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# Does Structural Racism Influence How Black/African Americans Define Memory Loss and Cognitive Impairment? An Africana Phenomenological Study

by

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A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy
in
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Dissertation Committee:
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# STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

## Abstract

With the variety of research about dementia and Alzheimer's disease (AD), few studies have explored the effect of social structures, such as racism, on how Black/African Americans conceptualize memory loss, dementia, or AD. Furthermore, limited within the scholarship are the environmental factors and structural racism that are thought to influence cognitive impairments and meaning making about cognitive decline impacting Black/African Americans.

Most U.S. research centers on methodologies and epistemologies grounded in Eurocentric ways of knowing (objectivity, individuality, either/or logic). However, Eurocentric methodologies fail to acknowledge the cultural experiences with memory loss, cognitive impairment, dementia, and AD, as well as the influence of racist structures and cultural perspectives, specifically Black/African American ways of understanding (affect symbolic imagery, communal, diunital logic). When researching Black/African Americans, the methodology needs to incorporate cultural nuances to accurately reflect the responses of the research participants.

This dissertation explored the utility of the Africana worldview (paradigm) by exploring the process Black/African American Americans use to define memory loss and how structural racism may influence their definition and meaning making about memory loss. The Africana worldview was used to explore the following research questions: (a) What is the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans? (b) What are the different ways the Africana

Worldview aids in the interpretation of Black/African Americans' understanding of memory loss, dementia, and AD?

Findings from this research focus on the importance of maintaining belonging, cultural meaning making, and the impacts of structural racism on the lived experiences of people living with cognitive decline and their caregivers. Implications for social work education, practice, and future research are also discussed.

## Dedication

The ancestors who led the path to be where I am today are the driving force for this dissertation. This dissertation is dedicated to 13 Black/African Americans featured in this study, who shared their wisdom with me. I learned a lot from the people who trusted me as they shared their lived experience.

In loving memory of

Grandma and Grandpa: Letitia and Asa Brock

Grandma: Mary Chapel

Father: Dr. Clarence O. Pruitt

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I also wish to thank the Black African American community of Portland, OR, and all the fantastic leaders who gave input in this research in various ways.

### Acknowledgment to the dissertation committee

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I want to thank Victoria Cotrell, who began as the chair and graciously passed it on to Gita Mehrotra. Vicki ignited my interest in working with older adults and scholarly writing. She brought joy into research and enhanced my belief in my research skills.

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# Table of Contents

## List of Abbreviations

| | |
|---|---|
| AD | Alzheimer's disease |
| AADAPt | African American Dementia and Aging Project |
| CPT | Color people's time |
| ER | Emergency room |
| LGBTQ | Lesbian, gay, bisexual, transgender, queer |
| LGBTQI2-S | Lesbian, gay, bisexual, transgender, questioning/queer, intersex, two-spirit |
| SES | Socioeconomic status |

# Chapter I: Introduction

## Methodology Makes a Difference in Dementia Research

Dementia research is essential because of an increasing number of people living with Alzheimer’s dementia, which may grow to 13.8 million Americans aged 65 and older. Whereas deaths from stroke, HIV, and heart disease decreased between 2000 and 2018, deaths from Alzheimer’s increased by 146%. Alzheimer’s disease (AD) is now the sixth leading cause of death (Alzheimer’s Association, 2020). In Oregon, the projected number of people with Alzheimer’s dementia in 2020 was 69,000, potentially increasing to 84,000 by 2050. Most studies indicate that older Black/African Americans are twice as likely to have Alzheimer’s or other dementias than other racial/ethnic groups (Alzheimer’s Association, 2022; Epps et al., 2018). Per the Alzheimer’s Association (2022), “Structural racism pervades many aspects of life that may directly or indirectly alter dementia risk” (p. 717). The disparaging risk factors for Black/African Americans are rooted in historical and continued marginalization. Structural racism increases the importance of dementia research and its effect on the Black/African American community.

Despite the variety of research about dementia and AD, few studies have explored the effect of social structures, such as racism, on how Black/African Americans conceptualize memory loss, dementia, or AD. Furthermore, scholarship rarely examines the environmental factors and structural racism that are thought to influence assessment tools’ validity and influence the process of assessing cognitive impairments impacting Black/African Americans.

## STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

Most research (medical, social, environmental, etc.) in the United States centers on methodologies and epistemologies grounded in Eurocentric ways of knowing (objectivity, individuality, either/or logic). However, Eurocentric methodologies fail to acknowledge cultural experiences with memory loss, cognitive impairment, dementia, and AD, as well as the influence of racist structures and cultural perspectives, specifically Black/African American ways of understanding (affect symbolic imagery, communal, diunital logic). The Eurocentric ways of knowing struggle with recognizing and interpreting the cultural nuances that influence research and the evaluation of cognitive impairment (Carroll, 2008; Dixon, 1977; Ighodaro et al., 2017; Rabaka, 2006). The struggle occurs due to the Eurocentric methodologies being grounded in either/or logic that excludes evidence that cannot be measured or explained through the Eurocentric/Western ways of understanding (Dixon, 1977). Due to this struggle, cultural nuances are often ignored or assessed as irrelevant, causing a misunderstanding of the full meaning of Black/African Americans' responses to research instruments, leading to the potential of false positives in dementia diagnosis (Glymour & Manly, 2008; Gordon, 2000; Henry, 2005; Shadlen et al., 1999). When researching Black/African Americans, the methodology needs to incorporate cultural nuances to accurately reflect the responses of the research participants.

This dissertation explored the utility of the Africana worldview (paradigm) by exploring the process Black/African Americans use to define memory loss, which potentially leads to dementia, and how structural racism may influence their definition and meaning making about memory loss. Specifically, this research focused on some of this worldview's components to explore how the collective identity influences individual identity and, in turn, influences how people interpret permanent memory loss. The five African worldview components used in this research are (a) affect symbolic imagery, (b) felt time, (c) Africana teleology, (d) interdependence, and (e) diunital logic. The Africana worldview will be used to explore the following research questions:

1. What is the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans?
2. What are the different ways the Africana worldview aids in the interpretation of Black/African Americans' understanding of memory loss, dementia, and AD?

The answers to these research questions may lead to useful healthcare messages related to cognitive impairment that may alter how the Black/African American communities accept or act upon health care options.

Utilizing Africana worldview in this research highlights structural racism as a factor that could affect how Black/African Americans develop their identity, which affects meaning (Allen, 2001; Gordon, 2000; Layton, 2006). One's identity influences one's worldview, and that worldview shapes how people conceptualize health issues. People define memory loss and cognitive impairment through this conceptualization of selfhood. Because of the impact of structural racism on identity, it is important to understand how Black/African Americans define memory loss and cognitive impairment. This worldview reveals the cultural nuances that explain identity, which is the foundation of making meaning (Gordon, 2000). The paradigm that originates from the Africana worldview encompasses the Black/African American lived experience. The Black/African American lived experiences reveal meaning in a way that highlights the human existence of Black/African Americans, a reality that the Eurocentric worldview excludes (Dixon, 1977; Du Bois, 1903/2016; Rabaka, 2006). Understanding or knowledge about lived experiences, cultural identity, and meaning making is imperative when developing prevention or accessing care messages for Black/African Americans.

This research is important to the field of social work because it broadens knowledge in using the culturally responsive African worldview when developing policy and interventions and researching issues pertaining to Black/African Americans. As Dixon (1977) noted, "The axiology, epistemology, and logic attributable to the Africana world view will serve better to explain some behavioral phenomena for homeland and overseas Africans, and similarly for Euro-Americans" (p. 121).

Following the introduction, the second chapter of this dissertation defines the methodology and the philosophy that guided this research. The purpose of not following the traditional dissertation is to ground the research methods in the Africana worldview. Doing so exposes crucial segments that Black/African Americans utilize as they make sense of the world/life while addressing barriers to cultural nuances due to structural racism. The methodology section explores this worldview and its connection to the research paradigm.

The third chapter is a literature review, highlighting what is known about cognitive impairment, dementia, and AD in the Black/African American community. This section addresses cognitive impairment, dementia, and AD in Black/African

American communities as a social issue. Next, this review explores structural racism and its impact on identity, which informs meaning making and its relationship to defining the term “cognitive impairments.” Throughout this review, the connection of elements of the Africana worldview (affect symbolic imagery interdependence/communal, diunital logic) are explored to highlight how the reviewed articles address or do not address the cultural nuances expressed in Black/African American communities.

The fourth chapter is the research design section addresses the research procedures, including data analysis, using interpretive Africana phenomenology. Chapter V presents the critical aspects of the results, and Chapter VI is my interpretation of the data and provides discussion and implications based on the results of this research.

# Chapter II: Methodology: Africana Worldview/Paradigm/Philosophy

Research is an interpretive process guided by the researcher's worldview that incorporates their beliefs, values, and feelings about the world and how it should be studied (Denzin & Lincoln, 2005). A worldview is how people make sense of their lives, the meaning of interactions with people, the environment, and the interconnections between people and the environment (Carroll, 2008; Dixon, 1977; Guba & Lincoln, 2005). The worldview is also a product of lived experience influenced by ethnic culture. It provides the framework people use to make sense of their perceptions that is later used to describe facts (Carroll, 2008; Dixon, 1977). The Africana worldview is the direct outgrowth of the cultural and historical lived experiences of people from the African diaspora (Carroll, 2008).

## Africana Phenomenology

Africana phenomenology provides clarity around the cultural nuances that occur in research about Black/African American people as it centers the Black/African American lived experience within the universe. Africana phenomenology is a cultural approach to the study of consciousness where self-reflective knowledge arises from the lived experiences of people hailing from the African diaspora. It engages people from the African diaspora and corrects the racist perception that dehumanizes Black/African Americans, which arises from Western phenomenology (Henry, 2005). In the Africana paradigm, self-reflections bring light to "the systematic error producing foundations of the European humanities and social sciences that have had to legitimate and make appear as correct this racist reduction of African humanity" (Henry, 2005, p. 4).

## STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

The racist caricature of *the negro* is a result of the external colonization of the African life-world by the capitalism-fueled European life-world. European imperial domination and the enslavement of Africans shattered the traditional socio-cultural worlds of pre-colonial Africa (Henry, 2005). The shattering continues using European phenomenology, namely when it refuses to accept the Africana worldview and assigns skewed meanings to African spirituality, culture, and the process of meaning making while supporting racialized cultural identities of Black/African Americans (Carroll, 2010; Dixon, 1977; Henry, 2005). Henry (2005) argued the goals of Africana phenomenology are racial liberation, infusing humanity into African people, and honoring the lived experiences of Africana people in the United States and the universe.

Henry (2005) argued that Africana phenomenology is aligned with most phenomenology research in that it is a discursive and self-reflective description of activities of the consciousness. However, Africana phenomenology diverges from the western phenomenology of the founders (Husserl, Hegel, Sartre, Descartes) because it includes poetics, historical processes, and cultural self-reflection grounded in the human aspect of African people. Per Henry (2005),

> The occasion for self-reflection has not been the positivistic reduction of rationality and the mechanized caricature of the European subject that it threatens to produce. Rather, the occasion for reflection has been the racist negating of the humanity of Africans and the caricature of “the negro” that it has produced. (p. 4)

In this project, Africana phenomenology highlights the impact of memory loss incorporating the interconnectedness of people from the African diaspora through the Africana paradigm/worldview that values human dependency and universal harmony.

Schiele (1996) argued that the use of the Afrocentric paradigm, which I refer to as the Africana paradigm or worldview, is imperative to understand or explain the behavior of Black/African Americans. The Africana paradigm addresses the Eurocentric knowledge hegemony that is implicitly oppressive when used to describe Black/African American behavior (Schiele, 1996). The Africana paradigm reflects the Black/African American human identity as a collective identity, the spiritual component (life force), and the practical approach where reason and thoughts are filtered through emotions and value as well as the historical impact of colonialization (Carroll, 2010; Dixon, 1977; Henry, 2005; Schiele, 1996).

Schiele (1996) argued that more attention should be placed on structures or systems of oppression that marginalize Black/African Americans. Furthermore, research needs to explore how these structures produced by Eurocentric theories define human behavior, which influences research. The pervasive Europeanization of human consciousness and European political and economic hegemony have led to knowledge production and validation that omits or marginalizes the worldviews of Black/African Americans and other people of color (Schiele, 1996). The Africana worldview provides a perspective that focuses on Black/African Americans without results grounded in marginalization, and the Africana phenomenology describes their lived experiences. Africana methodology does not endorse perceptual space where the researcher is objective and detached from the phenomena or universalism (Dixon, 1977; Schiele, 1996).

In the Africana worldview, individual identity is fluid and interconnected and expresses the collective group ethos that "emphasizes sharing, cooperation, and social responsibility" (Schiele, 1996, p. 287). The Africana phenomenology, based in this worldview, promotes an alternative social science paradigm that reflects the cultural and political reality of Black/African Americans, dispels negative distortions about people from the African diaspora, provides a legitimized worldview that resides in the hearts and minds of most Black/African Americans, and endorses societal transformation (Schiele, 1996).

## Affect Symbolic Imagery

Carroll (2010) revealed the Africana worldview provides the best cultural understanding of the behavioral and cultural nuances and the mental and spiritual tendencies of people from the African diaspora. Through this understanding and application of this worldview, researchers can authentically analyze data about Black/African American communities, where meaning is grounded in symbolic imagery (Dixon, 1977).

> African persons know reality predominantly through the interaction of affect and Symbolic Imagery, i.e., the synthesis of these two factors produces knowledge. In the "pure" Africanized world view of the unity of man and the phenomenal world, there is no empty perceptual space between the self and phenomena. The affect

> refers to the feeling self, the emotive self-engaged in experiencing phenomena holistically. (Dixon, 1977, p. 134)

Affect symbolic imagery conveys meanings expressed in words, gestures, tones, rhythms, objects, and other forms of communication. In the Africana worldview, affect symbolic imagery becomes the phenomenal world itself, structurally oriented towards image construction and intervention. It is the physical response and gestures observed by Black/African American participants when the researcher is uncomfortable with the community members participating in the research. The researcher's physical gestures influence the participant's trust. The reading of the affect symbolic imagery impacts the participants' willingness to share information with the potential of holding back due to a lack of trust in the researcher. Dixon (1977) reported that affect symbolic imagery is an alternate form of thinking where verbal, discernible principles or generalizations exist. An example of generalizations, as reflected by Dixon (1977), is "proverbs of homeland and overseas Africans" (p. 135). He stated that proverbs are the collective experience of the Black community as a whole arising from generations of Black people. The veracity of the proverb is tested over time; only the ones that are valid are passed on to the following generations.

