer's Education in an African American Midwest Community

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A Dissertation Submitted to The Graduate School at the University of Missouri-St. Louis
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A SILENT EPIDEMIC: ALZHEIMER'S EDUCATION

ABSTRACT

Alzheimer's disease is a growing crisis in this country, particularly in the African American community. Despite this awareness by the health care community and educational programs offered about the disease, a deficit in research assessing the impact of these programs exists. Consequently, the purpose of this study is to analyze the key criterion relative to the educational programs about Alzheimer's offered by local organizations and the impact they have on a Midwest African American community.

According to research regarding Alzheimer's disease, African Americans continue to go undiagnosed and untreated. The literature review in this study explores the synergy of three theoretical constructs: Critical Race Theory, Community Theory and the Theory of Culture. The three theories were used to determine what influences if any, the theories may have on the key criterion relative to the educational programs provided by the local organizations in this study.

This intrinsic case study involved fieldwork, individual interviews, a focus group session and survey/questionnaire. The case boundary is a Midwest African American community and participants included two local organizations offering educational programs about Alzheimer's; two local service agencies and ten (10) African American caregivers from the community.

The findings suggest that both organizations are consistent in their efforts to offer educational programs to the community. However, two barriers that include the African American culture and lack of visibility in the African American community adversely influence the effectiveness of the educational programs about Alzheimer's disease.

Consequently, further research is recommended to determine strategies that will address the adverse influences and identify approaches to promote the visibility of both organizations in the African American community.

DEDICATION

This dissertation is dedicated to my loving parents who were always a source of inspiration, encouragement and strength. To my father, Gentry Fields for the wisdom and knowledge he shared with me about life and my mother, Nancy Fields for her prayers and rich spiritual nurturing.

ACKNOWLEDGEMENTS

The success in completing my dissertation required patience, encouragement and support from several special people I would like to recognize. First, when initially accepted into the doctoral program, my mother after several doctor visits was finally diagnosed with hydrocephalus. It was because of a misdiagnosis of her illness and delayed treatment that motivated me to select this topic on Alzheimer's education in the African American community. My mother passed away last year and did not witness the completion of my dissertation. However, I want to recognize her because even during her illness provided me with words of encouragement and support. Particularly, on those days when I felt like giving up, she would quote her favorite scripture to me found in Ecclesiastes 9:11, "The race is not given to the swift nor the strong but he who endures until the end." Mom thank you for your love, prayers and encouraging me to never give up on my dreams.

I would also like to thank my sister Ms. L. Annette McKenzie who was my greatest cheerleader. Thank you for those early morning "pep" talks and believing in me.

I would be seriously remiss if I did not thank my dissertation committee for their support, suggestions and recommendations in completing this document. Specifically, I would like to thank Dr. Matthew Davis for his patience and understanding during this process.

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Chapter 1

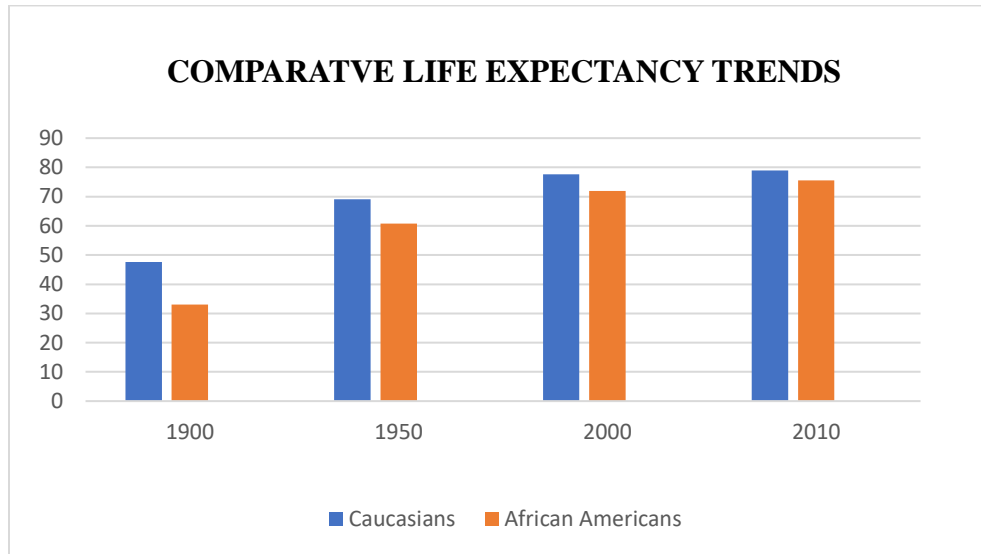
Introduction and Problem

Alzheimer's disease is the sixth leading cause of death in the United States for those over the age of 65 and estimated to be the third costliest illness after heart disease and cancer (Alzheimer's Association, 2018). It is non-discriminate and affects individuals from all lifestyles, cultures, families, and communities. As a progressive degenerative disease of the brain, Alzheimer's causes memory loss that gradually prevents a person from performing daily activities such as walking, speaking, eating, and maintaining employment. As reported by the Alzheimer's Association, individuals diagnosed with the disease is increasing annually due to life expectancy and growth rates of the older population (Alzheimer's Association, 2018).

Studies on population and longevity reveal that the median life expectancy for African Americans and Caucasians in the United States before the 1900s was below 50 years of age (Kreiger et al., 2008). Thereafter, the median age increased with an apparent disparity in life expectancy between both groups, as shown in the Comparative Life Expectancy chart below. Specifically, although living longer after the 1900s, the average life expectancy for Caucasians was 44.6 and 33.0 for African Americans representing an 11.6-year differential. Life expectancies for Caucasians in 1950 increased to 69.1 compared to 60.8 for African Americans with a disparity of 8.3- years. Figures in the year 2000 show a differential of 77.6 versus 71.9 years representing a 5.7-year gap and 2010 shows an increase for both groups of 78.9 for Caucasians and 75.5 for African Americans with a 3.4-year gap disparity. More importantly, the chart demonstrates that

over the past one-hundred years, the health and life expectancy rates for Caucasians continue to exceed that of African Americans.

Figure 1.1



U.S. Census Bureau-Demographic Trends (2017)
(Kreiger et al., 2008)

The comparative data demonstrates the longevity disparities and supports the findings from the United Nations Development Program (UNDP). According to these findings, the life expectancy of African Americans is comparable to individuals living in medium developed nations (Braithwaite et al., 2009). In addition, African Americans rank lowest on the Human Development Index compared to Caucasians due to health and morbidity disparities in the United States (Braithwaite et al., 2009).

Despite the life expectancy disparities between African Americans and Caucasians, the data also shows an overall increased life expectancy for both groups. Consequently, the National Institute of Aging suggests that the increased life expectancy rates attribute to the increase of age-related illnesses, with the most significant being

Alzheimer's disease (National Institute of Aging, 2008). For example, the Alzheimer's Association reports that approximately 5.5 million persons currently live with Alzheimer's disease in the United States. By 2025, this number will reach 7.1 million, and by 2050 it will double to over 13.8 million (Alzheimer's Association 2018).

Subsequently, these vast numbers have drawn national attention by individuals such as late former First Lady Nancy Reagan. As an advocate for Alzheimer's disease research, Nancy Reagan raised public awareness about Alzheimer's disease and established the Ronald and Nancy Reagan Research Institute. Additionally, she was instrumental in raising money for Alzheimer's disease research and provided clarity to politicians about the need and significance for stem cell research.

Another prominent figure, Maria Shriver and former First Lady of California became an Alzheimer's advocate after her father, former vice-presidential candidate Robert Sargent Shriver received an Alzheimer's diagnosis in 2003. As an advocate, Shriver authored a book entitled *What's Happening to Grandpa*, later produced by an HBO Alzheimer's segment called *Grandpa Do You Know Who I Am*. Mrs. Shriver also led a march and candlelight vigil to raise funds and awareness about the Alzheimer's crisis in the United States (Alzheimer's Association, 2010).

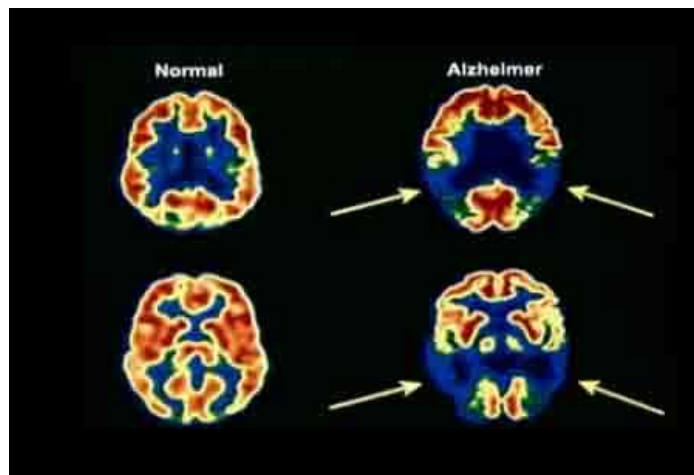
Alzheimer's Disease

Unlike cardiovascular disease, strokes, and cancer, Alzheimer's disease affects a person's cognitive functions. As one of the dementias, Alzheimer's is associated with memory loss, cognitive disabilities, language impairment, disrupted motor skills, perception problems, inability to function socially, or perform occupationally (AA,

2018). A person with the disease also experiences a continued decline in normal intellectual functioning (AA, 2018). Caused by the development of neurofibrillary tangles and beta-amyloid plaques, studies reveal that Alzheimer's can lead to neuronal loss and cortical atrophy (Mendez & Cummings, 2003).

Figure 1.2

Brain Comparison - Normal vs. Alzheimer's Diseased



(Schauss, 2013)

As shown in figure 1.2, as Alzheimer's disease advances, the nerve cells in the brain begin to die, causing a decline in cognition (National Institute of Neurological Disorders and Strokes, 2009). The disease is fatal, with death typically occurring between four to ten years after diagnosis (AA, 2018). Although, recent studies have shown that if in good health, some individuals can live up to 20 years (National Institute of Aging, 2006).

The causes of Alzheimer's disease are unknown, and no known cure available (AA, 2018). However, current medical and healthcare advancements have proven to

provide patients with modest symptomatic benefits. Reports show that these medical advancements also increase the efficiency of the neurotransmitters in the brain, which can slow the disease's progression (National Institute of Aging, 2008). More important, many researchers postulate that early diagnosis and education on the factors contributing to the onset of the disease the more significant the possibilities to delay or stop continued damage to the brain (National Institute of Aging, 2006).

Although given national attention by notable individuals, studies on community health reveal that groups who encounter the highest health disadvantages over their life span and bear a higher burden of death and disease are minorities specifically, African Americans. The reports reveal that African Americans are in disadvantaged positions relative to older Caucasians (Jackson, 1988) and are at a higher risk for debilitating cognitive diseases such as Alzheimer's (AA, 2018). In addition, an accumulating body of evidence about the scope and nature of Alzheimer's reveals that the disease and related cardiovascular dementia cases are increasing rapidly throughout the African American population. As reported by the Alzheimer's Association (2018), the disease is more prevalent among African Americans and estimated to range from 14% to 100% in older African Americans than in older Caucasians.

The health community acknowledges the disparities and the disproportionate number of older adult African Americans diagnosed with Alzheimer's; however, the issues never adequately addressed. Additionally, although research exists that provides possible factors in the higher incidence of Alzheimer's disease among older African Americans, there is still a significant deficiency in research about the impact of the educational programs offered to the African American community about the disease (AA,

2018). Consequently, the purpose of this study is to analyze the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community.

Alzheimer's Disease and the African American Community

Alzheimer's disease is described as a silent epidemic in the African American community and considered one of the top leading causes of death among older adults ages 65 and older (Braithe et al., 2009). Notably, according to the Alzheimer's Association, by 2030, the number of African Americans living with Alzheimer's and other related dementia diseases in the high-risk age group 65 and older, is anticipated to reach 6.9 million (AA, 2018). Research also suggests that African Americans are at an increased risk for developing Alzheimer's due to contributing health problems such as diabetes, hypertension, high cholesterol, and cardiovascular disease. (AA, 2018)

Other factors contributing to the increased number of older African Americans with Alzheimer's include socioeconomic factors, education, and the perception African Americans have about health professionals. Additional factors include lack of understanding about the disease, and lack of access to healthcare (Byrd & Clayton, 2000). More importantly, this anticipated increase can also be attributed to the biased attitudes healthcare professionals have for people of color, misdiagnosed cases, lack of formal treatment, and a significant number of patients diagnosed at later stages (Kennedy et al., 2007).

Studies on healthcare disparities also reveal that other significant factors contributing to the increased number of African Americans diagnosed with Alzheimer's

is the underutilization of healthcare services, attributed to cultural traditions, norms, and mistrust African Americans have for healthcare professionals (Braithe, et al., 2009). For example, older African Americans have a mistrust for healthcare professionals and institutions because of cases such as the 40-year (1932-1972) Tuskegee syphilis experiment (Jones, 1981). This study which, many older Africans Americans still recall, was an experiment approved by the United States Public Health Service (PHS) in the treatment of 399 African American males diagnosed with syphilis from Macon County, Alabama.

More alarmingly, the purpose of the experiment was not to provide adequate healthcare but to study the natural progression and long-term effects of syphilis when untreated (Washington, 2006). The studies reveal that the PHS deliberately denied 399 men penicillin, an antibiotic discovered in 1928, and first administered to syphilis patients in the United States in 1943 (Jones, 1981). Instead of penicillin, the PHS administered placebos to the 399 African, which allowed researchers to observe the gradual crippling and degenerative cognitive effects of the disease. Consequently, many older African Americans remember this study and as a result, refuse to seek medical treatment, refuse to participate in medical research or participate in educational programs for fear they will become victims of medical apartheid (Washington, 2006).

Critical race theorists' and researchers postulate that the underutilization of healthcare services by older African Americans are directly related to discriminatory experiences, as well as social, institutional, and systemic racist practices African Americans remember that extend as far back as slavery (Byrd & Clayton, 2000). Recognizing these issues warrant the need for additional research, studies, and programs

that will encourage African Americans to seek medical attention when ill and encourage them to participate in educational programs about Alzheimer's and other cognitive related diseases.

Purpose of Study

Although educational programs about Alzheimer's intended to educate older adults and caregivers are available, research has shown that African Americans continue to go undiagnosed and untreated. Additionally, studies show that individuals in the African American community do not fully understand the factors or symptoms related to Alzheimer's disease. This study will analyze the key criterion relative to the educational programs about Alzheimer's disease offered by two local organizations and the impact they have on a Midwest African American community about Alzheimer's disease.

Significance of the Study

Early detection and diagnosis about Alzheimer's disease are essential to the well-being of individuals diagnosed with the disease. Also, educating individuals on contributing factors, lifestyle changes, and available support services can assist individuals in managing the disease as it progresses (Mahoney et al., 2005). More importantly, education about the disease would motivate individuals to seek medical assistance earlier and because it is a shared familial experience, it would provide families with a level of comfort and information to caregivers on how to prepare for the decline in health of their family member (National Institute of Aging, 2006).

Finally, this study will advance the importance of recognizing the need for effective educational programs about Alzheimer's disease in the African American

community. It will also explore the challenges, if any, that may influence the impact these programs have on the African American community about Alzheimer's disease.

Problem Statement

Although research exists, which explores possible factors for the increased higher incidence of Alzheimer's disease among older African Americans; there is a significant deficiency in research on the impact of educational programs about Alzheimer's offered by local organizations in the African American community.

Research Questions

What is the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community?

Definition of Terms

Alzheimer's disease- is the most common form of dementia and is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks of daily living. (National Institute of Aging, 2009))

Caregiver - An unpaid relative or friend who supports people with disabilities (AA, 2008).

Community organizations- social organizations that constitute a conscious effort on the part of a community to control its affairs democratically and to secure the highest possible level of services from its specialists, organizations, and agencies. (Lindeman, 1989).

Cultural competence – the ability to understand, communicate with, and effectively interact with people from cultures other than their own. (Singelis, 1998)

Older adult - A person who is considered retired. It also refers to senior citizens. With improved healthcare and longevity, the age for an “older adult” continues to occur later and later.

Healthcare providers – a health professional responsible for providing healthcare professionally and in a proper, organized, and ethical manner to persons requiring health care services. Also referred to as informal caregivers. (AA, 2008)

Human Development Index – A prescribed indicator established by the United Nations Development Program (UNDP), which determines a nation's population health, population longevity, knowledge, education, and standard of living (Treadwell, Braithwaite, Taylor, 2009).

Chapter 2

Literature Review

This chapter is a review of the literature as it relates to the synergy of race, community, and culture. It will explore three theoretical constructs and determine whether they individually or collectively influence the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community. The chapter consists of three sections.

First, section one explores critical race theory and how race can impede programs and services developed to help African Americans. Specifically, this section will provide a synopsis of the literature about critical race. It will explore how race historically influenced and contributed to healthcare disparities in the United States. It will also explore many of the inequities in the distribution of health-related support services and educational opportunities for African Americans caring for individuals diagnosed with Alzheimer's disease.

Section two will provide an analysis of community and the role it plays in creating a context for change. For the benefit of this study, this section will focus on three concepts to include community education, community development, and community-based participatory research.

The third section is a review of culture and the theoretical construct that suggest how culture can affect attitude, behavior and interpret how certain groups in the society live. Mainly, this section will discuss studies on culture as it relates to the cultural patterns, ideological concepts, and beliefs that develop and transfer through generations

when groups are isolated (Hale, 1994). As an example, African Americans, according to Hale, have historically been isolated from American mainstream society, thereby allowing them to develop their own distinct culture (Hale, 1994). More importantly, culture incorporates the concepts, values, customs, and beliefs of a group. Culture determines how groups view society, it influences decisions made specific to medical care, and it can create mistrust for healthcare professionals and other healthcare organization (Durodye, 1995).