Proverbs reflect multiple meanings that move beyond a single meaning arising from a sign or symbol. "In sum, Affect-Symbolic Imagery Cognition means this: I feel phenomena; therefore, I think; I know" (Dixon, 1977, p. 136). To apply affect symbolic imagery, a researcher considers the tone of the response and if the nonverbal aligns with the spoken word. The researcher explored the incongruency, as it could provide depth to the response and open the possibility of capturing multiple understandings. Contrastingly, symbols within the Eurocentric paradigm reflect a singular meaning based on a one-to-one interaction between an individual and a phenomenon (Carroll, 2010; Dixon, 1977). Eurocentric paradigms do not explore the incongruency for multiple potential understandings.

Affect symbolic imagery is aligned with felt time in that they both incorporate experiences utilizing multiple functions of the brain.

## Felt Time

Felt time is a complex concept because it includes feelings, emotions, and a sense of being that cannot be measured and must be experienced. Furthermore, to understand felt time, one must be open to the multiple meanings depending on the region or country one resides. Felt time is centered around the interconnection between humans and the setting where the connection occurs. To begin to conceptualize felt time, we start with exploring how time is conceptualized within the Africana worldview. The orientation of time in this worldview is governed by current or past dimensions; the focus on future investment, as in the Western/Eurocentric worldview, becomes less important (Dixon, 1977).

In the African ways of time, it must be felt or experienced for it to be real. This felt time is the unison of humans with their phenomenal world, and time is continuous and not linear (Dixon, 1977). It is a sense of a feeling that resides outside of the cognitive language for description, and it is a biological connection. First, it utilizes the parts of the brain known as reptilian and mammalian when connecting with people and the surroundings. It is the nonverbal, a sense of belonging, as one connects with people and the situation of the meeting. It occurs in the first few minutes one enters the room for a focus group or the first meeting with the researcher.

Second, the felt time is assessed by the cortex through potential questions: (a) Can you feel me? (b) Can you understand my life experiences as a Black/African American? (c) Is this place safe, or do I need to be on guard? These are some of the questions that result from over 300 years of dehumanization, enslavement, and Jim Crow laws. It is also the result of faulty research to prove a superior race by denying Black/African Americans' human existence and seeing them as property (DeGruy, 2017; Dixon, 1977). The Africana worldview acknowledges the legacy of enslavement, Jim Crow laws, and other historical events and structures focused on dehumanizing people from the African diaspora. It is the process of this worldview to reinstitute the human experience and a process of liberation.

Another dimension of felt time is what most Black/African Americans know as CP (Color Peoples) time. In CP time, scheduled or planned times do not take precedence over events one is immediately experiencing (Dixon, 1977). An example is a Black/African American with an appointment scheduled at 10:00 am. At 9:30 am, that person experiences a struggle regarding a loved one's health that is not life-threatening. It can also be in the moment with a friend or event, feeling connected, grounded, and safe. The Black/African American continues with the loved one or friend even if the situation runs past 10:00 am. Felt time is also expressed in the proverb, "the party doesn't start 'til we get there." In this project, felt time and affect symbolic imagery were actualized in a focus group, which will be expounded upon in the design section of this dissertation.

## Africana Teleology

Another component of the Africana worldview is teleology, which is directness, definite ends, and definite purpose (Carroll, 2008). It is commitment and extended investments toward intended goals for research, scholarship, and intellectual endeavors. It is clarity in stating the intentions of the research and being direct about the plans to use the data when discussing the research project with Black/African American participants and community members. It also includes relevancy, functionality, and intended goals that benefit the Black/African American community. The direct result of the historical impact of egregious research on members of the African diaspora has influenced the Africana worldview and moved research beyond knowledge, incorporating multiple forms of liberation (Carroll, 2008; Dixon, 1977; Washington, 2008). The egregious research ranges, for example, from Dr. James Marion Sim's experimental surgeries on unanesthetized enslaved women to the U.S. syphilis trials, also wrongfully known as the Tuskegee syphilis trials (DeGruy, 2017; Washington, 2008). When applying this worldview, the researchers' directness also includes how the research guards against exploiting Black/African Americans and the steps taken to prevent undue harm to community members, ensuring their humanity. It also includes how the research benefits and establishes the human aspects of the Black/African American community (Carroll, 2008; Dixon, 1977).

## Interdependence

Dixon (1977) expressed that African axiology values the relationship between people, nature, the universe, and the spiritual world; this is reflected in the “person-to-person” relationship (Dixon, 1977, p. 122). There is a continuous energy connection between people, for it is the “invisible universal substance that connects all human beings to each other to a Creator or Supreme Being” (Schiele, 1996, p. 287). The energy connection is akin to electrons within the elements found in atoms and living cells. Africana axiology acknowledges the intrinsic value of each person, communalism, life force and one’s connection to nature, which is the continued energy connection. This value orientation views the person and the phenomenal world as mutually interdependent and views people as being in harmony with nature (Dixon, 1977). The component is actualized through the family, extended family (people who are not biologically connected), and connection to the community.

Interdependence is actualized when an element of research addresses strengthening the Black/African American community. It is also actualized when the research embraces the communal aspect of the Black/African American community, the human aspect while acknowledging the diversity within the community. It is when the research values a person’s existence or being that it honors one’s humanity. The Africana paradigm differs from Eurocentric paradigms, where the Eurocentric axiology acknowledges that the value of a person is in their productivity or their individualistic achievements (Carroll, 2010; Nichols, 1972). In Africana axiology, to study human nature, one must realize that people are an extension of the phenomena that one chooses to study.

In most research, there is the assumption that there is space between the researcher and the participants or the researcher and the phenomena. The perceptual space provides the researcher the ability to be objective because they are not an extension of the study, and their actions do not influence the results (Carroll, 2010; Dixon, 1977). Africana axiology argues that the separation of the self from the phenomenal world does not exist. The belief of separation (objectivity) creates the dynamic of othering, giving room for dehumanization. A separation does not exist between humans and nature, just like objectivity does not exist in research. The researcher is intertwined with the phenomena under study, and their worldview influences what is important or the focus of the research.

Furthermore, Africana axiology fosters working with the elements and creating harmony rather than against nature or humans: "the use of forces in nature to restore a more harmonious relationship between man and the universe" (Dixon, 1977, p. 128). For example, the Western worldview tends to study nature to rule over it. For example, if cancer is being studied in the context of the Western worldview, researchers would study cancer in the body to rule over it and eventually destroy it. Using the Africana worldview, researchers would study cancer to find out how the imbalance occurred within the body to learn how cancer exists. The study would seek to restore balance so that cancer could not live in the body. The two worldviews have the same goal but different ways of getting to the result.

Through the absence of perceptual space (space between research and the phenomena being studied), the collective identity found within the diverse array of African peoples draws the connection to the phenomena and the environment to regain balance/harmony. The absence of perceptual space and the collective identity are strengthened enough to resist the colonialism and racism reflected in research (Carr, 1997; Dixon, 1977). An individual's position in society is relative to others; people do not exist alone but communally. In short, people depend on each other and are interconnected with the environment. People and the phenomenal world are mutually interdependent, and the experience of humanness is in harmony with nature (Carroll, 2008; Dixon, 1977). The exploitation of nature is the end of humanity, and survival is directly linked to having a greater balance with the environment; this is the meaning of harmony with nature.

Africana worldview focuses on maintaining harmony and balance among multiple aspects of humans, nature, spirituality (life-force), and the universe (Dixon, 1977). This worldview states that the universe is not static, inanimate, or dead but is instead dynamic, animated, living, and powerful (Akbar, 1998; Carroll, 2008; Dixon, 1977). Africana ontology suggests that the nature of reality is spirit- energy or life force (Carr, 1997; Carroll, 2008; Dixon, 1977). "Therefore, at the most fundamental level of all that exists within the Universe is a spiritual/energy force manifesting itself on material and immaterial levels" (Carroll, 2008, p. 15). That is, energy/life force exists in everything, which also connects me as a researcher to the phenomena and causes me to continuously reflect upon my positionality.

## Diunital Logic

The Africana worldview utilizes diunital logic, compared to the Western worldview, which uses either/or logic. Diunital logic moves beyond black-and-white thinking and incorporates the harmonious union of opposites (Dixon, 1971). An example is a room where all the furniture is removed, and there is just empty space. Yet, the room is not totally empty, for it still full of air. Therefore, the room is both empty and full, and the harmonious union of opposite is the empty and full.

Culturally, the mutual affirmation of different ethnic cultures incorporates their uniqueness. Diunital logic does not destroy or rule over another culture. It values the diversity and the reality of interconnectedness. It is the difference creating harmonious unions of opposites, allowing us to live, for we are interdependent. Diunital logic does not engage in assimilation and recognizes the values of different cultures that stimulate the growth of the different ethnic groups that gather. It does not generate racial conflict or produce antagonistic negative tension or hostile confrontation (Dixon, 1971). In research, incorporating diunital logic acknowledges the potential for multiple understandings without one ruling over the other. It embraces diverse meanings and “enables one to conceive of and order the same phenomena so that opposites become radically different and at the same time united” (Dixon, 1971, p. 49).

## The Need for Africana Worldview

Dixon (1997) expanded on how social science research involves the process of testing constructed models, hypotheses, and theories and how the Eurocentric worldview decides what to research and what methodologies are used. Worldviews incorporate assumptions about the phenomena being studied. "Assumptions are statements about phenomena that are accepted as valid without submission to tests of their validity (Dixon, 1997, p. 119). Dixon (1977) provided a clear example of the impact that this worldview's assumptions have when researching issues about people from the African diaspora by referencing seminal research about the Daniel Moynihan model. This research assumed that the only valid form of organization of the family is the nuclear family, ignoring how the definition develops pathologies of the Black community due to an absence of a male head or egalitarian relationships. This research, which is bounded in assumptions, centering on the 21% of Black families without a male head in the household, fails to acknowledge the 79% of African American families where males are present. It fails to acknowledge the communal aspect (extended family and non-biological members who are part of the family) of Black/African American families that ensure family success (Boyd-Franklin, 1989; Parham et al., 2011; White & Cones, 1999).

When applying the Africana worldview, the research focuses on the multiple dimensions of the family (extended families, etc.) and supports the communal aspect of the Black/African American family and their connection to the community. The Daniel Moynihan study failed to incorporate the influence of structural racism. Daniel Moynihan's model utilized the European worldview assumptions that cultural experiences are not relevant and that systemic or institutional discrimination is nonexistent, thus forming the deficit model (Carroll, 2008; Dixon, 1977; Graham, 1999).

The deficit model focuses on what is lacking in the Black/African American population, based on Eurocentric values, as the issue and ignores social structures that created the social problem. The seminal Moynihan work hinders the exploration of the impact of structural racism and has pathologized Black families, whether or not they reside outside the Eurocentric notion of families (Dixon, 1977; Parham et al., 2011). The model supports the current negative view of Black/African Americans and justifies their continued dehumanization (Dixon, 1977; Washington, 2008; White & Cones, 1999).

Dixon (1977) discussed how research assumingly rules out positive aspects and strengths of the egalitarian Black/African American family and, in turn, maintains the deficit approach (Black/African American families lack substance) and influences how society views and defines Black/African American families. The deficit approach also impacts how researchers evaluate or manage cognitive impairments within Black/African American communities, ignoring the social structures that created societal barriers, which, in turn, influences how Blacks/African Americans respond to cognitive diagnostic tools and how researchers analyze results (Dixon, 1977; Ighodaro et al., 2017). Dixon (1977), Carroll (2008), and Graham (1999) provided more evidence that Eurocentric worldviews are the foundation of most research. The paradigms view Black/African Americans and descendants from the African diaspora from a deficit model. The model suggests that descendants of the African diaspora are different from the dominant culture, lack substance, and are, therefore, deficient.

In contrast to this deficit-based approach, Africana methodology operationalizes critical components of the Africana paradigm from an asset model, which focuses on the strength of the individual and community. Paradigms are considered the foundation of actualizing one’s view of the world within a research context. Paradigms include biases and assumptions that impact the paradigm, which in turn, influence the research (Carroll, 2008). The paradigm guides the phenomena investigated, the research question, and the methods used to gather information (Denzin & Lincoln, 2005; Dixon, 1977; Guba & Lincoln, 2005). It is the scheme that organizes one's first views in the quest for meaning (Dixon, 1977; Rubin & Babbie, 2011).

The operationalization of the Africana methodology focuses on the Africana worldview, ontology, logic, and epistemology by centering the lived experience of people from the African diaspora; this provides a process to authentically analyze the data, including the cultural nuances (Carroll, 2008; Dixon, 1977). As previously mentioned, this worldview serves better to explain some behavioral phenomena for Black/African Americans. Because of oppression based on race and the color of one's skin, supported by social structures (i.e., enslavement, Jim Crow Laws, 1969 Virginia casual killing, etc.) Africans in the homeland and overseas did not have the opportunity to express their experiences in the research results through different cultural nuances (Carroll, 2008; DeGruy, 2017; Dixon, 1977).

Graham (1999) argued that the ethnocentric nature of existing paradigms does not reflect Black/African American views, leading to a lack of appropriate preventative interventions within social work. The theoretical foundations established in the field of social work, both in Britain and the United States, do not reflect the diversity of worldviews and cultural values (Graham, 1999). Thus, in response to the increased awareness that current social work models have been ineffective and oppressive in addressing the needs of Black/African American people (Graham, 1999, p. 253), the use of the Africana worldview and Africana phenomenology is a corrective measure and key implication for the field when exploring phenomena about Black/African Americans. Utilizing this worldview/paradigm is fundamental in establishing how Black/African Americans define memory loss, which may lead to effective intervention.

The African worldview normalizes Black/African American behaviors that have been pathologized. It also accounts for my positionality as the researcher and the importance of the connection to researching issues pertaining to Black/African Americans.

### My Positionality in Relation to Africana Worldview

From an Africana worldview, there is no stance of objective viewpoint or a separation between the researcher and the phenomena, as previously mentioned. The researcher is part of the study because there is an interaction between the participants and the researcher. When a person walks into a room full of people, people take notice, and an exchange occurs in verbal or non-verbal action. In the relationship between self and others, we share the creative force within us that provides purpose and life fulfillment (Foster, 1971). For another example, if a person holds a gaze toward another person, sooner or later, the person receiving the gaze will look toward the person giving the gaze. This is the life force of one person interacting with the life force of another and a component of the Africana worldview that reinforces interdependence (Carroll, 2008, 2010; Dixon, 1977). In short, the participants feel the researcher’s presence, especially in a focus group; therefore, the researcher is part of the research. The components of this worldview bring clarity to my positionality. In short, there needs to be an understanding or a knowledge of my life experiences and their influence on me as a researcher. More importantly, the stance I take is a continuous connection to all living things, which is the interdependence component of the Africana worldview. The interdependence influences how I study and become a part of the phenomena.