Critical Race Theory

Even after the signing of the Emancipation Proclamation by Abraham Lincoln in 1863 to abolish slavery, and the passage of the 1964 Civil Rights Act that precipitated the emergence of laws and reforms to eradicate discrimination, racism continued to be a critical social problem in our society. According to Yosso (2005), racism has shaped the social institutions of our country, which began before the twentieth century and continues to influence institutions into the twenty-first century. Recognizing this phenomenon, researchers continue to analyze the history of racism that include its implicit and explicit influences on the social structures, practices, and adverse outcomes that range from lynching, physical, emotional and medical abuse; as well as exploitation, legalized racial segregation and discrimination (Bell, 1995).

Before analyzing the concept of critical race theory, it is essential to explore the history, meaning, and nature of race in American society. First, Audrey Smedley (2012) posits that although based on biology and physiology, race is a compilation of ideologies, beliefs, values, and assumptions that create a unique manner that all cultures perceive the

world. Consequently, this theory suggests that race is a perception that influences the manner that cultures interpret the world, which also includes their history and experiences (Smedley, 2012).

Although considered a modern concept, the word race does not appear in formal English literature until 1508 when the poet William Dunbar used the phrase, *Bakbyttaris of sindry racis*, which means backbiters of sundry races (Byrd & Clayton, 2000, p.34). The word, as we know it today, does not appear until the age of European exploration (Smedley, 2012). Smedley uses the word race to describe groups of indigenous people labeled unequal and ranked according to a scale from superior to inferior. Consequently, other countries later translated the ranking into their respective languages to include Spanish, Portuguese, Italian, French, German, Dutch, and English (Smedley, 2012).

More alarmingly, the concept of race devalued and degraded individuals both physically and culturally. Particularly, individuals with non-European characteristics. It determined a person's station in society, such as social, political, and economic status. In addition, utilizing European physical characteristics as a barometer, Francois Bernier introduced skin color as a concept of race. Bernier labeled anyone different or physically non-European as members of a different race (Stuurman, 2000). In 1735, Carolus Linnaeus, the founder of taxonomy, introduced the concept of racial groupings based on biological and cultural characteristics. He identified four specific racial groupings: White-European, Red-American, Dark- Asiatic, and Black-Negro (Mueller-Willie, 2014). Later, Linnaeus added psychosocial characteristics to his racial grouping, thereby categorizing Blacks as lascivious, inferior, and ape-like (Byrd and Clayton, 2000).

Furthermore, scientists such as Buffon, Cuvier, and Blumenbach engaged in racial studies that also contributed to racial taxonomies and understanding race classification. Their studies differed in classifying the number of human categories; however, their premise maintained that all races were not equal (De Gobineau, 1915). Moreover, to classify the varieties of man, scientists later expanded the racial classification to include skin color, hair texture, skull configuration, skull dimensions, and facial characteristics (Byrd and Clayton, 2000). These characteristics and classifications influenced the belief and attitude that Caucasians were the beautiful and superior race.

The racial taxonomies developed by Europeans not only influenced our social structure but influenced how individuals with non-European characteristics and skin color; especially, African Americans, were treated over the years. These racial taxonomies also defined those in society with power as it relates to wealth, access to education, and the availability of healthcare services (Stevens-Coon, 1972). For example, according to the documentary *Race: The Power of Illusion*, race is paramount in our society and provides access to opportunities as well as resources to people differently (PBS, 2000). The documentary further discusses how the government and social institutions because of racism inexplicably can channel money, power, capital, and resources to those they consider worthy.

Another example found in Alexis Tocqueville's book entitled *Democracy in America*, describes the influence of racism in America (Tocqueville, 2000). During his journey in the United States in 1830, Tocqueville described the interaction he observed between an Indian and Black female caring for a White settler's daughter while sitting on a riverbank. He describes the interaction of the Indian woman dressed in her native attire

and her behavior with the White child as maternal. Tocqueville includes in his observation that the Indian woman's behavior demonstrated her sense of pride and freedom. On the other hand, he describes the African American woman's behavior dressed in frayed European clothing interacting with the White child as timid, passive, and servile illustrating a sense of oppression created by racism. Tocqueville also observed how the White child, although much younger than the two women, displayed a sense of White entitlement. Her posture and dominating gestures both demonstrated an awareness of her superiority above the two women. What Tocqueville observed was the White child exercising white privilege and the subjugated roles of both the Indian and African American women created by the American racist society.

Racism in America

The founding fathers of the United States signed and endorsed the quote in the Declaration of Independence, "We hold these truths to be self-evident, that all men are created equal." However, did they intend to support this statement? Did they forget that African Americans brought over on slave ships to work on plantations were not equal to Caucasians? More importantly, this quote did not account for the number of slaves treated as property, separated from their families, and denied opportunities to purchase land. Although human, African Americans were not treated equally and not allowed to exercise their inalienable rights.

Levels of Racism

What slaves experienced during and after arriving in America was racism at the highest level. Racism has existed since the inception of colonialism and continues to exist today at three different levels to include Individual racism, Institutional racism, and

Systemic racism (Hinson, 2019). First, individual racism stems from a person's beliefs, opinions, or assumptions about certain groups generally learned from the family and society (Jones, 2000). It is the most overt of the three and defined as an intentional or sometimes unintentional act performed against a group or individual to cause harm, injury, or denial of services. An example includes the 1960 bombing of a church in Alabama, which killed five African American girls attending Sunday school (The Journal News, 1963). Another example is the gunman in 2015 who shot nine African American church parishioners in Charleston, North Carolina, during church Bible Class (Horowitz et al., 2015). In each case, White terrorists intentional sought to commit injury and harm to a specific group of individuals.

Not easily identified because of their bureaucratic structures, institutional racism operates in society, promoting and fostering discriminatory outcomes. Specifically, institutional racism influences the structural practices, policies, and procedures used by institutions to limit and prevent the access of services and goods for targeted groups (Hinson, 2019). These services may include access to quality education, housing, employment, and healthcare (Randle, 1993). Such practices, according to Feagin, suggest that racism can be conscious and unconscious acts reinforced and supported by authorities and dominating institutions of society (Feagin, 2006).

Such practices also foster unfair racial treatment by legal institutions responsible for serving and protecting individuals living in the community. For example, the beating death of Stephen Lawrence, a Black male from Great Britain. The investigation of the British case revealed that although the murder was racially motivated, the courts did not convict the five police officers. After a public inquiry conducted by Sir William

MacPherson, the findings revealed that the police department was institutionally racist (MacPherson, 1999).

Another example is the fatal shooting of Michael Brown by a local police officer in Ferguson, Missouri. Despite supporting evidence and testimonies, the investigation determined that the shooting was not racially motivated but self-defense. The grand jury cleared the local police officer of any wrongdoing, which led to several riots in Ferguson, Missouri (Salter, 2014).

The documentary entitled, *The Power of an Illusion*, produced by the Public Broadcasting Service (PBS) provides another example of institutional racism (PBS, 1999). This documentary covers the programs and services developed to assist soldiers and their families when readjusting back into society at the end of World War II. The programs included homeowner assistance programs through the Federal Housing Authority (FHA), entrepreneurial programs, and workforce education opportunities. The documentary uncovers how, because of institutional racism, specific institutions denied African American veterans and their families' services and support because of the color of their skin. These were the very soldiers who served their country and risked their lives fighting for freedom. More importantly, the documentary demonstrated institutional racism. It revealed how institutions could arbitrarily deny African Americans FHA loans, social benefits, privileges, and services offered to White veterans (PBS, 1999).

Systemic racism is a theoretical concept developed by sociologist Joe Feagin (2006), who asserts that racism is the cornerstone of American history. It has a long history in our society and fostered by those who have access to power. Enforced by the

legal system, racism influences the ideologies and discriminatory practices of slavery. Racism encouraged the ownership of Blacks in America and reinforced the notion that one group is superior to another (Anderson et al., 2012). For example, the support of slavery by the religious and scientific communities gave credence to the social and cultural beliefs that the Black race was different (Stampp, 1984). These negative social and cultural beliefs provided a basis for individual, institutional, and systemic policies and practices of racism in America that continue to exist even today.

History of Critical Race Theory

Critical Race Theory (CRT) is a methodology used to understand the root causes of all forms of racism. According to Taylor et al., (2009), Critical Race Theory (CRT) evolved out of the Critical Legal Studies movement (CLS). It later inspired social leaders such as Martin Luther King, W.E.B. Du Bois and Malcolm X. Founded by legal scholars in 1977, the CLS movement focused on the legal theory and unjust practices of the American legal system. Taylor et al. (2009) assert that although CLS scholars criticized the American legal system, they failed to include racism in their critique.

To understand racism, CRT was born. Initially focusing on aggression towards a group or individual, CRT extended the focus of racism to include both institutional and systemic racism. CRT unmask and exposes racism at various levels, thereby providing a framework to develop policy and initiate discussions on racial disparities in health care (Karsjens, 2007). It also attempts to deconstruct existing institutional structures that contributed to racial discrimination and inequality. For example, interviews with participants in this study revealed that in the 1950s and 1960s, one of the prominent hospitals in the targeted community historically, only treated pregnant African American

women. In addition, because of institutional racist practices, African American mothers received prenatal and delivery care in areas designated as the colored only ward located in the basement level of the hospital.

More importantly, CRT provides a framework for understanding human behavior, social processes, and examines the oppressive dynamics of society (Constantine, 2011). Constantine suggests that when investigating racism, researchers should place CRT at the center of analysis. In addition, positioning CRT at the center of any investigation will help provide a critical perspective on how race continues to affect the lives of racial/ethnic minorities in the United States.

CRT theorists also suggest that ignoring race promotes overt acts of racism, specifically in the delivery of healthcare services. Abrams and Moio (2009) assert that excluding race in any decision-making process relative to the level of healthcare promotes color blindness. This approach or color-blind paradigm advocated by many institutions and lawmakers is inconsistent with actual practices. The law is not color blind, and many CRT theorists argue that it is racially premised and not neutral as lawmakers lead people to believe (Abrams and Moio, 2009). Consequently, the concept of race intersects at the market place and woven within the fabric of our society. Delgado and Stefancic (2000) identify six basic themes or tenets guiding Critical Race Theory discussed below.

Tenets of Critical Race Theory

- (1) Racism is not arbitrary but a common experience for people of color,
- (2) Racism is the product of interest convergence,

- (3) Race is a social construct,
- (4) CRT utilizes differential racialization,
- (5) CRT recognizes the significance of intersectionality,
- (6) CRT acknowledges the importance of experiential knowledge of minorities.

First, racism is not arbitrary but is a common experience for people of color.

Racism is a prevalent and permanent fixture within American society. Unfortunately, the dominant culture only recognizes racism when it is visible, and they feel that it does not exist (Bell, 1995). Their attitude about race is color blindness, which promotes and legitimizes racism (Bonilla-Silva, 2006). For example, when African Americans visit department stores, store clerks will approach them immediately and security guards will follow them until they leave the store. Another example of racism is demonstrated when police officers are dispatched to investigate reports that an African American male is noticed driving in an all-White neighborhood. Although not reported to the media or visible to the community, these are examples of racism.

Second, racism is a product of interest convergence. Much of the literature asserts that racism overlaps and converges with the needs and self-interests of the dominant group (Bell, 1995). This theory recognizes the rewards that Whites gain from racism, whether it is materialistic or psychological. Specifically, it recognizes the support and role that White institutions and groups play in racial and social reform. Whites support racial or social reform only if they will benefit. For example, Whites supporting the 1960's civil rights legislation were also the primary recipients of the policies and programs implemented by the federal government to address discrimination. Bell

suggests that Whites will promote advances for African Americans only when they promote White interests (Bell, 1995).

Thirdly, race is a social construct and used to determine a person's social status as well as degrade and devalue anyone with non-European color and features (Delgado & Stefanie, 2012). Embedded in the fiber of our society racism influences decisions made by our political and judicial systems. For example, the first statute granting national citizenship in the United States was the Naturalization Act passed by Congress in 1790 (PBS, 1999). This act focused on granting naturalization to White men of good moral standing. This act remained in effect until 1952 (Tyson, 2006). Another racial classification was the One-drop rule, which asserted that anyone living in the United States with one ancestor of sub-Saharan-African ancestry would be labeled Black (Davis, 1991).

Fourth, CRT draws attention to the differential racialization of minorities in society by the dominant culture. It recognizes that all minorities in America are all here for different reasons and have their own distinct struggles and history. Consequently, each minority group is racialized differently through various discriminatory laws and legal policies designed to meet the needs of the dominant culture (Leary, 2005). For example, Jim Crow laws established by Southern states that promoted and legalized racial segregation. Specifically, the laws-imposed separation laws that included segregated neighborhoods, public transportation, schools, restaurants, theatres, and even cemeteries (Leary, 2005). The segregation laws were centered on race, thereby creating unimaginable hardships for African Americans, such as fear of incarceration or lynching. Also, these segregation laws establishment two unequal communities with unfair

treatment towards African Americans in the United States (Leary, 2005). Another example includes the Dred Scott vs. Sanford Case. The United States Supreme Court held that despite the liberties granted to American citizens, they did not apply to African Americans (Fehrenbacher, 1979).

Fifth, CRT recognizes the significance of intersectionality and essentialism, which has to do with identity. Unlike Carolus Linnaeus, who placed humans into four racial groupings, we now live in a society where individuals have more than one identity. Race alone does not define or determine a person's worth. Delgado and Stefancic (2000) assert that based on the notion of essentialism, race has evolved and is not stagnant. For example, an Asian woman may be a lesbian, working-class, and mother. Alternatively, a Latino may be Black, heterosexual, and a single parent. This concept acknowledges that everyone in society has overlapping identities, and at times, race, class, gender, and other characteristics will intersect (Delgado & Stefancic, 2012).

Finally, the sixth tenant draws attention to the importance of the experiential knowledge of minorities. Delgado and Stefancic (2000) refer to this as storytelling or voice-of-color. Instead of the typical scholarship of writing about racism, minorities share their experiences through personal stories. It is an effective way to convey the realities of racism for Whites who do not know or do not understand the effects of racism. Other active venues to expose the racist experiences of minorities include biography, autobiography, narratives, and counter-stories that provide personal perspectives of discrimination and racism (Delgado & Stefancic, 2000).

CRT is a methodological framework used to draw attention to and foster the struggle and need for social justice (Bell, 1995). It also attempts to explain, expose, and unmask racism in society and how it has affected the lives of people of color. In this study, Critical Race Theory (CRT) is used as a lens of analysis to examine race, ethnicity, and inequity of health care in the African American community. It is one of the three theoretical constructs of this study and provides a means to critique the cultural competence of healthcare providers and healthcare education in the African American community, including access to healthcare services and healthcare disparities.

Critical Race and Healthcare Disparities

Healthcare disparities towards the people of color have a long history in this country and date back to slavery. Byrd and Clayton (2000) refer to the poor treatment and behavior by healthcare professionals towards African Americans as the slave health deficit. This concept suggests that race, health disparities by medical institutions and healthcare professionals, and racial beliefs all developed in the context of slavery.

Black slaves, according to Byrd and Clayton (2000), entered the colonies with diseases and in poor health during the Atlantic slave trade, better known as the Middle Passage. Studies reveal that during the voyages, Blacks were housed in the bottom of ships and forced to live in crowded inhumane, and unsanitary living conditions. The over-crowdedness and unsanitary conditions exposed Blacks to life-threatening illnesses, diseases, as well as unimaginable contagions. Studies also reveal that countless numbers of women encountered sexual abuse, epidemics spread disproportionately, and slaves mistreated throughout the entire voyage (Byrd & Clayton, 2000). Ship personnel refused to provide medical treatment, and the slaves who survived the voyage entered the

colonies malnourished and in bad health. Consequently, poor health became the norm for Blacks, and they soon became accustomed to receiving disparate levels of medical care compared to the White colonists.

Following the end of the Civil War, the federal government implemented programs, policies, and laws to ensure that Blacks received equal and quality services, which included medical care. One program was the Freedman's Bureau established by Congress in 1865, created to address the needs of individuals and poor White communities left in ruins following the aftermath of the Civil War (Freedmen's Bureau Field Office Records, 2018). During this Reconstruction period, the Bureau was responsible for providing food, shelter, education, healthcare, and assisting freed Blacks with legal issues (Randall, 1993). Unfortunately, local and state institutions refused to comply with the new laws and continued to maintain discriminatory healthcare practices. These practices prevailed after World War II and even after the Civil Rights Acts passed in 1965 (Braithe et al., 2009).

More alarmingly, two hundred years after the abolition of slavery, African Americans are still subjected to healthcare disparities motivated by racism in America. Williams and Johnson (2002) suggest that when attempting to understand healthcare disparities, race cannot be ignored but must be the focal point. Furthermore, according to Randall (1993), the concept of race is motivated by factors that influence healthcare disparities visible by practitioners, medical schools, and service delivery personnel. These factors include (1) economics, (2) barriers to healthcare institutions and professionals, (4) racial policies and practices, (5) lack of understanding about the African American culture, (6) healthcare research, (7) marketing methods on healthcare,

(8) disrespect for the use of traditional medicine and (9) inequalities in the delivery of medical care.

Although many members of the medical community recognize the factors contributing to health care disparities, little to nothing has been done to address the problems. Instead, many health care professionals continue to associate a person's race with the level of treatment and healthcare provided. Coella, et al., (2004), affirm that race is a primary factor affecting the health of minorities. Also, because minorities have limited access to the political and economic systems responsible for enforcing equal healthcare and administering health care services, minorities specifically, African Americans remain victims in a biased health care structure.