As a member of the Black/African American community, I was born and raised in Portland, Oregon, and the interdependence provides me with a different lens to explore cognitive changes in this community. It also establishes a life force connection and the utility of the Africana worldview. Living in this predominantly White city founded on Black exclusion laws affects how I make sense of my world. It provides a diunital awareness of belonging due to my birth and not belonging due to my race. There is no separation through the Africana worldview; therefore, being Black and living in Portland connects me to the Black/African American community under study. This worldview, which supports no separation from the phenomena studied, includes me as part of the study. My interpretation of this view means that my experience as a Black/African American living in Portland provided an understanding of the participants' affect symbolic imagery and communal responses. It positioned me in a way to understand responses that are impacted by historical exclusion, terror, and abusive research (DeGruy, 2017; Washington, 2008). Due to a legacy of over 300 years of abuse, Black/African Americans have enhanced their ability to use affect symbolic imagery and felt time. My lived experiences of structural racism provide a foundation for my knowledge of affect symbolic imagery (cultural nonverbal responses, tones, and gestures) the participants expressed. With this awareness, I explored the incongruency of response and the urgency to follow the Africana worldview to explore multiple meanings.

As a volunteer providing care for an African American relative living with vascular dementia, I also have an understanding of the community's affect symbolic responses to memory loss. My positionality provided an easy avenue for my experience and bias to influence my interpretation of the affect symbolic responses. To manage this, I shared my understanding with a few research participants (member checking) to confirm or disconfirm the accuracy of my interpretations. The critical point is that I was in the position to actualize the Africana worldview where "I feel the phenomena … therefore I think, therefore I know" (Dixon, 1977, p. 136), which is also expressed in felt time.

The felt time is the process of being in unison with the Black/African American community because of my life experiences where I feel the phenomenal world of living in Portland as a Black/African American gay male. Throughout the United States, Black/African Americans have a different historic life experience as gay individuals that has been problematic and even life-threatening. My experience in the Black/African American and Portland community has been more of an issue of race than being gay. In the gay community, I have lived the experience of being excluded because of my Black/African American heritage. I have yet to experience being excluded for being gay in the Black/African American community because they are more concerned with my stance on issues important to this community. The focus is on what I am doing to strengthen the Black/African American community, which is another aspect of the

Africana worldview. The sense of belonging (a component of felt time) within the Black/African American community is important because my blackness is not accepted in the White community or the Gay community.

I lived in environments where some White people gave me the illusion of safety as they smiled yet were adamant in forcing me to believe I was incompetent and less of a human being. Some of the experiences became verbally and physically violent and excluded me from participating in events in certain areas of Oregon. Through my own experience of systems of oppression and exclusion, I grew up with the notion of difference, and safe spaces had the potential to be an illusion when people were smiling. I also took to heart my grandmother's advice: "Pay attention to what people do, not what they say." She emphasized that one must discern people's potential intent to know whether the place and the person are safe. One of the impacts is constantly being aware of my position as a Black/African American gay male, especially in environments that embrace the subtle belief that I do not belong because of my socially constructed race, gender, and sexual orientation. Through my lived experience with structural oppression, again, I am in unison with the Black/African American community through felt time.

These experiences taught me the value of my community and healthy ways to engage Black/African Americans in talking about experiences of exclusion in a way that stimulates healing. I also learned that I must fight against internalizing people's belief that I am inferior and assist members in my community from internalizing negative beliefs that are supported by systemic racism. This is the reason for using a focus group in this research: to provide a space of healing and increase connection, which strengthens the community as individuals heal.

My childhood also included being raised in a family that embraced egalitarian paternal leadership that honored their elders. It was a family of activists that pushed against structures of oppression, where my mother had worked in the Urban League during her college years. She was one of the first African American women to attend and graduate from Linfield College in McMinnville. She married my father, who was the first African American to graduate from Oregon Health Science School of Dentistry. There was also a time when my father was president of the NAACP's Portland, Oregon, chapter. At 5 years old, a major influence in my life occurred when my grandparents won the National Urban League's award for family of the year. My family was recognized on a national level for their fight for equality through education, services to the Black/African American community, and instilling these values over three generations. I learned the power of activism and the responsibility to work toward equity across environments (work, school, social events, etc.) in which I engage.

These experiences and the limited number of Black/African Americans living in Portland, Oregon, influenced how I connect with my cultural identity, research, and gay identity. As previously mentioned, it is the process of not internalizing negative beliefs about Black/African Americans that are supported by social structures. It is also being mindful as I construct my identities through an Africana worldview, which will be addressed further in the meaning-making section. Through this previously mentioned socialization, my location (Black/African American, gay, educated, middle class) and my life experiences shaped how I move in the world and how I approached this study. In the Africana way, this study invokes interdependence, healing, cultural connection, and knowledge production through affect symbolic imagery.

With my life experiences, I realized the connection between humans, the environment, and the importance of balance, which is one of the components of the Africana worldview. Also, through my social work education, providing mental health services and exploring culturally specific methodologies, I developed a deep understanding of balance (human interdependence/connection), which is essential for ethical research. The belief in separation gives room to othering that fosters racism and other forms of oppression (Bassey, 2007; Carroll, 2008; Dixon, 1977). I believe that systems of oppression result from the lack of knowledge or acknowledgment of the life force in all things, which is another component of the Africana worldview (Dixon, 1977).

Because of my life experience, commitment to empowering the Black/African American community, and acceptance of communal responsibility, my trustworthiness in my community has increased. As a Black/African American male researching a phenomenon in this community, the engagement caused the research participant to fully engage in the process. The Africana worldview invokes diunital aspects as a member of the community. Being a researcher moved me into a different yet still connected position in the community. This position is called an outsider under the Eurocentric or Western worldview belief of separation from the phenomena (Dixon, 1977; Guba & Lincoln, 2005). Yet, through this worldview, time is continuous of the past and present, focusing on the event and not based on measurable increments. Taking my positionality and stepping in draws the connection and sends a message of safety to the research participants. Stepping back in an objective position would send another message to the participants of warning and a need to guard their truth. When guarded, the participants then focus on giving the answers the researcher wants, which has the potential of not being a true lived experience.

As a mental health practitioner grounded in the Africana worldview working in the medical field, my life experiences also influence how I view health-related issues impacting Black/African Americans. Because of the racial exclusions that have and continue to exist, I am keenly aware of the lack of involvement of Black/African Americans in research and barriers to medical care. With this awareness, I fight for equality that invokes the humanization of Black/African Americans, and with my positionality, I engage in this study.

# Chapter III: Literature Review

This chapter is a literature review that includes articles related to the research questions and the Black/African American community. The first section begins with reviewing research on cognitive impairment, dementia, and AD related to Black/African Americans. The second section explores research on meaning making. The third section focuses on the Africana concept of self, and the fourth section explores work on Black/African Americans defining dementia and AD.

## Cognitive Impairment and the Africana Worldview

The following section explores cognitive impairment literature through the Africana worldview. The focus is on social structures and environmental factors that influence cognitive decline and how the impact is significant for Black/African Americans compared to other ethnic groups. In addition, the section explores the literature reflecting the environmental factors and state of being connected. Finally, the section discusses assessment tools, which are critical when using a culturally responsive paradigm to research health issues impacting Black/African Americans.

Current research reflects the influence of racial and social structures increasing stress that impacts cognitive functioning throughout the life span, along with other factors (Zahodne et al., 2016). Zahodne et al. (2016) argued that social environment, educational attainment, and external locus of control (environmental constraints that limit control over life outcomes) negatively impact cognitive function, and, due to structural racism, the impact is greater for Black/African Americans than non-Hispanic Whites.

## STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

Glymour and Manly (2008) explored the neurophysiology of cognitive impairment and the environmental factors that shape a person's performance on cognitive tests. They highlighted the impact of a life course of social conditioning and how racial and ethnic patterns impact cognitive impairment. They focused on the environmental conditions during early childhood and their impact on cognitive aging. They looked at environmental factors, such as structural racism (structures that support racism), that create barriers to education and social and economic positions that impact cognitive function throughout a person's life. Glymour and Manly drew the connections between social context, social patterning of harmful environmental exposures during early life conditions, and the potential for increased risk for cognitive impairment in old age.

Work by Glymour and Manly (2008) on patterns of cognitive aging demonstrated how structural racism affects racial disparities, socioeconomic position, interpretations of results, and the impact on the cognitive levels of Black/African Americans. Structural racism was evident through the effect of the Jim Crow laws, as approximately three million Black/African Americans fled from the south during the Great Migration for economic prosperity and to escape the physical, emotional, and racially motivated violence (Glymour & Manly, 2008). The authors re-emphasized the relevance of poverty, physical health, medical access, and health behaviors (Glymour & Manly, 2008). The scholars argued that structural racism resulted in unhealthy nutrition, inadequate housing, inadequate transportation, and limited resources for caregiving or caregiving relief. These factors have a neurological consequence that potentially influences cognitive outcomes, which is the result of the Jim Crow laws (Glymour & Manly, 2008).

Indirectly, Glymour and Manly (2008) discovered that researchers often failed to notice the relational interconnectedness and direct effects of environmental factors on cognitive impairment found within the Africana paradigm. Glymour and Manly highlighted the connection between the generational impact of social structures grounded in policy and laws that directly and indirectly impact cognitive functions over the lifespan. One social structure is racially stratified education, which is one direct result of the Jim Crow Laws. The laws perpetuate slavery in substance and created barriers that adversely impacted any connection between European Americans and Black/African Americans in public places (Alexander, 2010; Glymour & Manly, 2008; Klarman, 2004). A result of the laws was separate schools for Black/African Americans. Glymour and Manly argued that the impact of this segregation led to underfunded schools, lower cognitive scores for Black/African Americans, and lower verbal skills among young Black children (Glymour & Manly, 2008). Furthermore, they argued that broader environmental factors, such as poverty, poor physical health, and lack of medical access, are a direct result of Jim Crow laws and social policies, which are a pathway that “appears to influence vascular dementia” and “either exacerbate or expedite cognitive decline that is associated with Alzheimer’s dementia” (Glymour & Manly, 2008, p. 219).

Satizabal et al. (2016) explored the number of dementia cases over a 3-decade period during the Framingham Heart Study. They found a decrease in dementia rates but did not define the cultural or societal factors that affected the decline. They did, however, notice that the decline in dementia rates paralleled improvements in cardiovascular health. The research participants were predominately descendants of European ancestry, and the paradigm centered on the Western European worldview. While exploring the impact of related health issues through a European worldview, the researchers did not include relational interdependence or the effects of the environment as possible research factors.

The 2018 *Alzheimer's Disease and Facts and Figures* report a decrease in risk factors for dementia and AD due to education and improved cardiovascular risk factors, yet the data do not match the continued rise in hypertension, diabetes, obesity, and vascular occurrence in Black/African American patients. This report suggests that Black people have a higher incidence of AD and other dementias compared to their peers of Hispanic or European origin (Alzheimer's Association, 2018).

Few studies have explored the effect of social structures on how Black/African Americans conceptualize memory loss, dementia, or AD. Because most research is grounded in a Eurocentric worldview, which does not value cultural influences, the literature rarely addresses the cultural impact of cognitive impairment. As a result, the value of community members' interdependence is lacking, including relationships, connection to cultural group identity, and non-financial impacts. Africana worldview values dependence between people, the environment and life force (life in all things), possibly explaining why Black/African Americans talk about interdependence, loss of relationships, or environmental factors as issues related to cognitive impairment. When the research paradigm centers on a western European worldview, the data may fail to address cultural issues such as dependent human connection or environmental factors of balance (Carroll, 2008; Dixon, 1977; Rabaka, 2006). Another factor to consider when studying the impact of dementia on Black/African Americans is their socioeconomic status (Ighodaro et al., 2017), which is considered when utilizing the Africana worldview (Carroll, 2008; Dixon, 1997; Graham, 1999).

Bailey et al. (2017), Glymour and Manly (2008), and Ighodaro et al. (2017) exposed how these structures also influence the development and implementation of assessment tools that are often entwined with racial biases. In psychometric studies, most cognitive tests are based on people's reading ability, favoring higher education. "Reading level is a very powerful predictor of cognitive test performance, independent of years of education, age, or ethnicity" (Glymour & Manly, 2008, p. 245). People with lower reading levels have a higher chance of being assessed as cognitively impaired (Glymour & Manly, 2008). With social structures (Jim Crow Laws, negative racial socialization) and extreme racial segregation, a majority of Black/African Americans were prevented from obtaining robust education that could have led to high literacy or reading levels. The lack of educational opportunities may cause high-functioning Black/African Americans to perform poorly on standard cognitive screens used in clinical settings with the potential for being diagnosed with cognitive impairments, such as dementia (Glymour & Manly, 2008). Carroll (2010), Dixon (1977), and Graham (1999) found that it is difficult to challenge or eliminate subtle anti-Black messages as well as block racial prejudices when using a worldview or paradigm that centers on the Western worldview, which is grounded in the dehumanization of African Americans.

Ighodaro et al. (2017) presented another nonfinancial cost that occurs when researchers ignore racial biases, a cost that leads to the misinterpretation of research results, reification of race, delayed results, as well as over-diagnoses of Black/African Americans with AD, and failing to recognize preventable vascular dementia. Ighodaro et al. challenged researchers to incorporate paradigms that combine biological and socio-environmental factors to effectively understand dementia and improve treatment options for Black/African Americans. Ighodaro et al. also provided a brief history of unethical research using Black/African Americans and its influence on current dementia and biological research. They cited work from Slavitt's (1982) "The Use of Blacks for Medical Experimentation and Demonstration in the Old South" as well as Washington's (2006) *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. Even though current research recognizes the overlap of vascular dementia and AD, one example the scholars reported is the dangers of reporting that "Type II diabetes (T2D) is a risk factor of AD type dementia in the clinical (no autopsy) context." (Ighodaro et al., 2017, p. 5). The scholars argued that "the autopsy reveals that clinical diagnosis of AD was not completely accurate and that T2D appears to exert its impact through a different (potentially additive when comorbid disorder): cerebrovascular disease" (p. 5). They drew the connection to cerebrovascular disease, which can lead to a diagnosis of vascular dementia or other forms of dementia. They also drew attention to racism, socioeconomic status, and socio-environmental factors being prime reasons for the over-diagnosis of AD (Ighodaro et al., 2017).

## Structural Racism

In the previous section, we learned about several structural impacts on cognitive decline. In the following section, we take a deeper look at structural racism and the totality of its impact. It is important because Black/African American cultural identity is impacted by racism and cultural meaning making is dependent upon one's cultural identity. Examining structural racism is critical to thoroughly explore the research question about cultural meaning making and understanding memory loss among Black/African Americans.