More importantly, despite the studies and reports addressing the continued health care disparities targeted towards minorities, many individuals in the medical community refuse to accept these findings. Specifically, health disparity-denying groups continue to deny the reports, which uncovered blatant racism as an everyday practice in American medicine (Bloche, 2005). Bloche's (2005) analysis of the Institute of Medicine's (IOM) National Healthcare Disparities Report conducted in 2003, identified the differences in healthcare access, services, and quality of care. Unfortunately, groups criticized the motives of the report and accused the writers of providing prejudicial findings. They also suggested that no actual evidence confirmed the discriminatory healthcare practices and that the report did not consider national standards or socioeconomic status as factors in the findings (National Healthcare Disparities Report, 2003).

To dismiss the findings in the IOM Report, critics hired individuals to influence the media and to influence political officials to delete portions of the report. They also recommended the deletion of keywords such as disparity and comments on persistent disparate healthcare practices (Bloche, 2005).

Case Studies

One recognized case demonstrating racial disparities in healthcare and unethical acts committed by the American medical establishment is the story of Henrietta Lacks, an African American female diagnosed with stage 1 epidermoid carcinoma of the cervix in 1951. Henrietta was treated at John Hopkins Hospital, one of the most prestigious hospitals in the country at that time (Skloot, 2010). The hospital was near her home and one of the few hospitals despite Jim Crow laws that treated African Americans for free (Samuels, 2010). Henrietta was placed in a colored-only ward, received radiation treatment, and died six months later. More significantly, Henrietta never knew that she had unique blood cells. She did not know that her blood cells would later contribute to the development of the polio vaccine, create advancements in the study of cancer, and contribute to determining the effects of the atom bomb (Samuels, 2010). Also, her blood cells helped develop in-vitro fertilization, human replications, and gene mapping (Samuels, 2010).

Henrietta's story is one of many stories that remind us of the injustices perpetrated by the healthcare industries in the United States. Additionally, her blood cells birthed a million-dollar industry that she nor her descendants benefitted monetarily (Skloot, 2010).

Another example of healthcare disparity is the case of Deamonte Driver, a young 12-year old African American boy from Maryland who was denied preventive healthcare because of economics (Otto, 2007). After diagnosed with an infection and tooth abscess in 2007, Deamonte's mother visited several doctors who refused to treat him. They refused to make emergency exceptions because the family had no dental or healthcare coverage. Instead of treating Deamonte, his mother was told to apply for Medicaid and to locate a doctor who would accept this coverage. Unfortunately, this process took several months, and when finally approved, Deamonte's infection and tooth abscess had worsened. Because of the delay in treatment, the infection had progressed to his brain, which required two brain operations and significant hospital expenses to no avail. This young man died an untimely death because local doctors refused to provide treatment for a meager \$80.00 procedure (Otto, 2007).

Other examples include a case filed with the National Institute of Health by several pregnant African American women from North Carolina between 1976 through 1996 (Washington, 2006). The case findings revealed that the court incarcerated pregnant African American women after they tested positive for drug abuse. Also, their sentencing included participation in a nonconsensual research project conducted by a local medical hospital, condoned by local authorities. Another example includes an investigation conducted by the State of New York in 1998, of a psychiatric institute for discriminatory practices. Specifically, the state charged the institute with intentionally administering a cardio-toxic drug to 34 young African American boys between 6 to 10 years of age (Washington, 2006).

These are only a few of the many horrific documented experiments that create fear in the minds of many older African Americans about healthcare professionals and organizations in this country. The cases also bring attention to the misconduct in human research, the arrogance of physicians who took the Hippocratic Oath to uphold specific ethical standards, and researchers who disregard human life. (Kennedy, et al., 2007)).

Critical Race Theory -Healthcare and Slavery

Most of the literature on slavery focuses primarily on the abuses of slavery, the African American experiences, and how slavery shaped America (Stampp, 1984). This section will discuss the effects of slavery with an emphasis on healthcare. Particularly, this section will cover the absence of healthcare for African Americans since slavery and how it influenced the perception that African Americans have about healthcare in the United States.

First, many of the physicians in the colonies were apprentices trained in England and lacked the medical knowledge needed to understand the illness in the new world. Colonists arrived in America in poor health and many of them died from overexposure or other epidemic diseases. However, the African American slaves transported in the lower level of ships and denied medical care suffered the most severely (Byrd & Clayton, 2000). Many slaves died during the voyage after exposure to chronic illnesses and thrown overboard. Slaves who did survive the voyage, arrived in America suffering from various diseases caused by lack of medical care or unsanitary conditions aboard the ships. Additionally, upon arrival in America, slaves were still denied medical care, and physicians who did treat them did so only when forced (Byrd & Clayton, 2000).

It is important to note that this type of treatment and the institution of slavery were both acceptable norms in American. Slavery provided monetary and capital gain for plantation owners aspiring to become wealthy (Sven & Rockman, 2016). Stamp (1984) posits that slavery was not compulsory but deliberately embraced by plantation owners, which helped foster the negative race relations in the United States (Hargrave, 2010). Because plantation owners focused on economic opportunities, they had no concern for the emotional or physical experiences encountered by slaves. Consequently, these actions account for the demeaning experiences that slaves experienced, which included crude and crowded living conditions, merciless hard labor, limited medical care, and poor diets. These conditions also attributed to various diseases, chronic illnesses, and high mortality rates.

Furthermore, Stamp (1984) suggests that the institution of slavery did not grow overnight. It took years to develop, and for many slave owners, slavery became an accepted way of life. It defined who they were and determined their personal, social, and economic status. Slavery and life on the plantation also became the norm for African Americans and their families who labored tirelessly on the plantation for years. Slaves were considered property and became part of the plantation owner's family inheritance. As a result, slaves, as well as their children, were passed down from one generation to the next (Stamp, 1984).

Several studies on slavery reveal that slave owners who valued their healthy active slaves would, on occasion, provide minimal medical care (Hargrave, 2010). Why? Primarily because the healthy slaves provided owners with a higher profit than their investment. In his book entitled *Roll, Jordan, Roll: The World the Slaves Made*, Eugene

Genovese describes the harsh treatment and attitude slave owners had about their African American slaves. Genovese posits that slave owners viewed slaves as investments (Genovese, 1974). If slaves remained healthy, slave owners would provide them with some level of medical care. However, if they became ill or useless, the slave's value would depreciate, and his usefulness compared to a discharged animal.

When slaves became extremely sick or too old and unable to work the fields, they became financial liabilities. Also, even though compulsory laws existed requiring slave owners to care for slaves, particularly older adult slaves, the laws were generally ignored (Genovese, 1974). Slave owners would either sell older adult slaves, assign them minimal responsibilities, or offer them freedom knowing they had nowhere to go (Close, 1996). Another degrading consideration was to place older adult slaves on the streets to work as beggars to support themselves and to help generate money for the plantation (Genovese, 1974)).

The literature suggests that on occasions, some slave owners provided slaves with services and shelter when sick (Genovese, 1974). Although provided, the housing and medical facilities were inadequate, unsanitary, dirty, dark, and filthy with limited or no medical care. (Close, 1996). Plantation owners with large slave populations provided medical treatment for younger slaves working the fields through a slave health subsystem. This system allowed Black Healers to treat slaves requiring medical care using herbs and hands-on care (Byrd & Clayton, 2003)). The sick and older adults requiring healthcare received treatment from the slave community and received one of three types of treatment from the younger slaves (Hargrave, 2010). The treatment included: (1) Treatment consistent with the traditional cultural healing practices. (2)

Medication administered by root and herb doctor recommendations and (3) Care based on religious practices and faith.

More importantly, to maintain the African American community, younger slaves treated the older slaves with respect and recognized them as key figures in the slave community (Close, 1996). The younger slaves voluntarily took on the workload of the older slaves when they become too weak to work or discarded by the plantation owners (Close, 1996). Also, the younger slaves solicited advice from older slaves, listened to the stories about their heritage and learned their trades and skills. These stories and skills were then passed down from generation to the next, which sustained the African American culture.

Community Theory

Community is one of the main building blocks of society (McMillian & Chavis, 1986). It provides opportunities for the exchange of information, foster collaborations for cooperative action and can serve as the venue for change. The term comes from the Latin word *communitas*, which means a feeling of fellowship because of shared attitudes, interests, privileges, and identity (Oxford Dictionary Online, 2013). It has been used by various disciplines, thereby creating a plethora of definitions. Uses of the word include community development, community-based education, and community participatory research discussed in this section.

DeFilippis and North (2013) assert that community represents a broad spectrum of ideologies and proposes two definitions. First, it represents a group of people who share a common goal and have a defined purpose. They may not all reside in the same

local but meet at a designated location to share in their common goal. The second represents a specific location or venue. The two communities serve the same purpose, which is establishing and providing social relations.

Researchers such as Joseph Gusfield suggests that there are two types of communities in society (Gusfield, 1975). The first being a geographical location to include neighborhoods, communities, and towns. The second represents a group of individuals with common interests, struggles, concerns, and interactions within the community. The two communities are inclusive of the members in a location or those members with common interests. Also, social relationships are the primary factors of the groups, thereby creating an intersection between the individuals.

Paulo Freire, educator and advocate of social change postulates that community is based upon purpose. He connects community with empowerment and posits that community is a venue where people are empowered (Freire, 1973). Specifically, communities are empowered through listening, engaging in dialogue, recognizing their commonalities and struggles as well as identifying strategies for change (Freire, 1973). Likewise, Wallerstein and Bernstein propose that community empowerment evolves during the collaborative process of change, and during this process, both the institutions and communities transform. More importantly, this interactive change process occurs through dialogue and individuals learning from each other, which, in turn, helps to resolve community problems (Wallerstein & Bernstein, 1994).

Also, psychologists McMillian & Chavis introduced a theory of community in the 1980s that is still used today by researchers conducting qualitative and quantitative

studies (Fremlin, 2013). They postulate that community is composed of four elements: (1) Membership (2) Influence (3) Integration on fulfillment of needs and (3) shared emotional connections.

1. Membership – represents the individual. It is having a sense or right of belonging. Also, having a connectedness with the community.
2. Influence – Need for significance to the group. Concern that the group has to its members and that members are heard.
3. Integration of fulfillment of needs – The group will meet the needs of the members through its resources. In turn, group members will help each other when able.
4. Shared emotional connections – Belief that the group will provide a venue for members to share history, experiences, and events, thereby creating relationships between members.

(McMillian & Chavis, 1986)

Critics such as Nowell and Boyd argue that McMillian & Chavis' sense of community is based on theory and not responsibility. They suggest that developing a theory on human needs discounts valued-based behavior (Nowell and Boyd, 2010). Additionally, they imply that the theory is elementary, does not adequately address the concept of community, and the primary focus, which is the community, is limited. Instead, community serves as a resource merely to meet the physiological and psychological needs of people such as affiliation, power, and affection.

Finally, Mel King postulates that both dominant and subordinate groups coexist in society. He refers to them as a community of the preferred and community of the oppressed indicated below (King, 1989).

1. Community of the preferred – Those who have power, status, money, and belong to the community of the advantaged or dominant culture.
2. Community of the oppressed- Those who are oppressed, disadvantaged, and do not belong to the dominant culture.

The community of the preferred or the advantaged culture represents individuals who have status and power in the broader community. Individuals in this community have advantages simply because of their race or socioeconomic status. In contrast, the community of the oppressed represents those individuals who are disadvantaged, have encountered difficult challenges, and included in this community because of their race, gender, ethnicity, age, or sexual orientation. King (1989) asserts that the two communities often intersect in the marketplace where often the community of the oppressed is exploited for the economic well-being of the community of the preferred.

Community Development

Community development, as defined by Adams et al., (2004), is a planned and organized process through which people and communities learn how they can help themselves. It is a developmental process organized and structured by individuals with the necessary skills and abilities needed to resolve community problems effectively (Mezirow, 1981). Specifically, the community development process involves the interaction between community residents and outside organizations working together with a shared goal or identity.

Other researchers such as Cavaye (2011) suggest that community development combines the idea of community with development. The community represents the

people with a shared identity and vision for the future of their community. It is a partnership with individuals or groups that have a goal to improve the social, economic, health, and environmental situation of a community (Cavaye, 2011).

For a collaborative process to work, the community must be an active voice, and the needs of the community met. For example, in 1988, the University of Illinois at Urbana-Champaign participated in an urban planning project that included working with community representatives in revitalizing East St. Louis (Reardon, 2000). Two years later, an assessment of the project was conducted, which involved interviewing 40 of the community leaders in East St. Louis. The interviews revealed that despite the efforts, the project failed to engage both the residents and University. Community participants were dissatisfied with the project because researchers failed to listen to the residents when determining the community needs. Consequently, because the University failed to include the community representatives actively, the community questioned the researchers' commitment to work with the community in carrying out the proposed recommended plans (Reardon, 2000).

Community-Based Education

Expanding on the concept or theory of community, community-based education, also referred to as community education, goes beyond mainstream educational learning. It is not teacher-centered, but the emphasis is on the individual and community members who desire to improve the community and the surrounding environment (Weaver, 1992). It is a philosophy that encourages community member participation, fosters accountability, and promotes independence. Community-based education also provides members an atmosphere to share, develop, and work collaboratively in resolving

community issues (Weaver, 1992). Researchers such as Checkoway (2001) suggests that community education provides a safe learning environment for those ostracized by mainstream society. Additionally, Galbraith (1995) describes community education as an educational process that allows an individual to become proficient in their abilities and skills. It helps to provide an understanding of the community, and it encourages an individual to embrace all aspects of the community through participation.

More importantly, the focus of community-based education is the community. The concept is not new and has a long history in the United States. Supported by educational reformists such as John Dewey and Jane Adams, they believed that education should be the center of the community (LERN, 2009). They believed that implementing a school focused model would meet the social life, educational, and social service needs of the community (LERN, 2009). Moreover, unlike the traditional educational setting, community education offers a venue where adults can share their experiences. They can develop skills, identify community needs, create strategies to address neighborhood issues, and meet specific individual needs of those living in the community.

Paulo Freire asserts that because we live in a constantly changing world, learning is essential. Also, Freire suggests that real emancipation from the oppressor through community education requires

- Social action – need for the learner to act against the unjust practices that impact the civil liberties of people,
- The learner should not accept the status quo, and
- The learner should be heard and articulate his or her deliberations and social actions (Freire, 2000)

Community-based education can be a powerful tool if accepted and supported by the community. It can encourage citizen participation, help in meeting the needs of the residents in community, provide training, serves as a venue to advocate change, and can offer opportunities for outside support and resources (Galbraith, 1995).

Community-Based Participatory Research

Community-Based Participatory Research, also referred to as Community Based Research (CBR), involves a process with community members and research institutions. The goal of this process is to transform the world, specifically, communities (Sclove et al., 1998). More importantly, CBR is a mutual exchange research process that includes faculty, students, and community members working collaboratively to identify and resolve community needs (Strand et al., 2003).

According to the Detroit Community-Academic Urban Research Center (Detroit URC), community-based research involves community members, local organizations, and researchers. The groups join to offer their skills, share in decision making, and ownership of a project (Detroit URC, 2011). Additionally, CBR consists of eight fundamental principles it

1. Promotes collaborations, partnerships, and empowers participating units.
2. Identifies and acknowledges community.
3. CBR utilizes resources within the community.
4. It promotes co-learning between partners.
5. Utilizes environmental approaches when attending to factors concerning health and disease within the community.

6. Ensures equitable benefits for all partners.
7. Distributes results and information to the community to include all participating partners.
8. Advocates for continuing program support and sustainability.
(Detroit URC, 2011)

Additionally, community-based participatory research is a collaborative process that validates the knowledge that community members bring to the table (Strand et al., 2003). Stringer (1999) suggests that in this process, community members be heard and allowed to contribute to defining the community issues and solutions that are acceptable to them (Stringer, 1999). Also, outside collaborators should understand that in the community-based research process, the community is the primary focus and that the research should be conducted by, with, and for communities (Sclove et al., 1998).

As stated earlier, community is one of the main building blocks of our society that can be influenced by community education, community development, and community-based research (McMillian & Chavis, 1986). One would conclude that through these three processes, members of a community should be able to organize, seek solutions among themselves, identify resources, and implement strategies for change. More importantly, external organizations working collaboratively with community groups must operate within the parameters of the community by allowing community members to participate in decisions made about the community (Detroit URC, 2011). They must also understand the community's culture, which plays a vital role for minority groups, specifically, African Americans.

Theory of Culture

According to Hugh Scott, culture serves as a lens when interpreting one's environment and represents the cultural characteristics learned by a person in a group or society (Scott, 2005). Also, anthropologists such as Jay Sokolosky assert that culture is made up of symbols and meanings created by certain groups in society. He suggests that these groups create cultural scripts, which define their behavior to include making decisions and how individuals in the group navigate through life as he or she ages. Furthermore, he posits that culture represents a way of life, mode of thinking and represents the learned behavior such as attitude, beliefs, and norms of a group passed down from one generation to the next (Sokolosky, 2009).

Because we now live in an integrated society with cultures coexisting, many times, cultures intersect in the market place, especially when there is an exchange of goods and services (Skolosky, 2009). One group responsible for providing services many times must interact with another group in need of services. For example, when African Americans seek medical care from a predominantly Caucasian healthcare system, the two cultures intersect. Caucasian healthcare professionals find themselves interfacing with African Americans and often are not culturally competent. They do not share the same cultural beliefs, norms, or understand the challenges and experiences African Americans have encountered (Kennedy et al., 2007). As a result, this type of cross-cultural dialogue during patient interviews, can be nonproductive for both groups (Riser & Ellis, 2007).

African American Culture

Historical accounts of the slave trade reveal that Africans came to the United States from several different countries within the continent of Africa (Stamp, 1984). Each group arrived with unique cultural patterns, languages, music, dances, self-expressions, beliefs, and customs. Although different culturally, the slaves shared a history of captivity, discrimination, and domination that created a bond for the African heritage (Scott, 2005). Additionally, through cross-cultural exchanges, the various African cultures survived, and new cultural elements merged, creating what we now call African American culture.