First, the section begins with defining structural racism and the influence of racism on the self-view of Black/African Americans. Second, the focus is on the connection between racism and toxic stress and the impact on child development, cultural identity, and cognitive impairment. Third, the section ends by highlighting the societal impact of racism and socioeconomic status (SES) and their impact on the health system.

When we think of structural racism, we are looking at factors embedded in the fabric of society. It is the awareness that our society is stratified along the lines of race, class, gender, sexuality, ability, and religion/atheism creating barriers. The stratification is unequal, pushing some people to the margins of society and preventing access to basic life necessities (Sensoy & DiAngelo, 2017). Structural racism is a macro-level system that combines social forces, institutions, ideologies, and ways of interacting with others to generate and reinforce inequalities among racial and ethnic groups (Gee & Ford, 2011; Powell, 2008).

The literature reveals how racism has affected the social structures that influence how society currently views Black/African Americans (Williams & Sternthal, 2010). Racism affects everything from residential segregation, discriminatory incarceration, healthcare inequality, and access barriers to policies that support structural discrimination. This type of anti-Blackness discrimination impacts Black/African Americans more than other socially constructed racial groups (Bailey et al., 2017; Gee & Ford, 2011; Powell, 2008). To understand the degree of racism impacting Black/African American communities, we need to understand that enslavement created legal and tacit systems of racial oppression. This institutionalized racism—through policies and practices—dehumanized Africans based on color that contrasted Black and White worlds (Bailey et al., 2017). “The modern concepts of ‘race’ emerged at the cusp of the country’s nationhood, as early European settlers sought to preserve an economy largely from the labor of enslaved African people and their descendants” (Bailey et al., 2017, p. 1454). Enslavement of African people is in direct conflict with the universal rights of all people. To circumnavigate that concept, a legal framework and a new worldview that dehumanized Black/African Americans were established (Bailey et al., 2017; Dixon, 1977; Henry, 2005). The enslavement also created a hierarchy using the social construction of race, where White was and still is the measuring tool for everything in society (Bailey et al., 2017; Dixon, 1977; Henry, 2005).

The devastation of racism might influence the self-view of Black/African Americans, which can result in internalized racism, a lack of cultural identity, and impaired social advancement (Du Bois, 1903/2016; Powell, 2008; Williams & Sternthal, 2010). Gordon (2000) argued that the effects of racism influence one’s identity and influence resilience achieved by developing a culturally specific identity. Racism opens the door to two questions: (a) If racism shapes one’s identity, an identity that can lead to a negative belief of oneself, then will it affect how African Americans and Black people make sense of the world? (b) If people struggle to make sense of the world, how will Black/African American people make sense of life-changing illnesses such as dementia or AD? Ensuring a healthy Black/African American identity in a robust process as one makes sense of the world is a way to resolve the devastation of racism (Akbar, 1998; Belgrave & Allison, 2014; Carroll, 2010; Dixon, 1977; Gordon, 2000). Another way is to change or eliminate social structures that support racism or deny one's humanness.

In addressing racism, the research most often tends to focus on villainous individual or institutional acts (Bailey et al., 2017; Powell, 2008). Bailey et al. (2017) argued that diversity programs and cultural competency training sessions place the responsibility of addressing racism on an individual or an institution. These programs respond to interpersonal discrimination by having the individual or the institution increase their sensitivity and knowledge of other racial groups and have them focus more on the other. This response highlights a singular focus and fails to accurately address the social structures and the subconscious biases that encourage multiple structures of racism. This singular focus fails to recognize the cumulative impact of racism over time, which normalizes senseless acts of racism, and ignores the role of racist social structures (Bailey et al., 2017). This single focus also unintentionally contributes to racial stereotyping and prioritizes White experiences while avoiding the need for critical self-reflection about the participants in positions of power and their role in societal race relations (Bailey et al., 2017). The focus needs to broaden to incorporate knowledge about structural racism, racial power dynamics, and internalized scripts of racial superiority and inferiority. They also emphasize using approaches based on cultural humility, cultural safety, lifelong commitment to self-reflection, and engaging in changing power imbalance due to cultural differences (Bailey et al., 2017).

Harris (2018) linked racial structures to toxic stress and explored how stress influences childhood development, cultural identity, and cognitive impairment. Social structures support ideology, beliefs, and attitudes that condone racist actions, which are part of structural racism. One example of structural racism is federal subsidies that fuel racial and economic stratification, such as Redlining. Redlining is when a neighborhood is designated as the least desirable community. Those communities house mostly Black and Brown residents, often at or below the poverty level (Bailey et al., 2017; Powell, 2008). Redlining was legally sanctioned by the Federal Housing Administration, denying mortgages to people of color who resided in certain neighborhoods or who had businesses in redlined districts (Bailey et al., 2017). Redlining resulted in decreased property values, which impacted the funds generated by property taxes. This federal policy led to substandard quality of social and physical environments, exposure to pollutants and toxins, limited opportunities for higher-quality education and decent employment, and restricted access to quality healthcare (Bailey et al., 2017). Racial redlining became illegal with the passing of the Fair Housing Act of 1968, which "prohibited discrimination at any stage of the lending or home insurance process, and subsequent court decision have held that it does prohibit redlining" (Hiller, 2003, p. 395).

Even though redlining ended, the policy that reinforces segregation and White prejudice by perpetuating and strengthening the White-held belief that Black/ African Americans are different is the social ideology of the United States, influencing dementia research (Bailey et al., 2017; Carroll, 2010; Dixon, 1977; Henry, 2005). Powell (2008) argued that segregation is the product of the concepts of Black inferiority and White superiority. It manifests geographically when federal policies force African Americans to reside in subordinated neighborhoods plagued by stereotypical ideologies of race and poverty. "It is not simply that residential segregation and the institutional arrangements that support structure, and perpetuate segregation shape racial formation and racial attitudes; they also render the process itself invisible and seemingly natural" (Powell, 2008, p. 812). This racial formation, sanctioned in the United States, impacts how White Americans view race and how Black/African Americans make sense of their world. When Black/African Americans are continuously compared to animals, the media continuously connects a specific racial group to crime, when there is police violence toward unarmed Black/African Americans, when laws (Black codes/Jim Crow) constantly dehumanize people, one's self-belief is impacted (DeGruy, 2017; Johnson, 2017). When these racist structures also affect the health system, they create and enforce health disparities. These racist social structures have macro-level dynamics of racism that have micro-level consequences for people of color, which is called structural racism and affects all people (Powell, 2008).

Williams and Sternthal (2010) connected social stratification to critical determinants of health and patterns of social life that shape individuals' attitudes and beliefs, which sanction behaviors and actions that result in obtaining material and psychological resources (social structures). Along with social structures, social class, operationalized as SES, contributes to racial health disparities (Williams & Sternthal, 2010). Even though the two systems of social order are not interchangeable, race and SES contribute to health risks that reinforce racial health disparities and barriers to accumulated wealth (Williams & Sternthal, 2010). Structural racism and health disparities add to the potential negative identity of Black/African Americans, which influences the process of meaning making.

### Meaning Making

The meaning making part of the research question is explored in the following section through the Africana worldview. First, meaning making is defined. Second, attention is given to the connection between the worldview and "the concept of self which is always in the process of being formed" (Allen, 2001, p. 46) and this identity's link to the Black/African American community (Akbar, 1998; Allen, 2001). Third, the intention is to examine how the Du Bois double conscious identity (Bruce, 1992; Du Bois, 1903/2016) influences how Black/African Americans make sense of their environment in America, hence meaning making. Finally, the intention is to reflect on how the double consciousness is the direct result of racism and dehumanization, not different personalities. The focus will be grounded in resilience and not pathology.

In the realm of research, meaning making is the process of making assumptions and constructing models, hypotheses, or theories to study phenomena (Dixon, 1977). It is a worldview that helps people make sense of their surroundings, life, identity, and universe (Carroll, 2008). Hilgeman et al. (2017) argued that identity influences how people perceive themselves as they age and how they relate to their environment throughout their lives. They explored how identity assimilation, identity balance, and identity accommodation accounted for the difference in the overall memory changes (Hilgeman et al., 2017). Per Allen (2001),

> Nobles (1992) states that one cannot talk about the self-concept of Africans without talking about how this self-concept has been influenced by the Africans' domination by European peoples. He goes on to say that it is imperative that one gain a full understanding of the African concept of self before sound research can be done pertaining to Africans. (p. 53)

## The Africana Concept of Self

The worldview influences how people make sense of their surroundings and how they see themselves. This self-awareness is known as the self-concept or identity, and our lived experiences are the catalyst to developing meaning (Jackson-Lowman, 1998). The Africana worldview views the self-concept as dependent on the connection to the Black/African American community. Fundamental connection to the Black/African American community occurs when individuals see themselves reflected in that community and it reflected in themselves. The social environment also influences identity, including the negative impacts of the western worldview (continued dehumanization) and social structures that support racist ideology as well as the history of African enslavement (Carroll, 2010; Carruthers & Harris, 1997; Dixon, 1977). The influence of the social environment can lead to a strong cultural identity that supports resilience or internalized racial stereotypes. A strong cultural identity occurs when the social environment supports positive characters and eliminates stereotypes.

A strong concept of self emerges when Black/African Americans grapple with the idea of dehumanization by engaging with the cultural community in a healthy way. Self-reflection among the Black/African American community happens when a person maintains their identity, group membership, and group identity (Ogbonnaya, 1994). Ogbonnaya (1994) argued that the Africana worldview allows a person to develop their identity from the tension that arises from other complicated selves as one interacts with the Black/African American community and the larger social environment. The life force represents the mythical past, generational past, present nature, and the emerging self (the person to be), which guides the person through the process of making meaning of their world. Black/African American communities embrace the concept of “the individual self,” which adds to the Black/African American communal identity. Ogbonnaya noted that the spiritual/life force is intertwined with all aspects of the self, the environment, and the community. The connection to the Black/African American community reinforces the idea of self and humanity that is and always will be in the Black/African American. The Euro-centric worldview erases Black/African Americans’ human connection.

Belgrave and Allison (2014) defined the self in schemas where “self-concept is a part of our self-schema. A self-schema is a cognitive representation of the self” (p. 66). Belgrave et al. also argue that within the Black/African American community, the conceptualization of the self is directly linked to social identity because of the interdependent nature of Black/African American communities. They focus on how racism and dehumanization lead to racialized identity, evident when Black/African Americans experience oppression while engaging with White communities (e.g., employment, housing, education, religion). The salience of the Black/African American ethnic identity fosters resilience that can overcome systems of oppression. Even though race is an arbitrary social construction that forms a system of stratification, power, and ideology creating marginalized groups, it influences one's identity, worldview, and the process of meaning making (Belgrave & Allison, 2014; Lemberger-Truelove, 2016; Williams & Sternthal, 2010).

## Double Consciousness

Understanding double consciousness is essential for this research because it influences cultural identity, defining health changes and how Black/African Americans make sense of the world. W.E.B. Du Bois developed a theory that addresses societal resistance to accepting African Americans as full citizens. He used the terms "veil" (barrier from the world of Whites, both spoken and not spoken) and "double consciousness" to describe racial conflict and the Black/African American experience of being excluded from society (Du Bois, 1903/2016; Henry, 2005).

The veil represents the color line, the division between Whites and Blacks or Whites and Brown people. Lemert (1994) stated that the veil is a metaphor for race relations in the United States,

> A color line divides and separates, but a veil is the essential aspect of the communications between those divided. In setting off the other, a veil organizes information that passes between-blinding those who wish not to view the other; limiting the others in ways that affect in the deepest what they think of themselves. (p. 386)

The first publication that mentioned double consciousness was the book *The Souls of Black Folk*, published in 1903 (Du Bois, 1903/2016). Through this book, Du Bois explored the struggle that Black/African Americans had in developing an identity within a world of structural racism and constant dehumanization. Du Bois (1903/2016) argued that Black/African Americans developed their identity by continually viewing themselves through the eyes of the other, a concept currently known as the "White racial framework" (Johnson, 2017, p. 301). This development created two types of consciousness (identities) and explained how Black/African Americans may or may not experience internalized racism (Du Bois, 1903/2016; Johnson, 2017). Double consciousness was developed as a result of White stereotypes of Black/African Americans, structural racism, their exclusion from mainstream White society, and the impact of "being both an American and not an American" (Bruce, 1992, p. 301). People from the African diaspora develop their identity through the eyes of others, which Du Bois expresses in the following statement:

> It is a peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. One ever feels his two-ness, – an American and a Negro; two souls, two thoughts two unreconciled strivings; two warring ideals in one dark body. (Du Bois, 1903/2016, p. 2)

Bruce (1992) argued that there has been a misunderstanding of double consciousness, resulting in pathologies (dissociative personalities) that assume Black/African Americans are dysfunctional instead of viewing double consciousness as different identities or positions to deal with racism. The double consciousness is a struggle Black/African Americans experience in developing an identity and what it means to be an American based on the Eurocentric worldview that denies one's cultural identity. Double consciousness should be perceived as different identities or positions to deal with racism. Lyubansky and Eidelson (2005) argued that scholars have struggled with double consciousness "because of its sharp contrast to the unidimensional personality structure presumed to be characteristic of the dominant White culture" (Lyubansky & Eidelson, 2005, p. 4). The unidimensional personality structure is based on either/or logic, which prevents a different understanding. Du Bois's point was that African Americans/Blacks could not develop a healthy identity using the veil, which led to an internal struggle because it denied the existence of Black/African Americans. This point is evident through his poetic writing:

> The innate love of harmony and beauty that set the ruder souls of his people a-dancing and a-singing raised but confusion and doubt in the soul for the black artist; for the beauty revealed to him was the soul-beauty of a race which his larger audience despised, and he could not articulate the message of another people. This waste of double aims, this seeking to satisfy two unreconciled ideals, has wrought sad havoc with the courage and faith and deeds of ten thousand thousand people (Du Bois, 1903/2016, p. 3).

Du Bois (1903/2016) expanded the power of Black/African Americans as he drew attention to the way to manage structural racism through the "gift of the second sight" (Du Bois, 1903/2016, p. 2), which is the ability to know the truth of the oppressor and creating one's identity through a cultural framework grounded in Africana worldview

(Akbar, 1998; Dixon, 1977; Henry, 2005; Lemberger-Truelove, 2016). Through the Africana worldview impact, White people regain their humanity when they acknowledge the humanity of African Americans. This is tied to this worldview on interdependence and the interconnection of all things in the universe (Carroll, 2008; Dixon, 1977; Henry, 2005).