The African culture, traditions, practices, and slave experiences were passed down by slaves to their offspring through oral history practiced by Griots (Slavery & Remembrance, 2019). Because many African cultures had no written word, the griot provided the means of preserving African history, beliefs, and customs. The griot passed these practices down from generation to generation through storytelling, praise-singing, and musical entertainment (Agatucci, 1998). Specifically, drawing upon practiced and memorized history, Griots who were revered and respected men of the tribe, memorized the village's significant events, such as births, deaths, marriages, hunts, seasons, and wars to ensure that the village's heritage, culture, and the lineage continued (Agatucci, 1998). The Griot was known to speak for hours, even days, drawing upon the historical events of the village passed down from Griot to Griot.

Despite efforts made by slave owners to eradicate the African culture, values, beliefs, and traditions, slaves still maintained their culture and practice. Consequently,

these practices helped the slaves to survive the cruelty and atrocities of slavery (Slavery and Remembrance, 2019). For example, African Americans were forced to denounce their cultural, religious practices and to accept the Christian religious practices of their slave owners. Blassingame (1979) asserts that because of the physical isolation and separation of African slaves from Caucasians, African Americans were able to maintain many of the African religious practices and beliefs that, over time, became a significant part of the African American culture, demonstrated in the survival of African American music. The songs, dances, and musical instruments were elements of the slaves' African heritage used as a means of expression and communication (Slavery and Remembrance, 2019). Through this expression, slaves were able to build a strong musical tradition that became part of their community identity.

Over the years, the African American culture has transformed through a myriad of elements through acculturation. The literature suggests that acculturation, a process when a dominant group asserts their beliefs, values, and norms, either consciously or unconsciously, can influence an oppressed group (Wilson, 1990). More importantly, attempts were made by slave owners to replace the African culture with new ones built around the identity of slavery. Slave owners consciously treated slaves as property (Beckert & Rockman, 2016), separated families, and sold Black children who many times were the offspring of neighboring plantation owners for profit (Stampp, 1984). Through slave inheritance laws, slaves were passed down from one White family generation to the next (Beckert & Rockman, 2016). However, the Black culture and family structure were not destroyed but sustained through quasi-family units and kinship (Leary, 2005). These family units consisted of extended family structures to include aunts, uncles,

grandparents, cousins, and any individual living within the closed slave community (Leary, 2005). Unlike Europeans who function in isolation outside of kinship, African Americans maintained a communal cooperation born out of the necessity to survive (Littlejohn-Blake, Anderson-Darling, 1993). This extended family forged throughout slavery, the Emancipation Proclamation, and continues to exist even today.

Consequently, these practices, including experiences, traditions, customs, and community beliefs, are what have shaped how African Americans view society and health care organizations. For example, in the African American community, when older adults have dementia, the family takes on the responsibilities to care for their elderly (Yeo et al., 2006).

Understanding the African American culture and practices are essential for physicians and healthcare organizations providing services to the African American community. They should understand the lives of their patients, their culture, beliefs, and how African Americans make sense of a society that condoned 200-years of slavery, exploitation, and healthcare disparities (Byrd and Clayton, 2000). More significantly, practitioners and healthcare organizations should strive to improve relations with African Americans. Improving these relationships will help dispel the mistrust African Americans have for physicians and assist them to work within the cultural context of their patients (Kennedy, Mathis, eta, 2007).

Cultural Competency

Based on recent census data, America is gradually emerging into a multicultural nation. Minorities, including African Americans, Hispanics, Asians, and those labeled

others with non-European origins, currently make up over 30% of the population. As this number continues to grow, it has been projected to increase to over 50% by 2060 (U.S. Census Bureau, 2018).

Consequently, this projected increase in the minority population also draws attention to the number of patients that will require care from healthcare professionals and healthcare organizations (Kennedy et al., 2007). Additionally, because of our globalized society, healthcare professionals find themselves treating patients from various countries and backgrounds. Their patients enter their offices with language barriers, different cultural beliefs, and customs, as well as negative perceptions about healthcare providers (Kennedy et al., 2007). If not culturally competent, patients find themselves receiving treatment from physicians and healthcare professionals who know little or nothing about them.

More importantly, many healthcare professionals enter their field of study with limited or lack of cultural skills about the patients they serve. Ellen Grote (2008) asserts that educational institutions generally disregard culture, experiences, and client historical backgrounds when preparing students for healthcare and social service professions. Institutions must extend beyond the "one-size fits all" approach when treating patients and training healthcare professionals (Burns, 2014). They should offer cultural competency training and prepare healthcare professionals to better understand the various cultural attributes of their prospective patients and clients.

First, it is essential to note that cultural competency is a broad concept and used by various disciplines. It can improve the performance of professionals in cross-cultural

conditions and assist healthcare professionals working in minority communities ((U.S. Department of Health & Human Services, 2002). Studies suggest that no one can be entirely culturally competent. However, health care professionals should attempt to follow cultural competency principles that include respecting other cultures, recognize their differences, and serve others with compassion (Rust et al., 2006). Also, efforts should be made to prepare healthcare professionals and organizations through on-going cultural competency training. Two such models currently used by healthcare professionals and organizations are discussed in this section and include the Cultural Competence Model of Health Care Delivery designed by Dr. Campinha-Bacote and the Cross Model of Cultural Competence developed by Terry Cross.

The Cultural Competency Model of Health Care Delivery designed by Dr. Campinha-Bacote (2002) is based on a continuum and is an on-going process. It focuses on individuals becoming culturally competent and not being culturally competent. More specifically, becoming culturally competent involves more than just respecting another person's culture. Dr. Campinha-Bacote suggests that becoming culturally competent requires a person to be motivated and to have a desire to be responsive to patients within the context of their culture. The Cultural Competency Model of Health Care Delivery process consists of five components (Campinha-Bacote, 2002).

1. Cultural awareness- be aware of one's personal biases.
2. Cultural knowledge- become knowledgeable about the patient's culture.
3. Cultural skills- assess the client's culture, present issues, and conduct a substantial cultural assessment.

4. Cultural encounters- to dispel or adjust beliefs, attitudes, or stereotypes, meet directly with clients from culturally different backgrounds.
5. Cultural desires- healthcare professionals should be motivated and have a desire to want to be responsive to patients within the context of their culture.

(Campinha-Bacote, 2002)

Although each component of the Cultural Competency Model of Health Care Delivery is separate, all five concepts are interdependent of each other. As a result, health care providers entering the process must complete all five concepts before completing the program or training.

Another cultural competency model is the Cross Model of Cultural Competence developed by Terry Cross (1992). This model focuses on systems acknowledging and recognizing the importance of cultural competence, specifically when providing services. Cross asserts that cultural competence represents characteristics such as behaviors and attitudes that work together harmoniously. Consequently, working together allows systems and professionals to perform effective services even when in cross-cultural situations. The Cross Model of Cultural Competence consists of six stages:

1. Cultural Destructiveness- a detrimental phase when an individual sees culture as a problem.
2. Cultural Incapacity- a phase that individuals experience when they cannot handle cultural differences due to their limited skills and knowledge.
3. Cultural Blindness- unable to see other cultures outside his or her own.

4. Cultural Pre-competence- pursues information about cultural differences after identifying that differences exist.
5. Basic Cultural Competence-starts to respect, show sensitivity, and affirms cultural differences.
6. Advance Cultural Competence- now becoming culturally competent, begins to acknowledge cultural differences and inform others.

(Cross, 1992)

This model takes a system or an individual through a six-phase process. First, starting at the non-acceptance phase. Here, a person views other cultures as the problem to the acceptance phase, where the person now has an appreciation and acceptance for cultural differences. However, it is also designed to allow a person to matriculate from one phase to another based on their cultural competence level. For example, an individual dealing with race issues may have to begin at phase #1; however, an individual dealing with sexual orientation issues may have to begin at phase #4 (Cross, 1992). Cross also asserts that the time frame and matriculation process vary from one person to the next and based on how successful a person progresses from one phase to the next.

Although each model differs in its delivery format, Grote (2008) suggests that cultural competence programs follow Bloom's taxonomy of learning domains. He also postulates that the programs should encourage health care professionals to recognize, respect, be compassionate as well as identify the importance of patient, family, and community differences.

Critics of Cultural Competency Models

Critics such as Abrams and Moio (2009) posit that cultural competency models promote the concept of color blindness. This ideology suggests that treating everyone

equally in society can eliminate racism. However, this ideology places discrimination under an all-inclusive umbrella, which supports cultural harmony but ignores the differences. Carpenter-Song, Schwallie, and Longhofer (2007) posit that cultural competence models suggest that culture is constant, adaptable, and fail to acknowledge the differences between the cultural groups. Taking this approach can, many times, allow a health professional to blame culture as the cause of a patient's health condition.

Unfortunately, these critics fail to understand the need for cultural competency training. Training can help change the lens which health care professionals use when caring for individuals or groups from non-white, ethnic, or cultural origins. More importantly, healthcare professionals should understand the culture and experiences of older African Americans. They need to know and understand their experiences that include healthcare disparities because of cultural biases, racism, and segregation practices.

Healthcare and Older African Americans

For the benefit of this study, this section will provide a brief synopsis about the origins and development of geriatric healthcare in the United States. Mainly, geriatric healthcare is a specialized field of study with emphasizes for health and illnesses of older adults to include Alzheimer's. It is, therefore, necessary to discuss how, why, and when geriatric healthcare developed in the United States. Also, this section will focus on Medicaid services developed for older adults and its failure to address the health care needs of older African Americans.

First, modern geriatric health care evolved quite differently in the United States than in countries such as England. After World War II, families assumed the role of caregivers for older adults and nursing homes assumed the care for patients suffering from chronic illnesses. However, with the increased life expectancy of the older population, the medical community soon took a critical look at the demands and type of health care required for an aging population (Evans, 1997).

Over the past three decades, geriatric medicine has established itself as a significant field of study in America. It has received support from physicians, politicians, educators, as well as funding for research and education (Preyss-Friedman, 2009). As a result, the American Geriatric Society was established in 1943 and the first conference on aging sponsored by the White House in 1961. Congress also passed three pieces of legislation in 1965 that changed the face of healthcare in America for older adults (Niles-Yokum & Wagner, 2011).

To address the health and aging concerns in America, Congress passed the following significant pieces of legislation: Medicare, Medicaid, and the Older Americans Act (OAA). First, Medicare was established to provide medical coverage for older adults over the age of 65 and those permanently disabled. Medicare consisted of four parts. Part-A covers in-patient hospital services, physician costs, skilled nursing care, rehabilitation, and other services such as psychiatric care and hospice services for the critically ill. Medicare Part-B covers out-patient services, physician costs, and services such as physical and occupational therapy as well as home health care. Part-C allows individuals to enroll in private health care plans that offer Medicare benefits. Part-D offers a

Prescription Drug plan through private health insurance companies (Haber, 2013); (Hudson, 2010). Unfortunately, Medicare does not pay 100% for medical services, which forced patients to pay out of pocket, seek personal financing, or become impoverished, thereby qualifying them for Medicaid (Hudson, 2010).

Additionally, despite the health care reforms, governmental initiatives, and funding for research and education needed to improve healthcare for older Americans, state programs received inadequate funding. The money received was unevenly distributed, and because of the negative stigma given to Medicare and Medicaid, many doctors refused to provide services to individuals covered by the programs, specifically African Americans. Braithwaite and Taylor (2009) posit that states were permitted to establish eligibility guidelines. Consequently, they modify their guidelines yearly and denied benefits base on their discretion. Also, placing limits on coverage and developing policies that determined what a program would or would not pay, created financial hardships for the impoverished and the older African American population.

Healthcare Inequalities

During the 1960s, legislation was passed to prohibit these discriminatory practices and to improve African Americans' access to quality health care. Specifically, the Civil Rights Act of 1964, Medicare and Medicaid, as well as Title VI of the Civil Rights Act, passed in 1965. These laws mandated that institutions receiving federal funds should not engage in racial discrimination. They could not use race as a motive to deny individuals hospital admission and prohibited from using race as a reason to single out treatment to patients (Height, 1996).

Despite the civil rights legislation, policies, and laws, older adult African Americans continued to experience institutional racism, received inequitable treatment, and had limited access to health care. For example, during the 1960s, Congress worked to develop legislation for quality health care specifically for the poor and disabled. However, older African Americans were still denied civil rights and denied equal access to housing, education, and medical care (Braithwaite et al., 2009).

In the context of African Americans, the experiences of slavery created a sense of powerlessness. African Americans lived during an era when the local and state government, schools, health departments, and hospitals were all controlled by White middle and upper-class groups (Braithwaite et al., 2009). As a result, African Americans developed a passive acceptance of the treatment and power gained by the oppressive culture. Paulo Freire (1973), suggests that oppressed groups experience powerlessness due to combined attitudes. Powerlessness comes from self-blame, internalized racism, distrust of society, and a sense of despair. Also, research reveals that poor health experienced by African Americans historically can be linked to powerlessness (Braithwaite et al., 2009).

The years following the civil rights movement and legislation passed that prohibited racial discrimination; many African Americans realized the need for political empowerment. They realized that change could only occur, and healthcare disparities eliminated through political empowerment. For example, civil rights legislation passed in 1964, provided African Americans with upward economic mobility, better educational opportunities, the right to vote, and it opened employment opportunities (Elish, 2018).

To adequately understand health care in the African American community, it was essential to discuss the experiences of African Americans, particularly older adults, from slavery through the 20th century. This chronology revealed the experiences of older African American slaves, the treatment from slave owners, and lack of medical care. More importantly, the chronology demonstrated the long history of institutional racism entwined in the very fiber of American society. Also, despite the efforts made by the medical community and federal government to provide efficient geriatric health care for older adults, more should be done to address the discriminatory treatment and disparities in health care for older adults African Americans.

Chapter 3

Methodology

This chapter describes the procedures followed in conducting this research. It also provides the rationale for selecting a qualitative research method, outlines the research and analysis process, identifies the participants, describes the data collection methods, and provides an analysis of the procedures used in this study.

Introduction

The purpose of this study was to analyze the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community. To accomplish this, the researcher utilized a qualitative research case study analysis. The case boundary is a Midwest African American community and organizations that offer educational programs about Alzheimer's disease. It also includes two service agencies and ten (10) African American caregivers residing within the community.

The researcher selected a qualitative method, which provided a means for accessing facts about the organizations, institutions, and participants identified for this study. This method allowed the researcher the flexibility to address the research question in the participants' natural settings using exploratory approaches (Lune & Berg, 2017). Specifically, as purported by Marshall and Rossman (2002), human actions are significantly influenced by the natural setting in which they occur. Implementing a qualitative method of research also allowed the researcher to capture the participants' perspectives, attitudes, and behavior in their environment. Specifically, as an African

American woman, the researcher was able to utilize a critical lens in analyzing the participant responses with interpretive insight and trust with the African American community participants.

Research Design

A qualitative intrinsic case study was designed using triangulation methods from multiple data sources to increase validity. Berg and Lune identify three types of case studies: intrinsic case studies, instrumental case studies, and collective case studies (Lune & Berg, 2017). Using an intrinsic case study allows the researcher to understand a particular-case. Instrumental case studies focus on a theoretical explanation for a particular-issue, and collective case studies allow the researcher to contrast or compare multiple case studies.

Utilizing the intrinsic case study method allowed the researcher to organize and collect the appropriate data for this study. It also permitted the researcher to triangulate data sources and allow for the use of multiple data gathering techniques to investigate the same phenomenon (Lune & Berg, 2017). As postulated by many studies, triangulation allows a researcher to test the consistency of findings obtained through different instruments (Lune & Berg, 2017). Additionally, when conducting a case study, triangulation can increase a researcher's chance to assess some of the causes that could influence results. Oliver-Hoyo and Allen (2006) argue that triangulation involves the careful reviewing of data collected through different methods to achieve a more accurate and valid estimate of qualitative results for a particular construct. Consequently, utilizing triangulation methods provided the researcher to explore the participants' attitudes and behavior. It also assisted with identifying relationships within the participants'

environment and provided an opportunity to assess external causes that could influence the results of this research.

First, the primary research method of data collection was the in-depth interview conducted with two organizations, two service agencies, and five caregivers. According to Lune & Berg (2016), there are three types of interview structures: standardized interview, un-standardized interview, and the semi-standardized interview. The standardized or formal interview uses a formally structured schedule of interview questions and is designed to elicit information using a set of predetermined questions. The un-standardized interview (informal) is quite different from the standardized interview. It is generally used by researchers to expand their observations when working in the field. Also, the unstandardized interview is highly unstructured and has no predetermined schedule of questions. The semi-standardized interview utilizes predetermined questions asked in a systematic order. This method also allows the researcher to extend questions beyond the schedule of questions for clarity in answers from a participant (Lune & Berg, 2017). The researcher selected the semi-standardized interview for gathering data from the individual interviews and focus group interview sessions. As stated, this method will provide the interviewer the flexibility to probe outside the scheduled line of questions when necessary.

Second, one focus group session was conducted that included five caregivers from two Adult Day Care Centers and one faith-based organization, all responsible for the care of a family member diagnosed with Alzheimer's disease. According to Gall and Borg (2007), individuals selected to participate in a focus group interview must be well

informed about the research topic. Furthermore, researchers posit that utilizing focus groups in multi-method studies allows the researcher to combine two or more means of gathering data (Lune & Berg, 2017).

As such, the focus group session in this study helped determine what the participants knew about Alzheimer's disease. It also determined whether the caregivers were knowledgeable of factors contributing to Alzheimer's and whether they knew about the healthcare and support services available to individuals suffering from the disease. Additionally, it determined what limitations if any, did they feel could impede the success of the educational programs offered to the African American community.