Bruce (1992) argued that there are three components to Du Bois's theory of double consciousness, which are (a) the real power of White stereotypes in Black life and thought, (b) Racism excluding African Americans from mainstream society, and (c) internal conflict between the "African American" and the "American." This internal conflict stems from knowing that one is American and yet is denied full membership into American society, a society that continually fights to justify violence toward Black/African Americans through constant dehumanization (Lemberger-Truelove, 2016). DeGruy (2017) and Johnson (2017) argued that the dehumanization of Black/African American political leaders is portrayed in the media and society's structures. By delegitimizing Black leaders—portraying them as uncivilized or un-American—all Black/African Americans are seen as uncivilized or un-American. Even President Barack Obama did not escape being labeled as un-American. This was evident during the Birther Movement, which was ingrained in the Republican party and was pivotal to Donald Trump's political career (Johnson, 2017).

For this research, double consciousness is a reaction to dealing with a racist experience, such as being blocked from societal structures that support being human and American or being forced into the dichotomous belief of one's identity (African or

American) and that belief's impact on one's worldview. Double consciousness also incorporates one's connection to Black/African American group identity and the acceptance of multiple identities that occur not due to pathology but to navigating through structural racism.

It took over a century until the notion of multiple identities was thoroughly ingrained in aspects of society and accepted in the field of behavioral health (Lyubansky & Eidelson, 2005). The acceptance of multiple identities leads to positive mental health and impacts the process of making meaning for Black/African American people. Black/African Americans continue to be deprived of having various identities, as expressed in the negative responses to kneeling during the national anthem, the Black Lives Matter Movement, and the fight against multiple killings of unarmed Black and Brown people (Johnson, 2017). Most Black/African Americans continue to be resilient in the face of racism. To develop a healthy identity, or as Akbar (1998) puts it, to know thy self, Black/African Americans must address the dilemma of double consciousness, connecting with their cultural group and redefining their culture so that it centers on the Black experience; in other words, using the Africana worldview strengthens one's identity (Akbar, 1998; Bruce, 1992; Du Bois, 1903/2016; Johnson, 2017).

Through the Africana worldview, identity is viewed through a diunital logic where the union of opposite identities exists. When using the diunital logic, identity unifies the concept of double consciousness by bringing together Black/African American and American identity. In the Western worldview, either/or logic defines one's identity, creating racial polarization (Dixon, 1971). The either/or process infuses "if I am pro-Black, then I must be anti-White. If I am pro-White, then I must be anti-Black" (Dixon, 1971, p. 28). The either/or identity is a cultural absorption where White immigrant groups were acculturated into the dominant American values and behavior of the Western civilization, Anglo-Saxon culture, and industrialization, which is the American identity (Dixon, 1971). The American identity is synonymous with White identity, and through the either/or logic, it excludes all non-White identities. Therefore, American identity excludes Black/African American identities when using Western logic of either/or.

Africana worldview utilizes a diunital identity that sees the values of both identities without destroying or ruling over either identity. It is not assimilation; it is recognizing the value of both cultures and how they grow or develop, honoring the differences, which supports the development of both cultures. In short, diunital identity unifies the differences without destroying the other. It holds space for both cultural identities without overshadowing either and recognizes their interdependence for development. The diunital identity gives room for two identities: Black/African American in Western civilization and non-White American (Dixon, 1971). Double consciousness is the process of developing a Black/African American identity. Awareness of the dominant cultural view of Black/African Americans and developing one's identity through a cultural lens prevents dehumanization or racist ideology as the foundation of one's identity.

The strength of one's racial/cultural identity assists in how Black/African Americans explain our understanding of illness, which is explored in the following section.

## Black/African American Definitions of Dementia and Alzheimer's Disease

The previous sections provided a cultural foundation of Black/African Americans' meaning making not applied to defining dementia and AD. This section reviews literature pertaining to the definition of dementia and AD by Black/African Americans. We explore the history of definition through caregivers and the impact of enslavement on current definitions of dementia and AD. Next, the literature explores structural systems like the Jim Crow laws and redlining and their connection to dementia and AD. Then, we explore the impact of structural racism and religion on meaning making and defining AD.

Rarely does the literature reveal how Black African Americans define cognitive impairments. The closest we come to knowing how Black/African Americans define dementia and AD is mostly through caregivers' experiences. Lindauer et al. (2015) explored the meaning African American caregivers ascribe to dementia. The qualitative research used an interpretive phenomenology approach where the scholars discovered themes to explain how caregivers defined dementia. One theme was hanging on, which helped Black/African American caregivers hold on to their loved ones living with cognitive shifts that caused behavioral and personality changes. The scholars argued that even though the loved ones were physically present, personalities changed to the point that parts of their loved ones were lost. This change forced caregivers to focus on what was still here, which helped them hold on to their love for the person they knew and what remained even though their loved one was extremely cognitively impaired.

For African American caregivers, the losses in cognitive decline were considered relatively insignificant compared to other life experiences. The caregiver's key focus was maintaining the elder care recipient's current abilities and status in the family. Lindauer and colleagues (2015) connected the history of enslavement to shaping caregiving values and the desire to hang on to older relatives with cognitive impairment. One caregiver stated, "Way back when … even in the struggles, and slavery, all we had is each other. So that's why we hang on to each other." (p. 737). Another caregiver reflected on the enslavement period: "If you look back in slavery days … all we had was each other to keep each other going. From young to old we took care of everyone" (p.738). The researchers connected the history of enslavement and family separation (family member being sold), as well as other historical aspects of oppression, to the importance of maintaining family relationships for present-day Black/African Americans. Moreover, they connected the closeness of Black/African American families and the desire to hang on to declining relatives to current racism, which leads Black families to rely strongly on each other. The value of the person was more important than dementia or AD, or a biological disruption (Burns et al., 2006; Connell et al., 2009; Sullivan & Beard, 2014).

Belgrave et al. (2004) had a similar understanding as Lindauer et al.'s (2015) themes, hanging on and still here, but utilized continuity and discontinuity to represent changes in suffering (people living with dementia). Caregivers used continuity/discontinuity to describe who the loved one was and whom they had become due to dementia. Caregivers and people living with Alzheimer's talked about their lived experiences to make sense of the illness. They defined AD in ways of being more than using medical definitions (Belgrave et al., 2004). They ascribed meaning to a global way of being and episodes of daily manifestations. Belgrave et al. also presented a conflict of view between the caregiver and care recipient about the definition of "childlike." Caregivers ascribed childlike meaning to daily behaviors, whereas people living with cognitive impairment did not refer to themselves as childlike.

Fox et al. (1999) reported on a pilot study that reviewed transcripts of extended in-home interviews with caregivers who had worked with non-institutional Black/African Americans living with dementia. Fox et al. posited that historical experiences of racial oppression are connected to current caregiving experiences and cultural representations of caregiver burden. Fox et al. argued that most research ignored the structural racism that impacted Black/African Americans living with cognitive decline and their caregivers. They found the Black/African American family defined cognitive changes through maintaining relationships. They also found that most research about Black/African American caregiving is presented in social gerontology as "unassuming, unconditionally loyal, self-satisfied, less burdened and less taxed servant in contrast to the prototypical "White" caregiver" (p. 511).

Furthermore, Fox et al. (1999) posed that these large-scale social forces like structural racism (Jim Crow laws and redlining) become embodied by Black/African Americans who experience cognitive impairments and their caregivers. The embodiment translates to enhanced stress for providing care and individual symptomatology, where past experiences of racism partially manifest in psychotic and persecutory delusions. They drew the connection between social forces like institutional racism, racial and social class oppression, and terror and how these experiences fuel meaning making:

> However, the legacy and urgency of racial and class oppression suffered by many of these African-American families is no random outlying accident of history – personal or collective. Moreover, structural realities of racial exclusion, exploitation and terror generate a great deal of meaning-making – including, perhaps, the world of meaning around the experience of caregiver burden (Fox et al., 1999, p. 509)

Another result indicated that Black/African Americans experience caregiver burden that is not reflected in social gerontology:

> These caregiver accounts speak of deep frustration and trauma. They are stories full of burden and loss, emptiness, and alienation. These aspects of African-American caregivers' experience have not been adequately captured in comparative social gerontology on caregiver burden. (Fox et al., 1999, p. 520)

As they explored how African American caregivers made sense of dementing illness among their elders, they found that the legacy and urgency of racial and class oppression are key components of meaning making, reflected in the following quote: "The meanings of illness represented in these caregiver accounts may be a mirror for large-scale social forces at work as they construct lives ravaged by racism, economic exploitation, poverty loss, and cultural misrepresentation" (Fox et al., 1999, p. 520).

## STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

From a macro level, the meaning of dementia is an illness created or worsened by social disparities in health. The definition of cognitive decline from a micro-level included behavioral changes such as losing keys or money and an argumentative stance by the ones living with dementia. They also posited that the cognitive changes were not significant until the behavior change became challenging. For one Black/African American participant, the mother's memory loss became important when persecutory behavior changes occurred that incorporated aggressive behavior: "We knew something was wrong when mom accused her 13-year granddaughter of stealing her credit card. She almost became violent with this child. We found the card later on" (Mrs. Banks, caregiver for her mother)" (Fox et al., 1999, p. 517).

Fox and colleagues found that the impact of racialized subordination, political economy, and terror Black/African Americans experience is reflected in the paranoid persecutory accusations and caregiver burden.

> There may be many different roads to a final common pathway of paranoid, psychotic delusions among dementia patients. What we are suggesting is that the structural contexts of inequality – past and present – may be made to matter in the distribution, content, and logic of symptoms. These structural realities may also register in the course of dementing illness and caregivers experience of burden." (p.530) Some symptoms are interpreted through a lens of racial persecution. They also reported the impact of structural racism/oppression and the reproduction of inequality on economic wealth denied to Black/African Americans.

Fox and colleagues (1999) did not connect structural racism with cultural or individual Black/African American identity, which has the potential to influence how Black/African American define memory loss, dementia, and AD (Akbar, 1998; Allen, 2001; Lindauer et al., 2015). Their findings did not support other research pertaining to faith and the role of the church. They found that "when people are asked about how they cope with illness and the burdens of caregiving, they never spontaneously mention faith in God or church support" (Fox et al., 1999, p. 514).

In another study, Sullivan and Beard (2014) provided a secondary analysis aimed at understanding the role of religion and spirituality in narratives of Black/African Americans and European Americans living with AD and their caregivers. The scholars presented how religion was more salient to Black/African Americans than European Americans when making sense of their experience living with AD or mild cognitive impairment. The scholars indicated that religion also assisted Black/African American caregivers with making meaning of the cognitive changes occurring in their loved ones. This qualitative research revealed that religion is central to developing a healthy sense of self and identity and creating resilience as the physical and mental changes occur for Black/African Americans diagnosed with AD. Resilience is also evident as family members provide care for loved ones living with AD, utilizing spiritual practices to make sense of their experiences and stay connected.

The researchers did not connect the impact of structural racism to research participants' definition of dementia or how it caused marginalization that influences meaning making (Fox et al., 1999). The scholars did address how the lived experience of oppression has the potential to foster resiliency, which has the potential to influence one's definition of dementia. Sullivan and Beard (2014) presented the protective factors of strength and hope, never feeling alone, social and interpersonal benefits, and keeping a positive attitude that arose out of one's religious/spiritual experience. It also moved one's identity living with AD from a medicalized to a healthy view of oneself with the potential ability to interact with the community.

The healthy view is also aligned with work by Rovner et al. (2013):

> We found that more highly religious subjects tended to endorse having a greater sense of control over their health. It is reasonable to assume that their great faith and religious practices reinforce a sense of empowerment or self-efficacy. (p. 6)

Other authors, including Dilworth-Anderson and Gibson (1999) and Rovner et al. (2013), found that Black/African Americans defined Alzheimer's as a natural aging process, God's will and that they had some control over the risk factors. Sullivan and Beard (2014) provided depth to the understanding of the influence of religion in defining how Black/African Americans experience AD or mild cognitive impairment (MCI).

Sullivan and Beard's (2014) and Connell et al.'s (2009) findings of the influence of religion in defining or managing dementia or AD are in direct contrast to Fox et al. (1999). The results of this discrepancy are potentially due to different population sizes, methods, historical effects, and methodology. Fox et al. (1999) utilized a macro lens that gave meaning to the micro result. They incorporated a historical framework that exposed social structures and their impact on Black/African Americans. Sullivan and Beard utilized a Christian perspective, and all their research participants identified as Christian.

They did not interview or include other faith-based participants or participants who identified as atheists.

It is plausible that the differences in the two studies are due to different sample populations, which inadvertently highlights the diversity that each study ignores. Utilizing the Africana worldview would increase the awareness and the importance of drawing out the cultural heterogeneity, cultural nuances, and the varying impact of structural racism when analyzing the research participants' responses (Carroll, 2008; Schiele, 1996). Incorporating the influences of structural racism has could provide a different meaning of dementia and potential key points for effective messaging to encourage seeking medical professionals as well as culturally responsive prevention messages. Africana worldview infuses the willingness to find other spiritual faiths within the existing data to support or refute their findings. The results would not assume that specific religions are salient for all Black/African Americans, and spiritual/religious diversity would be highlighted.

This chapter presented a few critical points. First, using the Africana worldview highlights oppression impacting Black/African Americans. Second, racism impacts social structures and how we assess, address, and interpret cognitive issues impacting Black/African Americans. Third, to decrease cognitive issues in the Black/African American community, knowledge of a healthy cultural identity incorporating double consciousness needs to occur. Finally, we must address the social, political, and environmental aspects that negatively impact Black/African Americans.

### STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

Overall, the literature in this section provided several themes to consider, such as enduring racism over time influencing the definition of cognitive impairment (Ayalon, 2013; Connell et al., 2009; Dilworth-Anderson & Gibson, 1999; Fox et al., 1999). God's will, normal aging, and Black/African Americans are "more than the disease" were other themes that influenced culturally specific definitions of dementia and AD (Connell et al., 2009; Rovner et al., 2013). A final theme was the aim of caregivers to show that family members living with cognitive impairments are whole and not defined by the disease (Belgrave et al., 2004; Burns et al., 2006; Connell et al., 2009; Lindauer et al., 2015; Sullivan & Beard, 2014). The connection to people living with dementia was more important than the cognitive problems. As previously mentioned, the literature used a Western/European worldview, and the results could differ if an Africana worldview were utilized. The hope is that the current research will provide clarity around Black/African American definitions of dementia and AD utilizing the Africana worldview.

# Chapter IV: Methods

This chapter has four sections, beginning with community input, recruitment, and sampling. This section includes a brief history of the exploitation of Black/African Americans in research and its impact on this study. Next, I continue discussing my role and what I did to ensure equitable research in this study and using the input from the community. The focus group members are described. Next are the risk, benefits, and the use of informed consent, which reinforces equitable research. Succeeding that, the focus group configuration section describes how the focus groups were set up. Next, the procedure section presents the workings of the focus groups. Finally, this section ends with a discussion of the data analysis process.