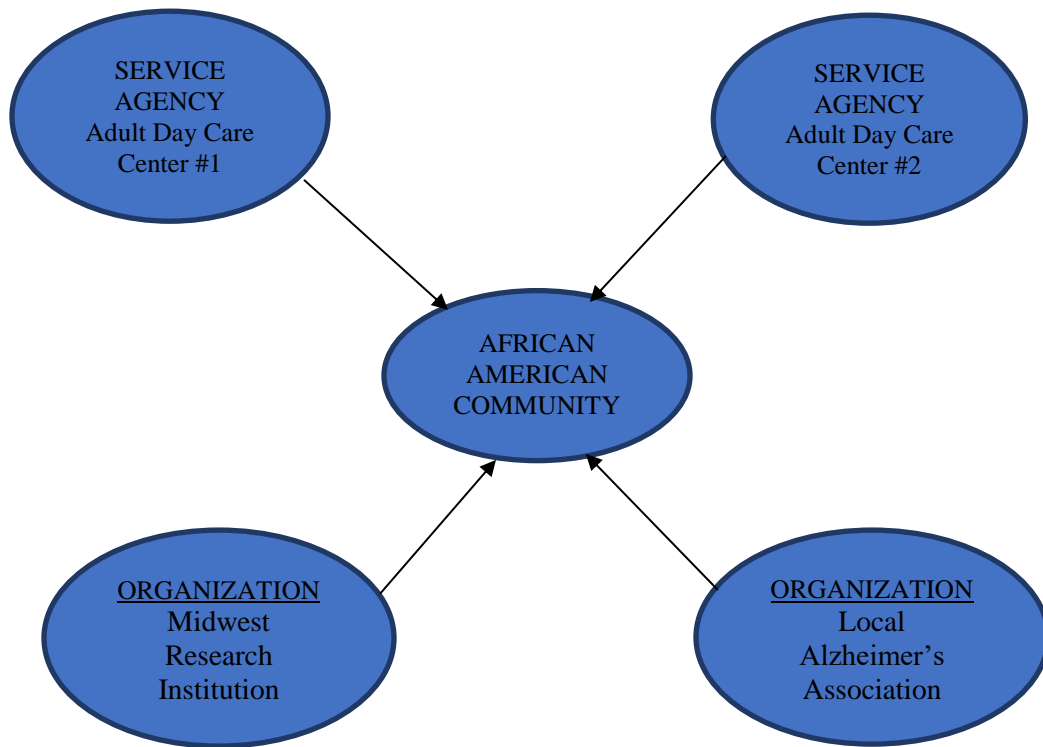
The third method in gathering data for this study was the use of a questionnaire. Questionnaires distributed to participants provide data from the respondents and corroborates the findings from other research tools. Although a small sample, the questionnaire was still used primarily to gather both quantitative and qualitative information from caregivers with family members diagnosed with Alzheimer's disease. Additionally, the questionnaires were anonymous and used to obtain information about the participants not revealed during the focus group sessions. Data obtained included demographic information, the caregivers' knowledge about Alzheimer's and personal experiences caring for someone with the disease.

Last, documents were collected to corroborate data gathered from other sources. The documents included fliers, pamphlets, or any documents germane to the research study. The researcher analyzed the information for content, language, and cultural presentation.

Participants (Sample)

The participants were not randomly selected. Based on the purpose of the study, the researcher selected the two local organizations because of the educational programs they offer the African American community. Also, the researcher selected the local service agencies because of the adult services they provide older African Americans. Caregivers recruited for the study cared for family members or loved ones diagnosed with Alzheimer's disease. Additionally, the caregivers participating in the study were recruited from two Adult Day Care Centers and one Faith-Based Organization.

First, the representatives from the two organizations include a director from a Midwest research institution and director from the Alzheimer's Association - St. Louis Chapter. The service agencies include directors from two local Adult Day Care Centers. Indicated below is the connection the two groups have with the African American community.

Figure 3.1**Community Group Relationships and Dynamics****Data Collection**

All subjects participating in this research study were required to sign a consent form as part of an approved study by the University's Internal Review Board (IRB). Additionally, the purpose of this research study was explained to all the participants and consent forms voluntarily signed.

The study used qualitative research methods for gathering and analyzing data. Also, utilizing a case study approach as a principal means of organizing and collecting the data allowed for triangulation strategies. The data collection included individual and focus group interviews, distributing an open-ended questionnaire, and collecting relevant documents germane to the research study.

Data Collection Process

The data collection process included a five-step sequence:

Table 3.2- Data Collection Sequence

SEQUENCE	DATA TYPE	SOURCE	STRATEGY
Step I	Participant consent	2 - Service Agencies 2 - Local organizations 10 - Caregivers	Discuss study and consent Provide participants with Consent Forms and obtain signatures
Step II	Interviews	1- Director-Research Institute 1- Director-Alzheimer's Ass. 5- Caregivers 2- Adult Day Care- Directors	Conduct semi-structured 45-60-minute interviews Audio record interviews Transcribe and code
Step III	Focus Group	1-Focus group (5-Caregivers)	Conduct focus group session (1-2hrs) Audio-record, transcribe and code
Step IV	Questionnaire	10 Caregivers	Distribute 2-part questionnaire 1-Open-ended questions 2-Multiple-choice questions
Step V	Data Collection	1- Local Organizations	Collect archival data relevant to the study

Step I. – Identified and contacted participants to discuss the purpose of the study. Obtained consent (Appendix A) and scheduled individual interviews and focus group sessions. Visited (2) Adult Day Care Centers to distribute information about the study, recruited prospective candidates, answered questions, and obtained signed consent letters. (Appendix B).

Step II. –Nine (9) individual 45-60 minutes recorded interviews were conducted in a comfortable setting for the participants and observations documented as well. The semi-structured interview format was used (Appendix B). This format provided a more fruitful extraction of information relevant to the study. An interview guide was prepared

in advance to ensure that the participants received the same open-ended questions. This line of questioning provided a venue to probe and ask additional questions needed to obtain in-depth information on the research subject. The interviews with the (2) key organizations and (2) Adult Day Care Center Directors consisted of questions regarding the organization or agency's role, responsibilities, cultural competency training provided to staff and opinion regarding African American community's understanding about Alzheimer's disease. The questions were also designed to obtain the participants' views on Alzheimer's outreach and educational initiative activities, progress, and effectiveness.

Interviews with five (5) African American caregivers with family members diagnosed with Alzheimer's allowed for a more intimate perspective. The interview consisted of questions about their knowledge concerning Alzheimer's disease, their family history, and the existence of other health-related illnesses. They were also asked to provide strategies they felt could improve the current strategies used by organizations to educate the African American community about the disease. Additionally, immediately following each interview, perceptions of the interviews and observation notes were documented and reviewed for clarity and accuracy.

Step III. – Conduct one audio-recorded focus group session with five (5) African American caregivers recruited from two Adult Day Care Centers, and one faith-based organization conducted at a local church in the community. The session consisted of five (5) African American caregivers responsible for the care of a relative diagnosed with Alzheimer's disease. The sessions lasted approximately one and a half hours. Also, the researcher documented the participants' interactions and behavior. The participants who completed the focus group session from start to finish received a twenty (\$20) dollar

stipend. They were given a consent letter (Appendix C) before the focus group session, which was read and signed. Also, the researcher prepared a focus group discussion questionnaire in advance (Appendix D). When completed, the researcher reviewed and compared the responses, which included documenting the data as well.

Step IV. – Distributed questionnaires to the ten African American caregivers immediately following the individual interviews and focus group sessions. The questionnaire is two pages in length and consisted of two sections (Appendix E). It included information explaining the purpose of the study and the anonymity of the questionnaire designed to maintain the confidentiality of the participants. The two sections of the questionnaire consisted of the following:

1. Demographic data- to include the participants' age, education, marital status, profession, employment status, and ethnicity.
2. Participant's knowledge about Alzheimer's disease to include:
 - a. Describing the symptoms associated with Alzheimer's disease.
 - b. Knowledge of tests available to determine if an individual has Alzheimer's disease.
 - c. Understanding health problems that can contribute to developing the disease.
 - d. Knowledge of a cure for the disease.

Participants will be allowed to answer the items in any order, take more than one sitting to complete it, make marginal comments, or skip questions (Gall et al., 1996).

Step V. –Relevant archival data and documents made available by the organizations and service agencies were collected. The data and documents collected included fliers, pamphlets, handouts, and any other documents germane to the study.

Chapter 4

Data Analysis

Introduction

The purpose of this case study was to analyze the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community. The analytical constructs used to assess the collected data included three theories: Critical Race Theory, Community Theory, and Theory of Culture. These three constructs were used to determine if they individually or collectively could influence the key criterion relative to the educational programs offered by the two organizations and the impact they have on a Midwest African American community.

The principle data collection was the semi-structured interview process that included a series of questions presented to the participants and conducted in a three-part process. This method allowed the participants to speak openly and allowed the interviewer to probe beyond the responses given (Lune & Berg, 2017). Part one consisted of individual interviews with community directors from two local organizations that included the Alzheimer's Association and a Midwest research institution. Part two included individual interviews with local service agency directors from two adult daycare centers. Part three included individual interviews with five (5) African American caregivers and one focus group interview session with five African American caregivers. Additionally, the ten African American caregivers completed a 2-part questionnaire at the end of the individual interview and focus group session.

Analysis Procedures

Utilizing the standard qualitative theme analysis procedures, the individual and focus group interviews were audiotaped and transcribed verbatim into textual data for review and accuracy. The transcripts were reread several times through an open coding (line by line) process, which helped to identify significant reoccurring themes, categories, and meaning. Saldana suggests that codes used in the qualitative analysis can be one word or several phrases that can capture specific attributes or meanings (Saldana, 2009). After reoccurring patterns emerged, they were coded according to general themes based on similarities and analyzed for consistencies or reoccurring words and phrases. The researcher then identified the words and narratives that gave voice to the participants.

Discussion of Analysis

Part I – Local organization Interviews

The directors from the two local organizations were selected for this study because of the programs and research opportunities they offered the African American community about Alzheimer's disease. Particularly, the Alzheimer's Association was selected because of the organization's mission to advise and educate communities about Alzheimer's disease. The Midwest research institution was selected because of the organization's objective to educate African Americans community about Alzheimer's disease and encourage African Americans to participate in Alzheimer's research. Both participants agreed to participate in a 45-60- minute face to face interview, as outlined in chapter 3 – Methods. The researcher contacted the participants by telephone to request their participation in the study and schedule an interview at an agreed location. A follow-up call was later made to confirm the scheduled dates and to discuss the purpose and content of the consent letter that all participants were required to sign before participating in the study. The researcher informed the two directors about the anonymity of the study

and provided them with a contact at the university if they had any additional questions about the study. Additionally, the interview with the director from the Alzheimer's Association director took place in December at a local university and the interview conducted with the Midwest Research institute director in November at her office.

After completing the interviews, transcriptions, and coding, general themes emerged and categorized. The common themes revealed the following: 1. Cultural awareness is critical when working with the African American community; 2. Engaging African Americans in discussions about Alzheimer's disease is difficult; and 3. Goal is to educate the African American community about Alzheimer's disease.

Theme 1: Cultural awareness is critical when working with the African American community

Theme one reflects the responses from the two community organizations participating in this study regarding cultural competency. Both directors during the interviews indicated that their respective organizations, at some point, realized the importance of understanding and recognizing the culture of the community that they served. Consequently, both developed on-going cultural competency classes and programs designed to educate their staff about the diversity and cultural differences of the African American community. Recognizing the importance of diversity and cultural competency training, the Alzheimer's Association also requires the Board of Directors to participate in the diversity and cultural competency training as well. Responses from the directors are as follows:

Midwest Research Institution

“Dr. Jones made sure that our organization received training so, that is a plus for him. Now, let's fast forward that was about five years ago, fast forward, the university has implemented diversity, and cultural awareness program, and our department has participated and gone through it. There like four levels of it and our department has gone through all of them.

Alzheimer's Association

“I personally am one of those people who believe that cultural competency is not a destination, but a journey, and you get better every day at what you do. So, some things that we require are standards, and every person that comes on to our organization goes through a 2-part cultural competency training.”

“... We're constantly confronting almost the institutional bias and institutional racism that we see in our culture and fighting against that. Not being passive to it but really fighting against it. Two things we've done recently that I'm proud of is one, the entire Board of Directors have gone through cultural competency training. It's interesting because some of them don't come from that background. Some of them don't come with; they've built their business in corporate America on their own foundation. So, it's interesting to challenge some of their assumptions and opinions. That was an interesting experience.”

Theme 2: Engaging discussions with African Americans about Alzheimer's disease can be difficult.

The transcribed narratives in theme two reveal that both organizations encountered similar experiences from the community when attempting to engage individuals in discussions about Alzheimer's disease. Explicitly, the directors expressed how African Americans are generally afraid, embarrassed, and reluctant to talk about Alzheimer's.

Midwest Research Institution

“They are embracing it. It was a process.....” “There was an incubation period; I call it that. In terms of getting the word out, what are we doing? What are we talking about? Alzheimer's disease, in my estimation, was like when someone said they had cancer. No one talked about it. It was the C-word that you did not talk about. And so, our thrust in seeing growth in that area with respect to getting the word out about Alzheimer's disease. That knowledge is power, and the more, so you know about it, the more you understand it and do not have that attitude of not talking about.”

Alzheimer's Association

"There are so many people afraid to talk about Alzheimer's. Very similar to how they use to talk about cancer where you kind of whisper about it or keep it in the closet. And I particularly see the younger generation being bold about that and confronting the disease and saying we cannot just keep this in the closet. So, I think more and more community partners who are out there educating about the disease and recognizing that it is not a part of normal aging, and this helps. It's ok to ask for help. That's the biggest thing we look for."

As demonstrated from the narratives, the two organizations emphasized the challenges they experience when engaging African Americans in discussions about Alzheimer's. They compared it with trying to encourage participants to talk about cancer, which is another illness many African Americans avoid and prefer not to discuss.

Theme 3: Goal is to educate the African American Community about Alzheimer's Theme three disclosed the efforts made by both organizations to educate the African American community about Alzheimer's disease. The Midwest Research Institute utilizes several different strategies to include partnerships and working with local professional organizations. The Alzheimer's Association also utilizes local professional organizations, but she indicated that partnerships with faith-based groups in the community have been much more successful.

Midwest Research Institute

“My primary aim is to increase the awareness of Alzheimer's disease and uh, and to get African Americans to participate in research at (Midwest Research Institution)?

“We have... we have offered workshops to one of the several of the LINKs organizations in the city, and we do, do that. We do offer workshops in that regard. But our thrust is to, as I mentioned, we have an organized list of organizations, and then we also invite and make it known throughout the community through our health fairs and other health resource initiatives.” “Our common goal is to cure and prevent Alzheimer's disease.”

Alzheimer's Association

“So, our goal is to reach more African Americans than we currently are. We are right now serving more than the metropolitan statistical area tells us that we should, based on population. So, if you look at numbers or percentage of African Americans in the community, Uh, we're serving more than that. But we believe that we should be serving twice as many people or that twice as many people have the disease that we are currently serving.”

Recognizing the importance of establishing collaborations with key groups and organizations within the African American community, the director provided the following statement.

"Our most successful program to reach African Americans is our faith in outreach programs. So, we formed this about five years ago, where we partner with a congregation to put in a volunteer who is the bridge or liaison between the Alzheimer's Association and that church. And that volunteer's job is to bring education to the congregation...."

Part II – Service Agency Interviews (Adult Day Care Centers)

The two Adult Day Care Centers provide services to older African Americans residing within the African American community and selected for that reason. As service agencies located in the African American community, their agencies are under the direction of the State Department of Human Services. Also, because of the services they provide, they would recognize the organizations visible in the community responsible for providing services to older adults diagnosed with Alzheimer's disease

Both service agency participants agreed to a 45-60-minute face to face. The researcher contacted the directors by phone to request their participation in the study and to schedule an interview. Both interviews were conducted in November and held at their respective offices. The participants received consent letters, which they were required to read and signed before the interviews. After completing the transcription and coding process, the following specific themes emerged.

Theme 1: Understanding culture is important when working with community

This theme reflects the responses made by the two Adult Day Care Center directors participating in this study and their position about cultural competency. Although answers varied, responses revealed that both directors recognized the importance of understanding and recognizing the cultural differences of the community, as demonstrated in the narratives below.

Adult Day Care Center #1

“We do a lot of in-servicing, uh, with our staff.... Because you, it's differences in how you take care of somebody.”

“So, yes, we do in-service, we've had uh, employees sent to workshops, work programs, you know, uh, to get training.... They offer the workshops and things like that dealing with the different diagnoses, behaviors, things like that.”

Adult Day Care #2

“We always enhance diversity with working with our participants and employees...”

The narratives reveal that although the directors were not familiar with the concept or actual definition of cultural competency, both recognized the need to understand and recognize the diverse populations they serve.

Theme 2: African American Community is not aware of available support services

According to the narratives from the service agency directors in theme number, residents in the African American community are not aware of the services available to those diagnosed with Alzheimer's disease or other cognitive related illnesses. Also, Adult Day Care Center #1 participant indicated that her agency operates two locations, one in the City and one in the County. Working at both locations that served different populations, she recognized that individuals at the county location had better access to support services than individuals residing in the city.

Adult Day Care Center #1

“I think that there is a lot that needs to be done. I don't think they always have the resources available or know where to go to get the resources.”

“You know, uh, I do a lot of referring back to the different associations to try to get the family in participant education and different support groups or programs that are available. But I don't think that if you are just out in the community, that you have access to that.”

"I think in the city...I don't think they have enough resources, you know, I think more of my participants that I have in my other building are mainly from Webster Groves or

St. Louis County, and I think they have better access than someone that lives in the city."