As a reminder, there are two research questions. The first asks about the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans. The second pertains to the different ways the Africana worldview aids in interpreting Black/African Americans' understanding of memory loss, dementia, and AD. This was a qualitative phenomenological study exploring the research questions through the lived experiences of Black/African Americans. Lived experiences were gathered through focus groups, which aligned with interdependence.

## Community Input, Recruitment, and Sampling

Because of the "long history of horrific biomedical experimentation on Black/African Americans" (Ighodaro et al., 2017, p. 2), including the impact of the government syphilis study that occurred at Tuskegee University, radiation trials, and other harmful research, Black/African Americans distrust medical institutions, researchers, and public health officials, and are reluctant to participate in research programs (Gamble, 1997; Washington, 2008). The lack of Black/African American research participants and the effects of structural racism led to ineffective research and maintain social hierarchies based on race (Ighodaro et al., 2017). Effective research impacting Black/African Americans occurs when researchers utilize key leaders and obtain their support for the research, incorporate cultural nuances, and center their experiences (Carroll, 2010; Dixon, 1977; Graham, 1999). The support of both informal and formal leaders (key informants) was important because they assisted in addressing the historical impact of the research. In this study, the informal and formal leaders reassured the research participants that they would not be exploited and that the research would strengthen the Black/African American community. They provided the assurance that resides outside the researchers and within the community. When key informants supported the research, following the tenet of giving back to the Black/African American community, approval for the research was spread throughout the community. Also, Black/African Americans were more likely to participate in the research. With this knowledge, I was mindful when selecting informal and formal leaders to guide me in this research.

Before this study, I was a research assistant/coordinator for the African American Dementia and Aging Project (AADAPt). The AADAPt study focused on improving understanding of age-related memory loss in African Americans. The project led me to some key informants in the Black/African American community in Portland, Oregon, who provided guidance on this study. I discussed my ideas about researching memory loss from a cultural framework. A married couple who are community leaders gave suggestions to a few other people from the community to consider. Two other key informants involved in the conception of this research were Black/African American researcher(s) working on the AADAPt study and living in Portland, Oregon.

Growing up in Portland and the roles my parents had in the community provided me with the opportunity to learn about a variety of leaders in Oregon. I spent time with well-respected Black/African American leaders in the community. Because of my connections, I chose to speak to a few people who were kind and strong advocates for Black/African American issues. I spoke with them about exploring memory loss in our community using a culturally specific framework and explored with them who might be important to include. I specifically talked about the historical impact of research on Black/African Americans and what I was doing to prevent harm from reoccurring. The discussion included using a culturally responsive methodology and talking about the Africana worldview. The discussion led to a list of over 25 people that gave input to this research design. There were 10 people with whom I was constantly communicating about this research, and a few were a part of the coding team. This study grew out of the community I am a part of, which led to using purposive sampling.

Purposive sampling is a strategy to choose participants to gain insight and depth of understanding by hearing from members who knew or lived experience with the research topic (Morgan, 1998). I used purposive sampling to gain insight and in-depth knowledge (Morgan, 1998). Because of my extensive work within the Black/African American community, I established connections with key informants who provided potential participants that could provide the depth of knowledge to this study. Another reason purposive sampling was used was to obtain insights into Black/African American community members' process of meaning making.

In Portland, the Black/African American experience is unique due to the history of Oregon's exclusion policies and White utopia(n) dream and the low percentage of Black/African Americans living in Portland, Oregon. The lived experiences were different in Portland compared to other cities in the United States due to the percentage of Black/African Americans who moved to this city from 1942 to 1946 to work in the Kaiser shipyards. Between 1942 and 1946, the population of Black/African Americans grew from 1,800 to about 15,000, disrupting the goal of a White-only state (Oliver, 2022). The White utopia was supported by several exclusion laws enacted in Oregon, and the first Black exclusion law was passed in 1884. This law was to whip up to 39 times every 6 months for any Black/African American who did not leave Oregon territory (Chandler, 2013). When this law was repealed in 1885, several other anti-Black exclusion laws were enacted. Liberal Whites bragged that restrooms and drinking fountains were never segregated, ignoring the fact that businesses refused to hire Black/African Americans except for menial positions, and public swimming facilities were for only White people (Chandler, 2013).

Despite the exclusion laws, the population of Black/African Americans increased due to the increased work in the Kaiser shipyards toward the end of World War II. The increased numbers were not large enough to challenge the stereotypical views of Black/African Americans. Therefore, consciously or unconsciously, White supremacist ideology influenced White people's interaction with Black/African Americans, creating different challenges for the people who stayed (Burke & Jefferies, 2016; Chandler, 2013; McLagan, 1980; Oregon Black Pioneers & Stowers Moreland, 2013). The racist attitudes became unwritten laws that were reinforced through structural discrimination, such as redlining, busing, and property taxes used to fund schools. These unwritten laws caused negative impacts on financial resources in most communities with a large number of Black/African Americans, including in Portland, Oregon (Burke & Jefferies, 2016; Chandler, 2013; McLagan, 1980).

To capture this impact, I used purposive sampling to recruit research participants utilizing people who are key leaders in the community (formal leaders) to assist with participant recruitment and participation in the research. I engaged people who are not recognized as formal leaders yet are followed, related to, and respected for guidance (informal leaders). Recruitment mainly occurred through word of mouth and referral from leaders and Black/African American community members. I gave a few presentations at Black/African American community meetings about this research. One presentation was at the Black American Association of Retired Persons (AARP) Portland chapter meeting, and another at the AADAPt annual celebration. In addition, a few participants in this study participated in AADAPt and other research projects I facilitated.

The participants wanted to maintain their involvement in future research projects pertaining to memory issues impacting the Black/African American community. The specific criteria used to select participants were lived experience as Black/African American in the United States, lived experience with memory loss or caring for someone with memory loss, effective communication skills to talk about their experiences, aged 45 or older, residence within a 50-mile radius of Portland, Oregon, and the willingness to participate in this study. Individuals who could not communicate due to cognitive impairment were excluded from the study. Also, I attended to other intersections of identity in the sample, such as gender, class, education, sexual orientation, and physical abilities.

The research sample comprised 13 individuals. Seven were women. Everyone had some college education, and eight people owned their homes. Not everyone was born in Portland, but all had over 10 years of lived experience in this city. The participants had different individual experiences of racism due to geographic location and place of birth, yet there was a collective experience among them.

**Risks, Benefits, and Informed Consent**

The potential risk to research participants was possible emotional distress due to difficulties or challenges related to their lived experiences of racism, declining cognitive health, or caregiving for people living with dementia. The risk of serious distress was minimal. If a participant had been seriously affected by the discussion, as a trained mental health practitioner, I would have met with that person following the focus group and referred them to mental health services. Fortunately, in this study, no one experienced harm; in contrast, they experienced healing and validation.

The potential benefits to research participants were the opportunity to talk about issues of concern about cognitive change, learning positive ways to manage experiences of racism, increased self-esteem and personal well-being, a positive cultural identity, and a stronger connection to the Black/African American community. They experienced cultural interdependence by contributing to knowledge about cognitive health that benefits other Black/African Americans living in Oregon.

Measures to protect privacy included storing all information in a locked file cabinet; only I had access to the data collected. To protect personal information, consent forms were not kept with demographic information, which was encoded. The Portland State Institutional Review Board (IRB) oversaw and approved this study and ensured the rights and welfare of the participants were protected.

## Focus Group Configuration

Focus groups were used as this method was compatible with core tenets of the Africana worldview. Focus group dynamics brought out aspects of data that would have been less accessible without the interaction of the participants and perspectives that the researcher had not anticipated (Morgan, 1988; Rubin & Babbie, 2011). They provided the process of learning about a phenomenon that is poorly understood. The focus group discussion created the process of sharing and comparing among participants, exploration, discovery, and the opportunity to understand different experiences (Morgan, 1998). Utilizing the Africana phenomenology, the focus group of Black/African Americans produced the collective experience that shaped meaning through their lived experiences. It provides the cultural nuances that shape meaning from a communal perspective and the collective experience of structural oppression because of one's race. I used focus groups to provide a space that potentially enabled healing and increased connection, which strengthens the Black/African American community through individual healing. The focus group supports collective interdependence.

Denzin and Lincoln (2005) have noted how claims of saturation can reflect rationalization instead of reason. They claimed that saturation could be subjective and a rationalization for small numbers. Moving beyond justifying or rationalizing and reducing the risk of being subjective, I used “interpretive sufficiency which takes into account cultural complexity and multiple interpretations of life” (Denzin & Lincoln, 2005, p. 528). This approach includes gathering data until information does not create new findings, ends with repeated themes, and provides room for multiple understandings (Carroll, 2010; Denzin & Lincoln, 2005; Dixon, 1977; Henry, 2005). However, due to the ongoing impacts of COVID-19, face-to-face meetings were discouraged. Therefore, only three focus groups occurred.

The three focus groups explored the collective response to experiences with memory loss, caregiving, racism, and their lived experiences in Portland, Oregon. The unique struggles of Black/African American experience potentially influence identity and defining memory loss because of the Oregon exclusion laws and the goal of settlers to create a White utopia (Burke & Jefferies, 2016; Chandler, 2013; McLagan, 1980). Research participants discussed their experience of racism and with memory loss or caring for someone experiencing dementia, AD, or other cognitive impairments. The interdependent component of the Africana worldview and the impact of structural racism led to unique experiences revealed in the focus groups.

The group sessions were 120 minutes, began in November 2019, and ended by February 2020 due to COVID-19. Because of the time constraints and the depth of the questions being explored, each focus group consisted of three to eight people. One group consisted of people who self-identify as living with memory loss, and one member in this group also provided care. The other two groups consisted of members who provided care for people experiencing memory loss. The LGBTQ groups also had members who revealed they were living with cognitive decline. The focus groups strengthen the researchers' grasp of the empirical world and phenomena being studied and assist in discerning variations that arise from the diversity within the Black/African American communities (Carroll, 2010; Denzin & Lincoln, 2005).

The strength of using focus groups for this study was that they are socially intense with a unique power to get at the hows and whys of what is being studied (Kamberelis & Dimitriadis, 2013). They provided a way to build and strengthen connections in a way that honors cultural identity and captures the lived experience in relation to other lived experiences in real time. I used focus groups because they normalize the experiences of racism through other people's experiences and remove the feeling of being alone. They also counteract gaslighting when Black/African Americans talk about experiences of racism, removing the minimization of one's experience. I wanted to capture the collective experience within the Black/African American experiences through stories without the pressure to protect White people's feelings. Focus groups were used to capture insight and information through naturally occurring dialogue rarely found in one-to-one interviews or observation research (Kamberelis & Dimitriadis, 2013). Finally, I used the focus groups to capture symbolic affect interactionism in action in a Black/African American setting.

While there are many strengths to using focus groups, a few risks could have potentially occurred. First, privacy is an issue for focus groups and all human subject research. I used numbers to represent participants in the transcripts. As previously mentioned, I stored all identifying information in a locked file cabinet. Second, in focus groups, there is a risk of a participant dominating the group, influencing what research participants say (Morgan, 2019). The assumptions are that group influences have a negative impact and that people would not feel comfortable discussing complex and sensitive topics. To address the risks, I designed questions that would invoke everyone's opinions, and I stated, "there are no wrong answers." I informed participants that I was interested in their lived experiences. The result was that the participants created an environment where everyone's opinion mattered. For example, participants asked people who were silent what they thought to get their opinion and ensure their participation. The questioning reassured participants that everyone's opinion mattered. I led the focus groups and analyzed the data with the support of a research assistant, both of us Black/African American community members. The following section explores the application of the Africana worldview to this research, starting with the focus groups and ending with the analysis process.

## Procedure

First, research participants attended an initial meeting, where I reviewed the criteria for participating in this study. During the initial meeting, I discussed the purpose of the research, and if participants met the criteria and wanted to participate, we reviewed the consent required to do so (Appendix A). The research participants also completed a demographic survey (Appendix B). I gave the participants the date and place for the focus group after they completed the questionnaire.

This study was a one-time focus group interview with a follow-up to confirm cultural meanings and recurrent themes. I started the focus group by sharing food, greeting the participants, and giving them their $15.00 stipend for taking part in this focus group. The participants talked with each other exploring how people joined the research and if they were born in Portland or moved to the area. The greeting session was important because this was the process of assessing if people were supportive of the community and if they felt it was a safe space to share information. While we were connecting, people gathered food and sat in chairs arranged in a circle.

Once everyone was seated, I reviewed the consent form they signed during the initial screening process (Appendix A). After reviewing the consent, I answered questions and confirmed they wanted to participate in the focus group. One consistent set of questions from participants in all the focus groups was about my purpose for research, how it impacted the Black/African American community, and my commitment not to exploit the participants. Once I finished, I informed the participants that I wanted to record the session, and with their agreement, I started the recording and began with a formal introduction. The formal introduction was each participant stating their name and how long they had lived in Portland. Along with a research assistant, I recorded field notes about the participants' interactions, including cultural nuances and notes on the affect symbolic imagery. The discussion explored Black/African Americans' experience living in Portland and memory loss or caring for someone living with cognitive impairments. Appendix C presents the focus group discussion guide.

One focal point was on the group perspective, a perspective that aligned with Africana methodology and phenomenology and the connection to Black/African American Identity that was previously mentioned. The discussion explored the cultural aspect of the lived experiences, including the impact of structural racism, which occurred naturally from the participants as they talked about their lived experience in Portland. A second aspect provided some clarity around group interdependence and how participants define memory loss within the collective group identity and collective meaning making. The entire group supported the communal aspect of the community, a nonverbal sense of belonging and the diversity that resided within this cultural group.

Group sessions lasted approximately 120 minutes and were held in confidential settings, exclusively with group participants and the research assistant. The venues included research participants' homes and a community meeting space.

### Data Analysis

A professional organization transcribed the focus groups verbatim, and all data (audio/transcription) were stored in a locked cabinet. This included all audio recordings and field notes used for this study. During the focus groups, a research assistant, a Black/African American woman, and I, an African American male, gathered field notes. We recorded the affect symbolic imagery (nonverbal action, emotions, etc.) in the interaction between participants, cultural nuances, and nonverbal expressions related to the research questions. We discussed our recording and came up with an agreed-upon interpretation. I loaded the coded transcripts of the three focus groups on the qualitative analysis software ATLAS.ti and analyzed the data for themes for interpretation.

Many methods of interpretative phenomenological analysis are grounded in the Western Eurocentric worldview, which is often problematic when cultural nuances are not included and data are analyzed through a dichotomous logic. A problem occurs when the human aspects of Black/African Americans are minimized or ignored, such as when J. Marion Sims, a physician in the 1800s, conducted surgical experiments on unanesthetized enslaved African women. Ignoring the human aspect occurred when he ignored the woman's screams due to his cutting the vagina without anesthesia. However, even though Dr. Sims inflicted unnecessary pain, he was credited for the vaginal speculum (DeGruy, 2005). Second, a problem occurs when research does not address or explain how the process will not exploit research participants.