Adult Day Care Center #2

"I believe that the African American community does not know a lot about the programs that can be help for the clients and the community in general because we don't know what we have out there unless we research and it's kind of hard because a lot of companies are saying they don't have those funding, those funds available."

Recognizing the disparity of available services to the African American community, the director also stated:

"They are not aware of the support. Just like a lot of people are not aware of the grants that the Alzheimer's Association offers. It may not be much, but it helps when you need to relieve for those family members who are the caregivers in the home."

Part III – Caregivers

Part III consisted of individual interviews and a focus group interview session with ten (10) caregivers. The caregivers selected were African Americans recruited from the two participating Adult Day Care Centers. However, due to the limited number of responses from the Adult Day Care Centers, volunteers from a local faith-based organization agreed to participate in the study as well. The researcher selected the ten caregivers because of the roles they played as a caregiver for a family member or friend diagnosed with Alzheimer's or other cognitive diseases.

Five African American caregivers agreed to participate in an individual forty-five to sixty-minute face to face interview. Also, a group of five African American caregivers agreed to participate in an hour to two-hour focus group interview session. As outlined in chapter three regarding the data collection process, each caregiver was contacted by telephone to confirm their participation and to confirm the date, time, and location of the interviews. Additionally, the caregivers received consent agreements, which they read and signed before the interviews. The consent agreements provided the caregivers with information regarding the purpose of the study and the assurance that all interviews were confidential. It also provided a contact name at the University for any questions the caregivers may have about the study.

The individual and focus group questions requested information from the caregiver about their personal experiences, relationship to the patient, and the stage that the family member received a diagnosis. They inquired about the caregiver's perception of the care provided by the physicians and whether the physicians demonstrated any biases or lack of cultural competency. Also, the questions obtain information from the caregivers about their awareness of organizations offering educational programs about Alzheimer's disease in the community and if they understood the factors contributing to the disease.

For clarity, the individual face-to-face interview and focus group interview methods allowed the investigator to compare the individual caregiver responses and focus group interview responses. Specifically, utilizing this strategy allowed the researcher to analyze and compare the individual and ten caregiver responses for consistency.

Finally, both the individual caregivers and focus group participants completed a two-part questionnaire. Section one of the questionnaire provided demographic information respective to gender, age, marital status, educational levels, employment, and ethnic/racial heritage. This information was analyzed to determine participants' similar backgrounds and differences as caregivers. Section two of the questionnaire consisted of multiple-choice questions to determine the similarities of the ten (10) caregivers such as family history and personal knowledge about Alzheimer's disease. The information obtained about the caregivers is in table 4.1 below.

Table 4.1

Demographic information for African American Caregivers (N=10)														
Sex		Age			Educational Level			Employment		Knowledge				
Male	2	20%	40-50	1	10%	High School	2	40%	Employed	5	5%	Aware	4	40%
Female	8	80%	51-60	3	30%	College	8	80%	Unemployed	1	1%	Limited	6	60%
			61-70	4	40%				Retired	4	40%			
			71-80	2	20%				Laid-Off	0	0%			
			81+	0	0%									

The data collected revealed that 80% of the caregivers were female, which coincides with the literature regarding gender and caregivers (Family Caregiver Alliance, 2019). The median age was 63 years, and educational levels ranged from high school through college. Sixty (60%) were employed, and 40% retired. Additionally, 40% were knowledgeable of Alzheimer's disease, and 60% had limited knowledge.

Caregivers - Individual Interviews

The research conducted individual face to face interviews with the five African American caregivers (CG) between November and March. Caregiver #1 agreed to meet at her place of employment after work; caregiver #2 agreed to meet during lunch at a local library. Caregivers #3, #4, and #5 consented to meet at a local church on a Wednesday night before Bible Study.

Three common themes emerged from the individual caregiver interviews, which included the following. (1) Late and undetermined diagnosis about Alzheimer's diseases, (2) Limited knowledge on factors contributing to Alzheimer's disease, Institutions, and (3) Organizations educating African Americans about Alzheimer's disease are not visible in the community.

Theme 1: Received late and undetermined diagnosis about Alzheimer's disease

The first theme represents responses made by the caregivers regarding the initial diagnosis received from their treating physicians. Specifically, the narratives are responses from the caregivers regarding whether the family was informed at the beginning, mid, or final stages of Alzheimer's the disease? The responses varied; however, the majority indicated that they did not receive a final diagnosis until the mid or final stages of the disease. More alarmingly, Caregiver #2 indicated that the family was not given an official diagnosis until after her mother sustained a severe fall in a hotel bathtub.

CG001 – “Uh, from where I come in with him, they told me that he had uh, full I guess you would consider 100% uh, form of the disease, final stages uh, uh.”

CG002– “Uh, I want to say it was the early...mid stages of the disease because at first it was just seen as maybe dementia or just because she was an older lady, they just thought oh, memory loss. But then uh, like I said, she had a fall and when she slipped in the tub uh, uh, in a hotel and uh, upon that uh, incident, after that incident....”

CG003 – “Hum, we kind of learned it was toward the late stages.”

CG004 – Uh, I think my brother was diagnosed, probably like, like, the midpoint."

CG005 – "I didn't attribute a lot of that forgetfulness to dementia or Alzheimer's because of her age...was just overbearing, and we found out later."

Theme 2: Had limited knowledge on factors contributing to Alzheimer's disease

Theme 2 emerged from responses to question #4, indicated in the narratives below. Question #4. "Are you aware, or were you ever informed of possible factors that cause or contribute to a person developing Alzheimer's disease or other memory loss disorders?"

The second theme reveals that many of the caregivers were not knowledgeable of the factors contributing to Alzheimer's disease.

CG001– "Um...yes, but uh, not truly understanding for as what actually could start happening as far as health-wise uh..... Yes, I've heard of it; I've heard of it. I'm not really aware of it."

Caregivers not fully aware of factors contributing to Alzheimer's disease responded with factors not recognized by medical professionals. For example, responses from caregiver #2 below.

CG002 - "I've heard of many things. One, uh, aluminum, metals uh, can cause and, environmental factors.... cause the brain to uh, to lose uh, brain cells, neutrons, and electrons losing uh, their connections due to environmental factors. So, uh, cans, aluminum and I also found that uh, though, uh my uh, investigations and reading up on it that some brains that have been dissected after uh after death, uh, been found with pieces of aluminum inside of them."

CG005 – "It was a learning experience. You learn things when you have to deal with things, and so, no, I had no clue."

Theme 3: Organizations providing educational services are not visible

Narratives for the third theme represent responses from question #7. Are you aware of the local institutions and organizations in your area responsible for educating the African American community about Alzheimer's disease? The responses reveal that caregivers in this study are not aware of the Alzheimer's Association or Midwest Research institution. More importantly, they are not aware of their goals, educational programs, partnerships established with groups in the community, or the support services available to families caring for individuals diagnosed with Alzheimer's disease.

CG001 – "Uh, uh, I never even knew they existed."

CG002– "No.... If they were around, in my opinion, they did not do a good job of

advertising. Because I live in the African American community, and I've not heard of any of them."

CG004 – "I don't know if they've been effective. I don't think so. I don't know; maybe I wasn't in the right place."

CG005 – Uh, I don't think they are doing a good job with it all.... because more people should know about it."

Focus Group Interviews

Five caregivers agreed to participate in a one or two-hour focus group (FG) interview session. The focus group session occurred in April and because of conflicting work and personal schedules, held on a Saturday afternoon at a local church. Also, the five caregivers were asked a series of ten questions and responded individually or collectively. The researcher transcribed the audio-recorded interviews, analyzed the transcriptions, and coded the data discussed in chapter three. Consequently, four common themes emerged. 1. Medical professionals do not always provide adequate information to patients; 2. There is an uncertainty of physician's cultural competency levels, 3. African Americans have limited knowledge about factors contributing to Alzheimer's disease, 4. Organizations responsible for educating African Americans about Alzheimer's have limited visibility and involvement in the community. The transcribed narratives from the focus group interview sessions are provided below for each theme.

Theme 1: Medical professionals do not always provide adequate information to patients

Theme one reveals the opinions that the focus group participants had about their physicians. Specifically, this theme emerged on responses from the caregivers regarding their perception of whether physicians provide patients sufficient information about Alzheimer's disease. Also, did the physicians offer available support services that assisted them in making sound decisions about medical care? Four of the five focus group participants felt that treating physicians failed to provide sufficient information about Alzheimer's disease or provide information about available support services. According to the caregivers, treating physicians only provided the family with brochures and handouts about Alzheimer's disease. Also, several caregivers indicated that they obtained additional information from personal research and investigation conducted by the caregiver.

FG (participant) - "For me uh, I was pretty much handed, I mean, brochures, I mean, and it was on me to take the initiative to read and try to inform myself about it..."

FG (participant) - "In my brother's case, he is living with another brother, and he finally convinced him to go in for care.... They just came away saying well; he needs medicine."

FG (participant) - "... the physician did not uh, educate us in what was going on. He told us that uh, at momma's age uh, that's pretty much normal that uh, you know, the forgetfulness. We didn't get a clear uh, understanding exactly what was going on with momma until 2010 until the speech started going."

FG (participant) - "Uh, no, they did not. I did my own research."

FG (participant) - "No" (Five participants respond in unison).

Additionally, the caregiver expressed that many times, physicians not only failed to provide them with information about Alzheimer's disease but demonstrated a lack of concern about the patient and family members.

Theme 2: There is an uncertainty of physician's cultural competency levels

The second theme answered interview question four: "Can you describe the treating physician's level of cultural sensitivity or awareness when meeting with you, the family or patient. Several of the caregivers were unfamiliar with the concept of cultural competency. However, they expressed that their physicians did not acknowledge or show any sensitivity to their culture.

FG (participant) – "I think there can be more uh, a better effort to understand the culture."

FG (participant) – "For me, uh, I was just going off what they said or what they gave me."

FG (participant) – "Uh, no because when she would have appointments and stuff, he would be concerned with her physical condition...."

FG (participant) – No, uh, physicians are not knowledgeable or as far as the culture concern, no."

FG (participant) – "My doctor was just focused on health problems, and a lot of times we'd have to call him..."

Theme 3: African Americans have limited knowledge about factors contributing to Alzheimer's disease

The third theme represents responses to interview question #5- Can you share with the group the factors you feel may contribute to a person developing Alzheimer's disease? Based on the narratives, many of the participants were unfamiliar with the factors that contribute to a person developing Alzheimer's disease or other cognitive related illnesses. Several identified environmental factors such as gas fumes, possible illness' or other unrelated factors that demonstrate the need to educate the African American community about Alzheimer's disease.

FG (participant) – "No, but I do know for a fact that momma is diabetic." "And, she has high blood pressure. So, no, I've never, this the first time even hearing this..."

FG (participant) – "Uh, and environmental, substances such as living in a house that has uh, gas. I've gone into some people's homes, and they, you could smell gas when you walked into the house. You could smell fumes, and they have lived in this all the time, and their behavior was such that uh, you'd wonder if they had been in a different environment what would take place."

FG (participant) – "No, um, because of my profession, I know some things can contribute, but I was never told, and a lot of what I've learned is through the Alzheimer's Association."

Other responses from the caregivers regarding factors contributing to Alzheimer's

demonstrate the lack of understanding and a need for effective educational programs that include the following narratives.

FG (participant) – "No, because my mother had never gone into the hospital.

She never, she had surgery when I was a baby, but she almost had perfect health continuously."

FG (participant) – "No, she never had no illnesses."

Many of the responses reveal that the caregivers in this study were unclear or had no knowledge of the factors contributing to Alzheimer's.

Theme 4: Organizations responsible for educating African Americans about Alzheimer's have limited visibility and involvement in the community.

The narratives below represent responses to interview question #6: Do you know of any local organizations responsible for alerting African Americans about Alzheimer's disease in your community? The transcribed narratives reveal that four of the five participants were not aware of organizations operating in the community responsible for alerting the community about Alzheimer's disease. Consequently, they were not aware of the outreach or educational programs provided by these organizations. Information that they did receive about the two organizations they obtained by word of mouth or received by mail. However, they received no follow-up from either of the two organizations.

FG (participant) - "I would say that they can do better because the stuff that I've learned about Alzheimer's was through experience and then with the googling it you know and that's the stuff from the most part that I've learned about it."

FG (participant) – “I don't know if they've been effective.” “I mean, are they in the churches?” “I mean places where African Americans at?” “I mean, you know, that's the only way we would know or find out about it.”

FG (participant) – “Uh, I don't think they're doing a good job with it at all. I'll be honest, uh, because more people should know about it.” “You know, didn't know any, I mean I've heard of it, but I didn't know the effects of it and how serious an uh, how dangerous it is until I dealt with someone that had it.”

FG (participant) – “All I know is that they exist. I think I got something in the mail for my mom. That was it, a packet.... that was about it.”

FG (participant) – “He got something in the mail in the mail. I don't think he read it. It didn't get his attention enough. “I asked him one day; I said, “Did you read the stuff?” “He said, “I can't read all that it's too much.”

FG (participant) – “Uh, I don't think they're doing a good job with it at all. I'll be honest because more people should know about it. You know, I didn't know any, I mean I've heard of it, but I didn't know the effects of it and how serious and uh, how dangerous....”

FG (participant) – “Not until my mom was involved did, I get more involved with it and was through the Alzheimer's Association.”

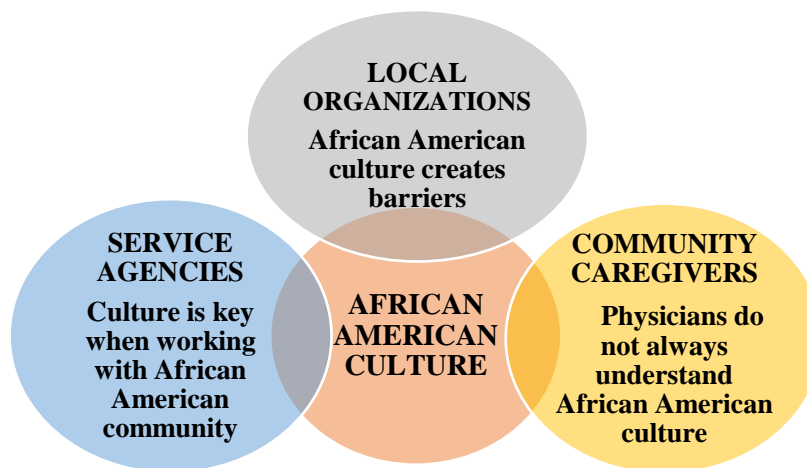
Not knowing was paramount for many of the caregivers participating in this study. For example, many of the caregivers' associated memory loss to just growing old. The caregivers had minimal to no information about Alzheimer's disease and according

to responses, never received adequate information from treating physicians. More importantly, they did not know what to do for a family member diagnosed with the disease or what to expect.

Group Cross-Theme Analysis

Finally, the data collection for this study included the individual interviews conducted with the two organizations, two service agencies, five (5) caregivers, and five (5) focus group participants. During the original coding process, the investigator recognized several themes that the three groups shared. As a result, the investigator conducted a cross-theme group analysis which revealed the African American culture as a common theme intersecting all three groups shown below.

Figure 4.1
Group Cross-Theme Analysis



Cross-Theme Analysis

Organizations

The two directors acknowledged the importance of understanding the culture of the communities they serve. Both directors emphasized the need for their staff to be culturally competent, although, working within the parameters of the African American culture has been challenging. For example, the community director of the Alzheimer's Association stated, "But overarching, the biggest challenge that we have in servicing the African American population is a deep-seated cultural value to care for one's self and not necessary to accept help from an outside organization like ours." The director from the Midwest Research Institution during her interview discussed the deep-rooted cultural fear that older African Americans from the region have about participating in research. She stated, "...if you're not from here, you don't know the history of Barnes Hospital, Barnes Jewish Hospital and what African Americans went through with that. Uh, some years back, only pregnant women could be at Barnes, and they had their babies in the basement." So, and then the Tuskegee, I guess, is the other one. So, history caused that distrust, and it has taken many a year to trust me."

Service Agencies

The two adult daycare service agencies located within the African American community provide serves primarily to older African Americans. During the interviews, the two directors emphasized that understanding a client's culture is a crucial objective for their agencies. Also, despite limited resources, management includes cultural competency training during in-service meetings. The director from service agency #1 stated, "There's...we do a lot of in-service uh, with our staff.... we do in-serving, we've

had uh, employees sent to workshops, work programs, you know, uh, to get training."

The director from Service Agency #2 indicated that the agency always encouraged diversity and stated, "We always enhance diversity when working with our participants and our employees."

Caregivers

Several caregiver responses focused on the physician's lack of understanding about the African American culture. One caregiver stated, "I think there can be more uh, a better effort to understand our culture." Other examples of responses from the caregivers include the following:

"Like he really didn't have any knowledge of her background, didn't make inquiries about uh, the ethnic uh character."

"No, uh physicians are not knowledgeable or as far as the culture is concerned, no."

"My doctor was just focused on health problems...."

Based on the examples, many of the caregivers who participated in this study felt that their treating physicians did not focus or attempt to understand the African American culture. Several felt that physicians primarily focused on scheduling appointments and writing prescriptions.

In this chapter, the researcher presented the participant narratives around key themes that emerged from the analysis of the transcribed interviews from the local organizations, service agencies, and ten caregivers. Additionally, a survey/questionnaire

provided demographic information about the ten African American caregivers. Finally, chapter five will provide the summary of findings, results, conclusion and suggestions for further research.

Chapter 5

Summary of Findings, Conclusion and Recommendations

Findings

Organizations

The organizations participating in this study include the Alzheimer's Association and a Midwest Research Institute. Both organizations offer educational programs on Alzheimer's disease to individuals residing in the community. During the analysis of the data collected from individual interviews with directors from both organizations, three major themes emerged.

1. Cultural competency training is necessary when working within the community.
2. Discussions with African Americans about Alzheimer's disease can be difficult.
3. Goal is to educate the African American community about Alzheimer's disease.

The three themes suggest that the prime objective of both participating organizations is to educate the African American community about Alzheimer's disease. To accomplish this, the two organizations established collaborations with several groups within the community, sponsored various activities, and require their staff to participate in cultural competency training.

As discussed in the literature, community represents a group of people who share common goals, interests, attitudes, struggles, ideologies, and behavior (DeFilippis &

North, 2013). Understanding these characteristics can assist organizations working with minority groups. Also, consistent with theories on cultural competency, recognizing a group's culture and implementing diversity training for personnel can improve the quality of services offered to minority communities (Cross, 1992). Particularly, cultural competency and diversity training will allow organizations to understand that the “one-size fits all” approach will not work for all communities (Institute for Healthcare Improvement, 2019).

Second, the study reveals that both organizations encounter communication barriers, which in turn, create obstacles when interacting with the African American community. For example, according to both directors, despite efforts made to encourage African American caregivers to participate in research or discussions about Alzheimer's, many refused to discuss their personal experiences. Caregivers are apprehensive when asked health-related questions or when asked to participate in group discussions about Alzheimer's. Consequently, studies reveal that factors contributing to these barriers include culture, education, race, family dynamics and mistrust of healthcare professionals (Cuevas, A.G., et al., 2016).

Research reveals that the family structure or dynamics, has always been the foundation and focus of the African American community (McCoy, 2011). The family structure consists of norms, values, traditions, and emotional bonds that have been passed down from one generation to the next (Scott, 2005). Based on this study, the African American family bonds, values, and traditions are significant factors that create communication barriers for both organizations. Essentially, it is because of the family norms, values, and traditions that African Americans are less likely to solicit outside

support when caring for older adults (Pharr, J., Dodge, C. & et al., 2014). Because of family norms, African Americans many times refrain from discussing family matters outside the family unit and less likely to participate in educational programs that exclude family. Consequently, this study reveals that these determinants have created communication barriers, which have negatively influenced the key criterion relative to the educational programs offered to the African American community.

Finally, this study reveals that despite the communication barriers, the two organizations continue to pursue their mission in educating the African American community about Alzheimer's disease. Specifically, utilizing a community development model, they engage in partnerships and collaborations established to improve the health conditions of the community (Cavage, 2016).). An example is the Alzheimer's Association's Ambassador Program with faith-based churches in the African American community. Through this program, they train delegates, provide materials about Alzheimer's disease, offer shadowing opportunities for delegates, and provide some level of oversight. Also, the Midwest Research Institute partners with various groups in the community, such as the LINKS, Alpha Kappa Alpha Sorority, Omega Psi Phi, and other local agencies. Through these partnerships, they offer informational sessions about Alzheimer's research, conduct workshops, distribute literature about Alzheimer's research and sponsor an annual luncheon for partners and financial donors.

Service Agencies

The findings in this section encapsulate the themes, which emerged during the interviews with the local service agency participants.

1. Understanding client culture is essential – (Culture Competency)
2. African American community is not aware of available health support services.

Located in the African American community, both agencies offer adult day care services to older adults. The two directors were unfamiliar with the concept of cultural competency; however, the agency administrators recognized a need for all staff to respect and understand the culture of the clients they serve. Consequently, Adult Daycare Center #1 incorporates cultural competency and diversity discussions with weekly staff meetings. Adult Day Care Center #2 provided information to staff about their client's culture and ensure that they recognize client cultural differences as well.

The second theme suggests that the two service agencies recognize that African Americans in the community are not aware of the healthcare or support services available to individuals diagnosed with Alzheimer's disease. Specifically, healthcare support services are services provided to patients during recovery that restore and improve one's quality of life (Aging in Place, 2019). According to both service agency directors, African Americans residing in urban areas are generally unaware of available healthcare and support services. Service Agency #1 director manages two adult daycare facilities with one located in the city and the other located in the county. More significantly, Adult Day Care #1 director indicated that African Americans residing in the city receive substandard support services and stated, "...I don't think they have enough resources, you know...I think more of my participants that I have in my other building are mainly from ...St. Louis County and I think they have better access than someone that lives in the city. It is important to note that the comparison provided may account for the

disparity of services provided. Specifically, according to the United States Census reports, African Americans make up 49% of the population living in the Midwest City and only 23.3% reside in the county (U.S. Census, 2010). This may have some bearing on the statements made by both agency directors.

The director from Adult Day Care Center #2 stressed how many of their African Americans clients are unaware of the services and funding available to caregivers and older African American adults. These services include respite care funds for caregivers, transportation services available for doctor visits, or funds accessible to individuals caring for a family member. More importantly, the director emphasized that many African Americans are not aware of the healthcare information or support services available to families caring for older adults living with Alzheimer's disease.

Caregivers

Research suggests that due to the demographic changes in age and ethnic composition in the United States, African Americans are at a higher prevalence of Alzheimer's disease compared to Whites (AA, 2018). Based on this study, factors contributing to these high prevalence rates include healthcare disparities, late diagnosis received from treating physicians, lack of education about Alzheimer's disease, and cultural differences. Other factors include diabetes, cardiovascular disease, hypertension, high cholesterol, obesity, diet, and lack of physical activity (AA, 2018).

This section will discuss the five themes that emerged from interviews conducted with the ten (10) caregivers participating in this study. The themes support the research regarding factors contributing to the high prevalence rates of African Americans and

Alzheimer's disease (AA, 2018). They also suggest that in addition to healthcare disparities, African American caregivers encounter other circumstances that contribute to the challenges when caring for a family member diagnosed with Alzheimer's disease.

The five themes are as follows:

1. Receive late and undetermined diagnosis of Alzheimer's disease.
2. Medical professionals do not always provide adequate information to patients.
3. There is uncertainty about a physician's cultural competency levels.
4. African Americans have limited knowledge about factors contributing to Alzheimer's disease.
5. Organizations responsible for educating African Americans about Alzheimer's have limited visibility and involvement in the community.

First, many of the caregivers stressed the challenges they experience when caring for a family member diagnosed with Alzheimer's disease. Many encountered a disease they knew nothing about that included preventive care, factors contributing to the disease, or the long-term debilitating effects of the disease. Also, several caregivers expressed how, after several doctor visits, the doctors finally gave them an Alzheimer's diagnosis, which in the 3rd or final stages of the disease. One caregiver stated,

"... He told us that uh, at momma's age uh, that's pretty much normal that uh, you know, the forgetfulness. We didn't get a clear uh, understanding exactly what was going on with momma until 2010 until her speech started going."

Additionally, they indicated that treating physicians failed to provide families with adequate information about Alzheimer's disease. Studies show that patients who are

informed about their health and factors contributing to certain illnesses, generally make better healthcare decisions (Warren et al., 2012). As one caregiver stated, "...the physician did not uh, educate us what was going on." The responses suggest that physicians who fail to educate their patients or explain what to expect as the disease begins to progress, leave patients unprepared for the inevitable.

The themes also suggest that health care professionals lack cultural competency skills. Specifically, the caregivers felt that many health care professionals do not understand the barriers, language, lived experiences, or reasons older African Americans distrust healthcare professionals. As one caregiver stated, "I think there can be more uh, a better effort to understand our culture." Also, several caregivers emphasized that treating physicians did not attempt to understand the African American culture but instead focused on rescheduling appointments and writing prescriptions. Several other caregivers stated,

"My doctor focused on health problems...."

"...Uh, like he really didn't have any knowledge of her background, didn't make inquiries about uh, the ethnic character."

"No.....physicians are not knowledgeable or as far as the culture is concerned, no."

As posited by many studies, healthcare professionals and organizations do not understand or respect the culture of minority populations, specifically African Americans (Kennedy et al., 2007). This lack of understanding and respect leads to mistrust by minorities of healthcare professionals, thereby creating a culture of fear (Kennedy et al.,

2007). As a result, African Americans avoid participating in research studies, become apprehensive when asked to engage in discussions about Alzheimer's disease, and are less inclined to discuss their symptoms with treating physicians.

More importantly, health literacy reports reveal that minority groups to include African Americans, are generally less informed of the factors or risks contributing to Alzheimer's disease (Luri et al., 2009). These reports align with theme #4 regarding the limited knowledge minorities have about the factors contributing to Alzheimer's disease. For example, two of the caregivers stated, "Um, yes, but uh, not truly understanding as far as what actually could start happen...."

"No, but I do know for a fact that momma is diabetic...so, no I've never; this is the first time even hearing this."

Other responses given by caregivers in this study supporting the literature regarding the misinformation on factors contributing to Alzheimer's disease by African Americans include the following statements, "I've heard many things. One, uh, aluminum, metals, uh, electrons losing their connections due to environmental factors." Another caregiver stated, "Uh, and environmental, substances such as living in a house that has uh, gas (Lurie et al., 2009)."

The responses from the caregivers demonstrate the limited knowledge African Americans have about Alzheimer's disease. More importantly, studies on minority health education suggest that low health literacy can contribute to poor health, inappropriate health behavior, poor health choices, and inadequate health care (Lurie et al., 2009).

Finally, theme #5, reveals that the African American caregivers participating in this study were not aware of the organizations offering educational programs and services to the community about Alzheimer's disease. Particularly, several of the caregivers emphasized that the organizations were not visible in the African American community and felt that they needed to do more. Statements from the caregivers include:

"If they are working in the community, where are they, and I think they are not doing a good job?"

"I don't know if they've been effective. I mean, are they in the churches? I mean places where African Americans at? I mean, you know, that's the only way we would know. You have to be seen; you have to be visible." Other statements from caregivers regarding the two organizations visibility in the African American community included,

"All I know is that they exist."

"No, this will be the first time I've sat and talked with someone that's professional in that field; you know that tried to get some answers or either give some answers on what I experienced and what did happen, you know."

The responses from the caregivers draw attention to the type of relationship the organizations offering educational programs have with the African American community. As discussed in the literature, many times, organizations and institutions will identify the needs of a community and strategies to implement without consulting individuals living in the community (Reardon, 2000). For example, the University of Illinois Urbana-Champaign East St. Louis landscape architectural and urban planning project. Two years

into the project, during an assessment phase, residents expressed their dissatisfaction with the urban planning project because the university did not engage the community in the development and execution of the plans (Reardon, 2000). This example demonstrates what can occur when organization's focus on meeting their own objectives and not the community needs. The relationship is not reciprocal but one sided. Additionally, in this type of relationship, the community representatives may appear to be the voice of the community; however, they are merely following instructions from the partnering organization. More importantly, this type of relationship can be ineffective and can reduce the visibility of the partnering organization working within the community.

To increase an organization's visibility within a community according to Yeo et al., and other researchers require creating an engagement relationship (Yeo et al., 2006). In this type of relationship, an organization works to establish a permanent collaboration with a community. The organization does more than provide a temporary fix, for an immediate crisis such as the Alzheimer's crisis in the African American community. This process requires working towards building solid relationships, which eventually evolve into a continuum relationship. Studies show that establishing continuum relationships include working with collaborators, groups, individuals, institutions, and agencies all coming together towards a common goal (Yeo et al., 2006).

Cross-Group Analysis

Finally, the researcher conducted a cross-analysis of the transcribed interviews of the three groups participating in this study. This analysis revealed that the three groups shared a common theme, which was the African American culture (see diagram 4.1).

Notably, the findings revealed that culture is a vital element that can influence programs or services operating in the African American community. This theme also supports studies that suggest that culture represents the systematic lens that individuals use to interpret the reality of the world they live (Sokolovsky, 2009). More significantly, this reality correlates with a group's experiences, background factors, and cultural expectations to include life scripts.

Sokolovsky postulates that many cultures maintain life scripts centered on a group's cultural expectations. The life scripts are not centered on an individual but the group's definition of an individual's progression into late adulthood (Sokolovsky, 2009). Such cultural life scripts exist within the African American community that survived the Mid-Atlantic slave trade, healthcare disparities, medical apartheid, and racism. Consequently, organizations operating within the African American community need to understand the contextual framework of the African American community, the established life scripts, and how culture dictates the family structure and filial beliefs in caregiving.

Recognizing the significance of a groups' culture, the findings in this study suggest that culture can influence the impact of efforts made by the organizations to educate the African American community about Alzheimer's disease. For example, the director from the Alzheimer's Association indicated that generally, African Americans are many times unwilling to pursue support outside the family structure when caring for an older adult and apprehensive about expressing their experiences caring for someone diagnosed with Alzheimer's disease. She also recognized that the role of caregivers in the African American community reflects the culture, which supports the traditional vs.

modern process of caregiving (Yeo et al., 2006). Specifically, African American caregiving is the responsibility of the family to include the extended family as well as kinship relations (Leary, 2005). It does not include soliciting support from outside the family structure.

Additionally, the Midwest Institute director emphasized how breaking cultural barriers has been a crucial dilemma her institution has encountered when working within the African American community. One specific barrier she sighted was the mistrust African Americans have for a local healthcare institution recognized for its historical discriminatory practices. She stated, "Care was limited and not as progressed for African Americans, so history caused that mistrust, and it has taken many a year to trust me." To address the cultural mistrust that African Americans have for healthcare organizations, the Midwest Research institution created an African American Advisory Board. The director stated, "So, that has increased the trust in the African American community in that there is an acknowledgment of the disease." Recognizing and initiating strategies to address cultural barriers is vital, particularly when the barriers can influence and impact the effectiveness of programs and services offered to the community.

The cross-analysis also revealed that the two local service agencies strongly recognized the importance of understanding African American culture. Both Adult Day Care Centers recognized culture as an essential element needed because of African American familial practices that include the family structure and cultural norms. Additionally, although unable to provide structured training opportunities for their employees, the two service agencies indicated that they did provide cultural competency training that all staff members are required to participate.

Finally, the study revealed that many of the caregivers interpret healthcare professional's behavior as lacking cultural competency and lacking sensitivity when treating African Americans. For example, caregivers expressed that physicians did not understand or ask questions about their culture. They did not investigate their family histories, did not offer information to the family about Alzheimer's disease, or inquire about their family structure. Additionally, several caregivers emphasized that generally, physicians focused more on scheduling appointments and writing prescriptions than understanding the African American culture.

More importantly, the study demonstrates how cultural lenses have shaped how African Americans view health care professionals and health care organizations. The responses further validate the need for health professionals and organizations to understand the culture, experiences, and biases of their African American patients (Williams et al., 2002). Specifically, when treating older African Americans, health professionals and organizations need to focus on the barriers, language, lived experiences, and lack of trust older African Americans have toward healthcare professionals and organizations. They should understand that the mistrust older African Americans have for healthcare professionals and memories of discriminatory medical practices, create barriers. More importantly, health care organizations should understand how these experiences create barriers that in turn, impede the key criterion relative to the educational programs offered by local organizations to the African American community about Alzheimer's disease.

Conclusion

The literature review in this study explored three theories that could influence the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community. For the most part, the study did not compare the three theories because of interrelated factors such as socio-economics, ethnicity, educational levels, and ancestral commonalities that exist within the African American community. Instead, the theories were independent theoretical constructs used to determine whether one or all three theories had any influence on the key criterion relative to the educational programs about Alzheimer's disease offered to the African American community.

The primary research method of data collection was the interview process, which included individual interviews and one focus group session. After the interview process, coding and analysis, several themes emerged for each of the three groups: (1) local organizations, (2) local service agencies, and (3) African American caregivers. The researcher conducted a cross-analysis of the themes for the three groups to identify the overlap or intersectionality of any common themes that existed between the three groups. The analysis revealed that the three groups shared one theme, which was their perception of the African American culture. More importantly, the analysis in this study revealed that the African American culture has been one of the underlying factors negatively influencing the key criterion relative to the educational programs offered to the African American community about Alzheimer's disease.

First, it is essential to understand that culture represents the lens used to interpret one's environment and represents the norms, values, and shared ideals of a group (Rust et al., 2006). An example is how African Americans interpret the responsibilities of caregiving. It is not an obligation but a responsibility that family members accept as a part of life and filial responsibility (Epps et al., 2019). Caregiving is a cultural norm that dates back since before slavery embedded within the African American family structure. It is passed down from one generation to the next and involves the extended family to include aunts, uncles, cousins, and kinship relations (Scott, 2005). More significantly, these practices and beliefs can influence how African Americans respond to physicians, healthcare professionals, as well as outside organizations offering educational programs to the community.

Understanding the African American culture is essential when working within the African American community. This study reveals that the lack of cultural understanding has created a cultural gap between African Americans and the organizations offering educational programs to the community. The directors from the two organizations recognized the African American culture as a factor contributing to the communication barriers that, in turn, have influenced the effectiveness of the educational programs offered to the community about Alzheimer's disease.

Also, although both organizations provide cultural competency training, the study suggests that a possible fault exists in their cultural competency training programs. Addressing this fault will require focusing on the training curriculum and that it focuses on the African American culture. Addressing the fault would also require assessing the programs to ensure that they include the African American historical experiences and

familial practices. Focusing on these issues would help employees understand the personal and lived experiences of older African Americans. It would also help organizations understand the fear and mistrust older African Americans have for physicians and healthcare organizations. More importantly, focusing on these issues would explain the apprehension African Americans have about research and why they do not solicit support outside the family.

Organizations need to recognize that older African Americans depend on family for caregiving. These practices extend back to slavery and support the literature that suggests that because of norms, religion, and filial piety practices, minorities have always relied on family and kinship relations for caregiving (Epps et al., 2019). More importantly, African Americans consider caregiving as the responsibility of the family, whether individually or collectively (Dilworth-Anderson et al., 1999). Recognizing these filial practices and incorporating them in a cultural competency training curriculum would assist organizations working with the African American community and would assist them in accomplishing their objectives. Additionally, organizations must understand the interrelationship of race, ethnicity, socio-economics, education, and personal experiences when designing cultural competency training programs.