Africana phenomenological analysis was valuable because it centers Black experience and enhances Black people's humanity (Carroll, 2008; Dixon, 1971, 1977). I used Africana phenomenological analysis rooted in the Africana worldview for this study to address the problems mentioned.

For the analysis, I included three additional members from the Black/African American community in the coding team to ensure the incorporation of cultural nuances, multiple understandings, and humanity of the Black/African American. The coding team consisted of three Black/African American women who volunteered their time and me. Of the three, one woman was a research participant, and one was a researcher from

Oregon Health Science University (OHSU). The third person was a friend who wanted to assist because she was interested in the topic and provided support throughout my time in the doctoral program. Due to the diversity within the Black/African American community, the coding team drew out the multiple meanings. For example, we had a code labeled racism, and the data revealed several meanings of racism. To include all the definitions of racism, we expanded this code.

For some coders, the expanded codes represented different independent codes or sub-codes. One expansion of racism was racial experience, which included subcodes, such as being reduced by a comparison, threat, self-defense, and desire for revenge. The expansion of racism included structural racism to include systems that supported racism. Some of the expansion of structural racism included forced labeling, creating confidence and not competence, ostracization, SES, historical influence, White privilege, and ghosting. The multiple meanings were supported by diunital logic, which is a tenet of the Africana worldview. This worldview does not give room for objectivity and maintains a focus on interdependency. Because of this viewpoint, the analysis process grounded requires a cooperative procedure grounded in the collective experience (Carroll, 2008; Dixon, 1977; Graham, 1999; Henry, 2005).

Using Africana critical theory, I began the analysis by immersing myself in the data by listening to the recorded focus groups and reading the written transcripts. This immersion in the data included connecting the historical impact of enslavement, Jim Crow laws, and how this experience potentially influences research responses. The immersion process consists of a continued discussion(s) with members of the

Black/African American community who are not part of the study and a few research participants. This type of analysis provides clarity and relevant historical facts that give context to the participants' responses. I considered the context of data collection by comparing the field notes (noted affect symbolic imagery that includes tone of voice and rhythm, etc.) with the transcripts and the current social factors that can influence responses. I was also aware of the resilience (including my own) born from experiencing oppression and refrained from utilizing a deficit approach leading to dehumanization, which is part of the Western worldview (Carroll, 2010; Dixon, 1977; Graham, 1999; Henry, 2005).

The goal was to ensure centering participants while paying attention to the cultural subtlety (tone of voice, cultural terminology, poetics). I kept in mind the historical impacts and cultural self-reflection that brings forth humanity denied of Black/African American people (Henry, 2005; Smith et al., 2009). I added some of the notes, tones, and historical influence in parentheses as the researcher's notes, which increased the depth of understanding of the participants' responses. For example, on the transcripts, I wrote, in parenthesis, the historical influence that the participant was referencing and did not mention it in their quote. I scribed the remainder in my reflective memo. This process brings life to the transcripts and context of the data. The method of centering lived experiences of Black/African Americans provides a cultural context and different ways the Africana worldview aids in interpreting how Black/African Americans make sense of memory loss. It also helps answer the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans. This process opens the door for a cultural framework/analysis that is divorced from a colonization interpretation of the data. Without this process, the researcher loses the true meaning of the participant's answers and increases the researcher's biases in analyzing the participant's responses.

Each member of the coding team received a copy of the first focus group transcript with my notes. The team members individually examined the transcripts' semantic content, language, and poetics. Each member explored the transcripts for patterns to emerge from the participants' responses and coded the transcript.

The coding team incorporated the cultural nuances that arose, including communal, affect symbolic imagery (field notes on the transcripts), felt time, and teleology within the participants' responses as they individually coded the transcripts. We maintained an open mind while noting anything of interest, semantic content, and language use as we coded the transcripts keeping in mind potential themes (Smith et al., 2009). The coding team came together via Zoom and brought their first focus group's coded transcript and shared their work. We reviewed the transcript by section and applied everyone's codes to a primary transcript. We chose the codes to represent the research participants' responses and only eliminated codes when we agreed that another one better defined the research participant's quote. For example, we agreed to eliminate childhood and used maintaining belonging and forced awareness of race. These codes accurately represented the participants' meaning when they referenced childhood experiences.

The field notes and reflective memos presented the phases of the collective experience with the notable difference in the team's depth in exploring the cultural history of racism in Portland, Oregon, which was mentioned by participants and assumed to be common knowledge. The exploration's expansiveness brought clarity to the responses, provided context and validation to the coding teams' lived experience, and aligned with the research participants' responses. It also brought forth the complexity of racism intertwined with education, healthcare systems, and impacts on identity. The connection between the coding team and the participants' responses is an integral part of the Africana worldview and Africana Phenomenology: the researcher's relationship with the phenomena maintains the harmonious oneness between the observer and the observed (Carroll, 2010). The lived experience is a part of felt time where the connection between the coding team, participants, and the phenomenal world adds clarity to the results.

In alignment with Africana paradigm, the coders' experience is critical. The coding team's experience provides depth to the research by incorporating their lived experience when coding and analyzing the findings. An example of the strength of this shared experience was in the coding team's identification and discussion of racism that appeared throughout the data before I asked any specific research question about racism. The coding team's discussion provided the historical and cultural context, increased clarity of the responses, and gave validity to the findings and the coding process itself. This process allowed the team to move away from society's racialized identity of Black/African Americans and see and experience the cultural connection to some of the research participants' responses.

Moving away from the racialized self allowed embodied resilience and affirmed the humanity that is denied to Black/African American people when using Eurocentric research methodology. The Africana worldview tenet of felt time was evident during the collaboration as the coding team revealed their lived experience dealing with structural racism intertwined with the current sociopolitical climate, such as in the unchecked rise of White Supremacy in current politics and White vigilantes killing unarmed Black men who were jogging in their neighborhood. The coding team members' lived experiences gave a deeper understanding of and context to the participants' responses. Group discussions strengthened the coding process, increased the depth of knowledge, focused on resilience, and solidified the humanity of Black/African Americans. We developed the first key code from a wholeness grounded in positive Black identity and team collaboration.

After reviewing the first focus group, which took four Zoom meetings lasting 2 hours per session, we combined the individually designed codes through a collective process that resulted in completing the first key code. Yet, being true to the Africana worldview, the coding team struggled with collapsing codes and clustering them to create super-ordinate themes (Smith et al., 2009). For example, I did not want to minimize or normalize participants' experiences of racism in accessing medical care. The struggle to develop super-ordinate themes originated from the concern of losing the essence of the meanings of the research participants' answers, decontextualizing their narratives, and trivializing their lived experiences. The coding team did not want to minimize participants' lived experiences and support Black/African Americans' dehumanization. We collectively felt that all codes provided a truer understanding of the research responses. I added definitions to the code sheet to ground the process in the participants' and coding teams' words and ideas. Through the analysis, we realized that the collection of the lived experience of Black/African Americans is grounded in a diverse culture and reactions to structures of racism, and the whole experience is the foundation for answering the research questions. It is impossible to grasp the scope of experiences and complexity of the impact of structural racism through traditional themes or categories. Therefore, it was important to add the cultural context to the quotes used.

The team used the agreed-upon key code and re-coded the first transcript. The team members participated in another Zoom meeting where each shared how they used the key code to recode the first focus group transcript. They discussed changes for the first key code that arose from re-coding the first focus group transcript. One change was expanding medical experience to include positive and negative experiences. In addition, the negative experiences expanded to racism and ageism to accurately reflect the responses. Unanimous agreement occurred on the changes to the key codes, and one team member coded the changes on the primary transcript for the first focus group by applying the updated codes. Each team member received an email copy of the corrected coded transcript and the final key code. Next, the coding team took the finalized key code and coded the second transcript.

The research team met and discussed the coding process. The discussion included how reading experiences of racism, memory loss, and loss of connections had an emotional impact on the relationship with their lived experience of racism and caring for loved ones dealing with memory loss. The discussion provided context to the transcripts providing multiple ways of understanding the research participants' meaning. The team discussed any changes they felt needed for the key code. For instance, we discussed expanding the theme of using your voice to include the subcodes of results/impact and advocacy to represent the results. The discussion included cultural nuances, insights, and historical content, which enhanced knowledge to reveal the research responses' meaning. The team also discussed the differences between the first and second focus groups, which are explored further in this study's results section. The team provided a depth of knowledge of the phenomena and cultural nuances from different perspectives. The discussions revealed multiple meanings due to the diversity within the coding team, which aligns with the Africana worldview's diunital logic.

We realized the interconnectedness of the multiple Black identities (Black, African American, Black and gay, Black and female, etc.) and how racism influences memory loss: this intersectionality cannot be separated from health issues impacting Black/African Americans. The coding team's discussion is reflected throughout the transcripts and summarizes the totality of the lived experience of structural racism. Coder 3 stated, "I felt like—and this is throughout the coding—that there is just this permeating well-being under attack. All other things are adjusting to the fact that your general well-being is being threatened under attack." Coder 2 noted,

> I think even with these Black Lives Matter stuff, people want to process with me. I do not want to process, and I wonder if it's like what we talked about because it's so painful. I am too busy trying to survive.

Coder 3 added, “All the protests that are happening, I feel this is just another day in this long, long history [racism/dehumanization/enslavement]. And when I feel I am looking into the future, it’s down there, too.” Lastly, Coder 2 mentioned,

> When White folks get done protesting, they are going to be White, and we’re still going to be Black. I can’t take a break. I can’t sit down and say, “Ooh, I’m tired. I gotta relax today.” And that is what I [am] hearing White people saying: “I’m so tired.” I mean, in the city of Portland, you can take 40 hours of bereavement, and someone who works there says White folks are taking the leave. Paid leave.
>
> That’s what I am saying. We don’t get a break. You can take the bereavement, but you still go back to work Black. I want to be part of structural change systemic change. (Coder 2)

Again, the process had a positive influence on the coding team members’ lives, enhancing resilience and a deeper understanding of how to effectively navigate systems of oppression from reading the transcript and coding discussions. The discussion led to combining a few codes to clarify the meaning of the research participants’ responses. The intensity of knowledge occurred when coding the second focus group and increased understanding of the first focus group. The same member who created the official, coded transcript applied the revised codes to the first and second focus groups.

During this coding session, one member talked about how reading the transcript, learning of people’s struggle around racism, and how the advocacy was apparent in the second focus group changed how she conducts business. She reflected on how participants’ resilience empowered her to use her voice, changing her negotiating style with companies in Multnomah County. This culturally specific coding process reinforces the tenet of Africana worldview and phenomenology wherein Black /African American people regain their humanity and provide space for healing from racism (Carroll, 2010; Dixon, 1997). This individualized process of coding reflects that there is no separation between the researcher and the research participant. The researcher is part of the research, including the coding team

Then, using the finalized version of the key codes, everyone individually coded the third transcript. The team reconvened and shared their coding process section by section. As we did in the previous meetings, we discussed the code for each segment. There were times when one code had a better fit, and with consensus, we agreed on the codes to use. We used a consensus process for coding, and again, the same person recorded all the codes on the primary transcript for the third focus group.

During the final meeting for coding, everyone reflected on the impact of reading all three focus groups, the discussions about coding, and how this process impacted their lives. The team explored how the Africana worldview and phenomenology encouraged applying the cultural framework to reveal the research responses' meaning. There was a universal awareness that the research structure could not understand the participants' double meaning without the Africana worldview and phenomenology. Incorporating the coding teams' experiences of structural racism, the historical context of racial oppression, and the history of White Oregonians' goal to make Oregon a White utopia provided the cultural context that clarified the deeper meaning of participants' multiple answers**.** Different meanings were allowed due to the Africana worldview and provided a deeper understanding of the transcripts. People sharing their historical information about Black/African Americans living in Portland and the United States provided context and knowledge to the research participants' responses.

As the team talked about their coding experience, they reflected on their lived experiences of memory loss and how racism impacted their lives and cognitive changes. The discussion mirrored some of the responses of the research participants indicated in the transcripts. The mirror process supports the African worldview tenet of interdependence. The conversation also reflected the Africana phenomenology of living in DuBois' two worlds, creating dual awareness and the importance of cultural identity. DuBois's double consciousness moving towards the second sight, which is the ability to see oneself through an Africana view and distance oneself from the racialization view, creates healing (Henry, 2005). The process of the second sight was evident in both the focus groups and the discussion during the coding process as people talked about their healing from participating in this study.

The second sight is also reflected in member checking that occurred throughout the research and not in a traditional way. Member checking started with discussing my areas of interest for research and how it would support or positively impact the Black/African American community in Portland and the healing of all people from the African diaspora. I shared my knowledge of the historical impact of research in the Black/African American community and the steps I am taking not to continue an unethical legacy. This process ensured that I was not researching for the sake of a degree or advancing my career. I showed the steps I was doing before, during, and after that; this research supports the community, maintains belonging and community healing, and strengthens Black/African American cultural identity.

Member checking was also applied within the analysis process as we developed the codes. I shared the codes with community members who gave input and historical references to create a context for the codes aligned with Africana phenomenology. Doing so highlighted the power of collective energy in the Black/African American community.

Resilience against structural racism reinforces this collective energy, which maintains the humanity of Black/African Americans. I included the interrogation of racialization, a self-reflective process to explore internalized racism, the social construction of race, and exploring the reflection with a community member. For example, when reading the data, I explored my interpretation and checked to see if there was an influence from the academy or if White supremacy and stereotypes influenced my decisions. I examined what influenced my decision, explored if there was another interpretation, and checked for rigidity in my interpretation. I also explored how racism influenced my interpretation. Racialization is the byproduct of colonialization and capitalism that influences data interpretation (Henry, 2005).

The interrogation techniques used increase cultural accuracy that centers the Black/African American experience while enhancing credibility within the Black/African American community. This type of inquiry maintains the data analysis process and the research participants' humanity. It also draws the researcher into the research and affirms the tenet of no objectivity. It provides a way to increase awareness of anti-Black socialization found in Eurocentric research methods. It prevents dehumanization or devaluing of the Africana worldview and Africana phenomenology.

After the team coded all three focus groups, I loaded the coded transcripts on ATLAS.ti and continued drawing a connection between the three coded transcripts. Through ATLAS.ti, I grouped the quotes for each code and continued the search for emerging themes. First, I listed the codes in chronological order. I then clustered similar codes, aligning with the super-ordinate codes that originated with the coding team; this resulted in a few common themes (Smith et al., 2009). I managed my biases and increased clarity in this research by sharing my reflective memos with the research assistants and formal and informal Black/African American community leaders.