Second, the local service agencies in this study operate within the African American community and provide adult day care services to older African Americans acknowledge the importance of understanding the culture of the clients they serve. Although privately owned with small staffing, the two directors expressed and recognized that to meet the needs of their clients effectively requires understanding their culture.

Consequently, both agencies engaged staff in cultural competency discussions during staff meetings and individual staff reviews.

Third, based on the themes that emerged from the caregiver's interviews, this study suggests that many physicians and healthcare organizations are not culturally competent or culturally sensitive to African Americans. For example, the caregivers believed that physicians and healthcare organizations rarely demonstrated concerns or make any attempts to understand the African American family dynamics or culture. Studies show that health care professionals who are not culturally competent or who do not understand the cultural differences of their minority patients many times will misread patient responses, language, and behavior (Kennedy et al., 2007). Consequently, these misread responses may create unfavorable diagnoses and irremediable relationships between physician and patient. (Betancourt et al., 2003).

Finally, several of the caregivers felt that the two local organizations were not visible in the African American community. The caregivers did not recognize the organizations and were not aware of their mission to educate the community about Alzheimer's disease. Also, they were not familiar with the programs offered or aware of the collaborations established with local sororities, fraternities and agencies. More importantly, this lack of visibility and recognition suggests that the two organizations are not reaching the more significant segment of the African American community. They are reaching a smaller segment of the community; however, missing the larger population of African Americans who need to know about Alzheimer's disease and the factors contributing to the disease.

In conclusion, this study sought to determine the key criterion relative to the educational programs about Alzheimer's disease offered by local organizations and the impact they have on a Midwest African American community about Alzheimer's disease. The study revealed that the organizations have been persistent in their efforts to educate the African American community through various programs to include workshops, community activities, local collaborations, faith-based initiatives, and offering cultural competency training to their staff. However, the study also suggests that despite their efforts, communication barriers created as a result of the African American culture to include family norms, beliefs, and filial piety practices have been significant obstacles. Also, despite the collaborations and partnerships with organizations and faith-based groups in the community, the organizations are still not visible or recognized by the African American caregivers in this study.

Recommendations

The findings in this study revealed two negative factors that create challenges for the local organizations in their effort to educate the African American community about Alzheimer's disease. First, the African American culture and filial practices passed down since before slavery has created communication barriers, making it impossible to establish meaningful dialogue or relationships with family members (Slavery & Remembrance, 2019). The literature posits that elderly African Americans prefer to be cared for by family members (Yeo et al., 2006). Additionally, the African American family generally assumes the role of caregiver and rarely solicit support outside the family structure (Close, 1966). Second, the African American caregivers in this study indicated that the two organizations offering educational programs about Alzheimer's

disease are not visible in the African American community. Also, they were not aware of the organization's goals or missions respective to the African American community.

The researcher suggests that further research be conducted to assess the current strategies used to educate the African American community. Also, recognizing the challenges, effective approaches should be identified and implemented to assist the local organizations in meeting their goals, objectives, and meeting the needs of the African American community. The researcher suggests the following recommendations.

1. Both organizations should continue to provide cultural competency and diversity training for employees-

Training should be an on-going initiative. It should include staff, volunteers and anyone working within the community as well as donors, and board members.

On-going training will allow staff and volunteers to understand the attitudes, family norms, filial practices, and beliefs of the culture of the community they serve.

2. Develop a media campaign in the African American community-

In our society, the media is the primary mode of communication. Since this study revealed that the two local organizations are not visible in the African American community, both organizations should utilize the media to bring awareness to the African American community about Alzheimer's disease. This will include awareness through the media such as newspaper advertisements, social media, radio, TV commercials, press releases, and public service announcements.

Additionally, both organizations should strive to be culturally sensitive and

include minorities in their advertisement, pictures, commercials, and print materials.

3. Solicit community involvement –

Studies show that successful inter-organizational projects must involve representatives of the community (Yeo et al., 2006). This interaction should include reaching beyond the select groups, which does not always represent the voice of the community. Forming an inter-organizational group would consist of local ward representatives, community development advocates, local healthcare centers, students, religious groups, and faith-based organizations. Also, this inter-organizational group would serve as an advisory committee with the members meeting regularly. The group would be the actual voice of the community and work in partnership with the local organizations offering programs to the African American community about Alzheimer's. More importantly, this would be an active group with participants willing to coordinate and assist in developing the educational workshops in tandem with the local organizations. Also, this inter-organizational group will be responsible for advising the two organizations of the best practices that would work in meeting the needs of the community and expanding awareness about Alzheimer's disease.

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Appendix A

Organizations & Agency - Consent Letter

Date

Participant name

Address

City/State – Zip code

Subject: Informed Consent for Participation in Research Activities

Dear Mr./Ms.

You are invited to participate in a research project conducted by Sandra Fields and Dr. Matthew Davis, Advisor. The purpose of this research is to explore the educational programs, collaborations and partnerships of your organization to educate the African American community about the symptoms, treatment, factors contributing to the disease and support services available to individuals diagnosed with Alzheimer's.

Your participation will provide invaluable information about Alzheimer's disease and the health crisis in the African American community. Additionally, it will allow the researcher to update the literature; learn about the outreach and educational programs available in the City of St. Louis; as well as provide your organization's mission by virtue of the interview process. You will be one of three people interviewed from different organizations in the City of St. Louis. The interview will be audio-taped, notes taken for accuracy and will last approximately 30 minutes. Also, once the interviews are completed, the information will be summarized and included in this study.

Your participation is voluntary, and you may choose not to participate in this research study or to withdraw your consent at any time. You may choose not to answer any questions that you do not want to answer. Also, you will NOT be penalized in any way should you choose not to participate or withdraw.

There are no anticipated risks with this research and information gathered during the interview will be confidential. We will do everything to protect your privacy. As part of this effort, your identity will not be revealed in any publication or presentation that may result from this study. Only in rare instances, a researcher's study must undergo an audit or program evaluation by an oversight agency (such as the Office of Human Research Protection). That agency would be required to maintain the confidentiality of your data. Additionally, all audio-recorded interview sessions will be maintained and secured for 6 months and destroyed at that time.

There are no direct benefits for your participating in this study. However, the possible benefits to you from participating in this research may include the information from the study and data gathered which may assist in your efforts to educate the community about Alzheimer's disease research and services.

If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator (Sandra Fields @ 314/322-2877) or the Faculty Advisor (Dr. Matthew Davis @ 314/516-8364). You may also ask questions or state concerns regarding your rights as a research participant to the Office of Research Administration, at 314/516-5897.

Sincerely

Sandra Fields

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. My signature indicates that I consent to participating in the research described above and have given permission to audio-tape the session.

Participant's Signature Date

Participant's Printed Name Date

Signature of Investigator Date

Investigator's Printed Name Date

Appendix B
Focus Group
Informed Consent for Participation in Research Activities

Participant _____ HSC Approval Number _____

Principal Investigator _____ PI's Phone Number _____

You are invited to participate in a research project conducted by Sandra Fields and Dr. Matthew Davis, Advisor. The purpose of this research is to explore the programs, collaborations and partnerships of organizations responsible for educating individuals in the African American community about the symptoms, treatment, factors contributing to the disease and support services available to individuals diagnosed with Alzheimer's.

We are asking you to participate in this study because of your personal experience assisting a family member suffering from the disease; or your professional experience working with older adults African Americans diagnosed with Alzheimer's disease. You will be one of 12 people participating in a recorded focus group session at two locations in the City of St. Louis. Once the focus groups are completed, the information will be summarized, a report written, and the results included in this study.

If you decide to participate, we will contact you regarding the date, time and place of the session where you will meet with 5 other participants. The group participants will be asked to describe their experiences as caregiver, your understanding and perceptions of the disease; as well as awareness of any programs or support services available for those diagnosed with the Alzheimer's. The group sessions will be audio-taped, notes taken for accuracy and will last approximately 2 hours. Also, each focus group participant will be asked to complete a survey consisting of 10 general questions to include demographic information and your personal knowledge about Alzheimer's disease. All participants completing the focus group session will receive a \$20 stipend provided by the Principle Investigator.

Your participation is voluntary, and you may choose not to participate in this research study or to withdraw your consent at any time. If you feel uncomfortable with any of the questions during the focus group session, please let me know and you will not be required to answer. Also, you will NOT be penalized in any way should you choose not to participate or withdraw.

There are no anticipated risks with this research and information gathered during the interview will be confidential. We will do everything to protect your privacy. As part of this effort, your identity will not be revealed in any publication or presentation that may result from this study. Group session results will be summarized therefore; your identity will remain unknown. We will not disclose any information that will identify you nor connect you with this study. Only in rare instances, a researcher's study must undergo an audit or program evaluation by an oversight agency (such as the Office of Human Research Protection). That agency would be required to maintain the confidentiality of your data. Additionally, all audio-recorded focus group sessions will be maintained and secured for 6 months and destroyed at that time.

There are no direct benefits for your participating in this study. However, your participation will contribute to the knowledge about the Alzheimer's disease educational programs, support and services available within your community.

Also, if you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator (Sandra Fields @ 314/322-2877) or the Faculty Advisor (Dr. Matthew Davis @ 314/516-5953). You may also ask questions or state concerns regarding your rights as a research participant to the Office of Research Administration, at 314/516-5897.

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. My signature indicates that I consent to participating in the research described above and have given permission to audio-tape the session.

Participant's Signature Date

Participant's Printed Name Date

Signature of Investigator/Designee Date

Investigator/Designee Printed Date

Appendix C

Caregiver- Consent Letter

Date

Participant name

Address

City/State – Zip code

Subject: Informed Consent for Participation in Research Activities

Dear Mr./Ms.

You are invited to participate in a research project conducted by Sandra Fields and Dr. Matthew Davis, Advisor. The purpose of this research is to explore the effectiveness of the educational programs designed to educate the African American community about the symptoms, treatment, factors contributing to the disease and support services available to individuals diagnosed with Alzheimer's disease.

Your participation will provide invaluable information on the impact that Alzheimer's disease has on African American families with loved ones diagnosed with the disease. Additionally, it will allow the researcher to review how effective if any, have the educational programs in the City of St. Louis been in reaching out to the African American community. You will be one of 2 caregivers interviewed from the City of St. Louis. The interview will be audio-taped, notes taken for accuracy and will last approximately 30 minutes. Also, once the interviews are completed, the information will be summarized and included in this study.

Your participation is voluntary, and you may choose not to participate in this research study or to withdraw your consent at any time. If you feel uncomfortable with any of the questions during the interview, please let me know and you will not be required to answer. Also, you will NOT be penalized in any way should you choose not to participate or withdraw.

There are no anticipated risks with this research and information gathered during the interview will be confidential. We will do everything to protect your privacy. As part of this effort, your identity will not be revealed in any publication or presentation that may result from this study. Only in rare instances, a researcher's study must undergo an audit or program evaluation by an oversight agency (such as the Office of Human Research Protection). That agency would be required to maintain the confidentiality of your data. Additionally, all audio-recorded interview sessions will be maintained and secured for 6 months and destroyed at that time.

There are no direct benefits for your participating in this study. However, the possible benefits to you from participating in this research may include information about the available research, educational programs and support services in your area. Additionally, your participation will assist in developing and/or improving the strategies that will better educate the community about Alzheimer's disease research and services.

If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator (Sandra Fields @ 314/322-2877) or the Faculty Advisor (Dr. Matthew Davis @ 314/516-8364). You may also ask questions or state concerns regarding your rights as a research participant to the Office of Research Administration, at 314/516-5897.

Sincerely

Sandra Fields

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. My signature indicates that I consent to participating in the research described above and have given permission to audio-tape the session.

Participant's Signature Date

Participant's Printed Name Date

Signature of Investigator Date

Investigator's Printed Name Date

Appendix D

Organization and Agency - Interview Questions

1. What is your title and/or position?
2. How long have you served in this position?
3. Could you please describe your scope of responsibilities?
4. What is your organization's mission as it relates to educating the African American community about Alzheimer's disease?
5. Does your organization receive federal or state funds to sponsor programs that will educate the community about Alzheimer's disease? If yes, what strategies have you implemented to ensure that you meet this object? Please explain.
6. What type of outreach or educational programs does your organization offer in the African American community on Alzheimer's disease?
7. In your opinion, how supportive if any, has the African American community been in promoting the educational awareness programs on Alzheimer's disease?
8. Does your organization work in partnership with any nonprofit or community organizations to implement these programs? If yes, please describe the partnerships or collaborations.
9. In your opinion, what are the benefits of these partnerships or collaborations?
10. Does your organization promote cultural competency when working with clients? If yes, what cultural competency techniques or activities does your organization implement to improve the delivery of services to African Americans?

Appendix E
Focus Group Interview Questions

1. Do you know someone diagnosed with Alzheimer's disease or with a cognitive disease? What is your relationship and is there a history of the disease in your family? If a client, from your knowledge, is there a history of the disease in the family?
2. From your understanding, at what stage of the disease was your family member or patient diagnosed with the disease?
3. Can you share with the group whether you feel treating physicians provide sufficient information about the disease and support services needed to assist in making decisions about the type of care needed? Please explain.
4. Do you feel that treating physicians lack cultural competencies when meeting with African American families with relatives diagnosed with Alzheimer's disease or any other cognitive related illness? What biases do you feel they have?
5. Can you share with the group the health problems you feel may contribute to a person developing Alzheimer's disease? Did you know that diabetes, hypertension, high cholesterol and cardiovascular disease are the leading illnesses that can contribute to a person developing Alzheimer's disease? Please explain?
6. Are you aware what role the local organizations responsible for alerting the African American community about Alzheimer's disease play in educating the community? Please explain.
7. Have you or your agency ever participated in an outreach or educational program about Alzheimer's disease? If yes, where? When? And how did you find out about the program?
8. In your opinion, how effective has the Alzheimer's Association and other local organizations been in alerting people about the Alzheimer's crisis in the African American community?
9. Do you have any ideas that can be used to better inform the African American community about the Alzheimer's disease crisis? Give examples.

10. Would you be willing to participate in any community campaigns or programs promoting awareness and education in the African American community about Alzheimer's disease?

Appendix F
Caregiver- Interview Questions

1. Has anyone in your family been diagnosed with Alzheimer's disease or any other cognitive disease? What is your relationship and is there a history of the disease in your family?
2. When were you made aware by the treating physician that your family member had Alzheimer's disease?
3. From your understanding, at what stage of the disease was your family member diagnosed with the disease?
4. Do you feel that the treating physician provided your family with sufficient information about the disease to assist in making decisions about the type of care needed? Please explain.
5. Were you or your family referred to any support services? If yes, were they helpful? Did they assist you in making health relate or life changing decisions for your family member diagnosed with Alzheimer's? Explain.
6. Are you aware of the health problems that may contribute to a person developing Alzheimer's disease? Did you know that diabetes, hypertension, high cholesterol and cardiovascular disease are the leading illnesses that can contribute to a person developing Alzheimer's disease? Please explain?
7. Are you aware of the local institutions and organizations in your area responsible for educating the African American community about Alzheimer's disease? Please explain.
8. Have you or your family ever participated in an outreach or educational program on Alzheimer's disease? If yes, do you feel that you were well informed?
9. In your opinion, how effective has the local institutions and organizations in your area been in educating and/or alerting the African American community about Alzheimer's disease health crisis?

10. Would you be willing to participate in any community campaigns or programs promoting awareness and education in the African American community about Alzheimer's disease?

Appendix G

Caregivers – Survey/Questionnaire

You were selected to participate in this survey because you are currently or have cared for a family member or individual diagnosed with Alzheimer's disease. The purpose of this survey is to collect base-line demographic information, opinions and personal reflections from the individuals participating in the focus group. Please complete the following questions to the best of your knowledge and as accurately as possible. To ensure that information obtained from this study remains confidential, you are not required to include your name.

Section I – Demographic information

Please check the appropriate response.

1. Gender: Male Female

2. Please write your age _____

3. Marital Status: Married Single Divorced Widow

4. Education: Elementary High School College

5. Employment status: Employed Unemployed Laid-Off

6. Which of the following best represents your ethnic or racial heritage?

Please check one of the following:

- | | |
|--|-------|
| Non-Hispanic White or Euro-American | _____ |
| Black, Afro-Caribbean, or African American | _____ |
| Latino or Hispanic American | _____ |
| East Asian or Asian American | _____ |
| South Asian or Indian American | _____ |
| Middle Eastern or Arab American | _____ |
| Native American or Alaskan Native | _____ |
| Other | _____ |

Section II – Personal knowledge about Alzheimer's disease –

A. To your knowledge, which item below best describes the symptoms associated with Alzheimer's disease? Please check the item(s) that best applies.

1. Memory loss _____
2. Increased appetite _____
3. Loss of cognitive abilities _____
4. Inability to hold a conversation _____
5. All of the above _____

B. Are you aware of any available tests that can determine if an individual has Alzheimer's disease? Please check the item(s) that best applies.

1. A person reading a paragraph aloud _____
2. Doctor conducting an MRI or CAT scan _____
3. Doctor conducting a series of neurological exams _____
4. None of the above _____
5. All of the above _____

C. What other health problems do you think can contribute to an individual developing Alzheimer's disease? Please check the items(s) that best applies.

1. Hypertension (high blood pressure) _____
2. Diabetes _____
3. Arthritis _____
4. Vascular disease (heart disease) _____
5. All of the above _____

D. From your knowledge, is there a cure for Alzheimer's disease?

1. Yes, with brain surgery _____
2. No, once diagnosed the brain cells continue to die _____
3. No, but it can be treated with medication _____
4. Yes, after surgery and required medication _____
5. None of the above _____

THANK YOU FOR YOUR PARTICIPATION!!