As separation does not exist in the Africana worldview, the researcher is part of the study. I used culturally responsive member checking and triangulation to ensure trustworthiness. I used peer debriefing and support for overlapping and triangulation; the triangulation method incorporated the literature review, observation of focus groups, participants' input for data interpretations, and reviewing my analysis with the female research assistant, research participants, and members within the Black/African American community.

I followed Africana worldview teleology by discussing with research participants and community leaders how this research supports the Black/African American community and how I would protect against the exploitation and dehumanization of community members. Sharing this information also increases trustworthiness from a cultural perspective. I shared ideas with community members as part of member checking following the emergence of super-ordinate themes discussed in the following section. The experience led the coding team to use their voice and strengthen their identity and inspired one coder to continue their pursuit of higher education. It also helped to recognize racism in their place of employment. Another powerful experience was that the coding team created and added cultural context to the regaining of one's humanity, which is also reflected in the themes that emerged from the data analysis.

# Chapter V: Understanding the Lived Experiences

In most research based on the Eurocentric western worldview, this section would be called results or findings. The researcher would provide the necessary information, including the research participants' statements, often without cultural context. Leaving out the cultural context leaves room for the depreciation of the participants' experience. It also has the potential to enhance dehumanization. This section would traditionally also focus on the statistical data and a description of the participants, such as the number of groups, the group categories, and group demographics. To assist people grounded in the Western worldview in understanding this study, I included simple demographics, such as age and focus group number. Most research that utilizes Western paradigms emphasizes an exploration of results that leads to one definitive meaning or conclusion; this emphasis is grounded in the dichotomous logic of a White/Eurocentric framework. In a quantitative, post-positivist, and positivist epistemology, the findings would then be applied as a generalization for most of the population in the study. The results potentially lead to developing evidence-based interventions as if a homogenous group existed, excluding diversity within all cultural groups, and generalizing people. Researchers working from this framework are not encouraged to employ multiple meanings or understanding. Qualitative research is informed by a community of globally dispersed people attempting to implement a critical interpretive approach in response to the positivist and neoconservative discourse (Denzin & Lincoln, 2005), but these methodologies are often still influenced by Western thought and Eurocentric paradigms.

I followed the Africana paradigm in my approach to this section, which means that I included cultural nuances and abbreviated narration (historical context to quotes, definitions) for clarity to the participants' quotes that are typically left for the researcher to interpret in the discussion section. In alignment with the Africana worldview, I provided multiple possible interpretations of the data rather than drawing a single conclusion. The research results are also grounded in Africana phenomenology in that the stories (verbal/nonverbal/symbolic imagery) and the research team's lived experiences are significant parts of understanding the data. The findings expressed in this section are not universal truths to be applied to all Black/African Americans. The concepts that follow are important to consider when working with Black/African Americans.

### Integrity of Lived Experience

As I reflected on the responses of the 13 45- to 90-year-old participants, it was essential to use a collective process to sustain integrity. Through the collective process of analyzing and synthesizing participants' narratives, I arrived at two central findings. One finding was apparent, and the other was implicit. The apparent finding was maintaining belonging to the Black/African American community*,* which is a sustained connection to the cultural community, resulting in strengthening one's humanity. This larger theme of maintaining belonging had four dimensions: maintaining belonging and connection to the community, disruptions to maintaining belonging, strategies to maintaining belonging, and maintaining belonging in the midst of cognitive changes. The dimensions included the smaller dimensions of family formation, mentorship, social movement, speaking up, dignity and belonging, hiding/minimizing cognitive losses and humor, fear, and strategies to address cognitive losses. Hierarchy among the themes does not exist; they are intertwined and overlap.

The implicit and powerful second main finding was racial experiences and the influence of structural racism. Racial experiences have been explored and reported extensively in the literature, yet they are still key, and this research provided another window into increased awareness of the multiple impacts of racism. Because of the implicit finding of racial experiences, I have woven racial experiences throughout the results when appropriate. These added clarity to the participants' answers, holding the integrity of their lived experiences in place. I have included cultural context throughout the following sections, which prevented minimizing people's experiences and reinforced the humanity of Black/African Americans. The narration gives the reader a window into these focus groups.

## Maintaining Belonging and Connection to Community

The data revealed the multiple ways Black/African Americans experience racism individually and collectively. The data also showed how maintaining belonging is a survival technique when living in White spaces and dealing with structural racism. It is applying double consciousness to retain one's humanity. We define maintaining belonging as being part of a whole and not being reduced to an object like descendants of slaves. It is the process of seeing your value reflected back to you by people because they look like you. It is the process where people see themselves as Black/African American, as descendants of African people, and where being Black is normalized. It is the process of remembering one's humanity (Henry, 2005).

Maintaining belonging is, in part, a direct reaction or response to the impact of slavery, which was maintained through violence (Berlin, 1998). When Africans were stolen from their land and forced into slavery, they were seen as free labor and propagated like livestock. Families were broken apart, sold, commodified, and denied their humanity (Berlin, 1998). Maintaining belonging is important because it recognizes the importance of family connections. It heals the dehumanization from slavery that continues today, which is a reason for the Black Lives Matter movement. In addition, maintaining belonging aligns with the communal aspect of the Africana worldview. Using the Africana methodology revealed that the lack of numbers of Black/African Americans in Oregon caused different impacts of racism and that belonging to the cultural community is especially significant. Maintaining belonging normalizes being Black/African American and enhances resilience. Structural racism reinforces the need to maintain belonging to remember one's humanity, for it is an act of survival. Through the connection to the community, identity and self-worth are regained, unity is centered, and a source of power as expressed, as in the following quotes:

> The first time I went to a brother-to-brother meeting [Black/African American gay and bisexual men], and I walked in there, I'm dealing with my own sexuality. I walked in and saw these Black gay men, and I knew just listening to you guys, I'm going to be okay. (Speaker 7)

> We come together [a gathering of Black/African American queer meeting people], we have a great time, but then we go off, and we do all kinds of really,

> really important work. And it just seemed like there needs to be always a time where then we'd come back, and you get that energy [The power to address racist situations and homophobia]. (Speaker 9)

In these examples, maintaining belonging sustained cultural identity and was a form of protection and safety from the violence people experienced because they were Black/African American. Participants talked about their individual experiences, which led to the awareness of the collective experience of racial trauma. The following quotes expressed the safety and protection felt through maintaining belonging:

> And so, you decided then that you could protect each other. When we'd go places, we'd go together, and that was one thing that my mother would always say, "Stick together." I think that the Black race during that time stuck together more than any other race because we were around Italians; we were around Jewish people. But we stuck together because we had no way out [not able to avoid racial attacks]. (Speaker 1)

> Church [Black/African American] because even if they couldn't define it [maintaining connection to the Black/African American community], they understood that they need that whether they were sitting up there listening to the word or not, they were in the presence of other African-Americans and getting that some type of unity before they had the Monday through Friday [daily racist events and dehumanization] … I'm grateful for that. (Speaker 2)

Even though there was a collective experience of racism living in Portland, a difference occurred across the United States. The discussion between people born in and those who moved to Portland showed the difference in racism. The difference stemmed from the small number of Black/African Americans living in Portland. This population lacks the numbers to challenge racist events causing fear in people who experienced racism. One participant expressed it well: "The brand of racism here was almost like the opposite of Chicago 'cause Black people were not a threat in Portland in Oregon." Due to this lack of threat, racism and White supremacy went unchecked in Portland. This participant, as well as two other focus groups, expressed that unchecked racism causes extreme actions from White people, such as touching Black/African American women's hair, verbal or physical harassment, and police racial violence. It also sustains anti-Black ideology. These situations impact Black/African American quality of life and the provision of care for people living with cognitive decline.

Because of the influence of the Jim Crow Laws and the goal to make Oregon a White utopia, Black/African Americans historically had a different experience living in Oregon (McLagan, 1980). The schools were integrated, yet Black/African Americans were denied opportunities to advance in school and build confidence, reflecting racial issues across the United States. In addition, the small numbers caused experiences of being the only Black/African American person at school or work, in town, or in other situations, which increased racist experiences and left no way out. To address this impact of racism, maintaining belonging was significant for Black/African Americans. The connection to the Black church and other culturally specific social clubs provided educational opportunities that were absent in the school system. It strengthens one's cultural identity and ability to address the racialized struggle of living within White spaces, as expressed in the following quotes:

> I know that was one thing that my family is really conscious of because we lived in a White neighborhood and school. Our school was the Black church [they attended public school, but the church allowed the chance to do school activities denied because of race]. (Speaker 3)
>
> You learn how to do your speaking at church [Black/African American church], and things that you were not able to participate in or maybe not always at school, you got the opportunity to do so in church. So, without that, and I think that's why our parents pushed us to attend. (Speaker 2)

Through affect symbolic imagery (tone of voices, nonverbal, body position), participants supported each other in talking about their lived experiences of racial situations and reinforced their connection to the group and the Black/African American community. One participant stated why they removed the label "Black" in the focus group discussion when talking about the role of the Black/African American church and maintaining belonging. They did this to resist the racialization of labeling Black/African American issues by race when the dominant culture is not classified by race. It was a way to fight against White supremacy and of being asset-based:

> I think that's like the Black church. Well, I'm just going to say the church because we are Black. Of course, we went to church, and then everybody looked like us because White people don't go around saying in the White church, but we always

> had the label [making people objects of less than]. So, the church was our basis for our support, and the beauty shop, and the barbershop. (Speaker 2)

Overall, the data reflected the diversity within the Black/African American community and the power of maintaining belonging. Our diverse group(s) includes ethnic (Black Puerto Rican, Black Columbian, Haitian etc.), sexual orientation, class, and locational differences. Each classification provides a different aspect of maintaining belonging. A significant point that the participants expressed is the difficulty in constructing a healthy cultural identity in a society that supports anti-Black ideology. They also reported the importance of maintaining belonging to community even with small numbers of Black/African American Oregonians. A healthy Black/African American identity is accomplished through maintaining belonging, and cultural identity is the foundation for resilience. The data also revealed the multiple ways Black/African Americans experience racism and how maintaining belonging builds resilience, which is a crucial component of navigating structural racism. Maintaining belonging is a process of being grounded in one’s cultural identity despite what one experiences to maintain safety. Safety, as expressed in the focus groups, has a variety of components but is specifically focused on decreasing the psychological impact of racism. Maintaining belonging enhances safety and is crucial to remembering one’s humanity and warding off the negative effects of racism.

The focus group discussions were a form of maintaining belonging and testing one’s commitment to the Black/African American community. For Black/African Americans, knowing people’s connection to their cultural identity and the community is essential. This knowledge provides safety and allows for honest conversations. The depth of connection provided a way to assess trust and solidify connection. One way to establish connection is to find out what school people attended. For example, Speaker 6 talked about a racial experience, and Speaker 3 asked, "What high school did you attend?" There was a slight inquisitive atmosphere created by Speaker 3. Speaker 6 answered and continued with their story. Speaker 3 had a few follow-up questions, and when they found a connection with her cousins who attended the same high school, the atmosphere changed. The connection and Speaker 6's responses passed the inquisition. The evaluation of Speaker 6 was to assess their commitment to the Black/African American community and determine whether they turned their back on the community, aligned with racist ideology, and whether it was safe for group members to discuss their lived experiences of racism. A key point of the evaluation was if someone minimized or denied experiences of racism. If people failed to talk about or acknowledge their experiences of racism, they became suspected of aligning with racists' ideology or turning their back on the community.

In addition to asking where people went to school, the assessment also explored people's families and whether they had a history of supporting the Black/African American community. If the family had a positive history, this increased trust in the focus group. If the family did not have a positive history, group members would push to see participants' positions on racial situations and what they did to support the Black/African American community. These discussions were ways that members expressed how they supported the Black/African American community, their commitment to the members in the focus group and how they maintained belonging.

Participants talked about negative and positive aspects of their racial experiences and how these experiences informed how they saw themselves and how they chose to interact in the world. Those racial experiences influenced meaning making as they dealt with life challenges and memory changes. If they had a supportive environment that reaffirmed their cultural identity, they would have a healthy sense of self-identity. Through this healthy identity, people were able to recognize racist situations and develop advocacy skills. This strength of endurance also influenced how they dealt with memory loss. People experiencing memory loss who sustained their connection to the Black/African American community were more likely to see the cognitive challenges as a normal part of the aging process, not a personality defect. They were more likely to advocate for needed medication and respect when it was not offered while accessing medical support. Once members' trust was confirmed, the focus group discussion revolved around racial experiences as also a form of bonding. They spoke about the variety of racial experiences throughout their time together, even after the session ended.

The data provided multiple strategies for maintaining belonging, including attending church, social organization, and living in certain geographical regions. Living in areas where most of the community members were Black/African American creates a sense of belonging and safety because one sees people who look like one. Participants reflected that seeing people like them created a sense of belonging that provided a sense of safety and a welcoming feeling. In Portland, one such neighborhood, Albina, once served as a place of belonging and feeling for many Black/African Americans. It held the majority of Black civil and religious institutions, homeowners, and businesses. The following quotes express the concept of safety and the importance of feeling at home:

> I'm a native Oregonian. Growing up here when this neighborhood that we're currently in was mostly Black, African American. I felt comfortable in my neighborhood that I grew up in. (Speaker 7)

> The community [Black/African American] that we lived in was just wonderful. It was near the Broadway Bridge in Portland. And it was a small community since we knew everybody. I could walk to Holiday School. It was a very warm, vibrant community. When they said a village, that's what I'd call it; it's like a village. (Speaker 2)

The connection to the Black/African American community included social justice movements of the past and the present as another form of bonding. The social justice discussions included the church's essential role in maintaining belonging. The church was a place of safety and learning about the community when one was new to the area. During segregation, the church and other social programs informed Black/African Americans about where the safe places existed and essential things for survival. The church was more than just a place of worship. It was a place of belonging. The discussion also included social organizations that increased connection to the cultural identity and the community:

> Of course, there were the debutantes [Black/African American social club], and they had a coming out that echoed the White establishment coming out and all of that. So, I think we had our own little society within the larger society, and we were protected that way. (Speaker 12)

Due to the small Black/African American population in Oregon caused by restrictive laws targeting the community, there was a time before the social groups formed when primary social connections were family outings. Since the turn of the 20th century, Oregon Black/African Americans have formed their own organizations and social clubs. Churches were often used as hubs for pageants and performances when Jim Crow Laws blocked access to city and state institutions. This was reflected after Speaker 12 finished their statement, and another participant responded and provided a different view of connection to the community. This participant highlighted that family connections and the drive for integration maintained belonging.

> Now, it’s interesting because when I came along, which is a lot earlier than you, those kinds of societies are very, very few and far between. And, so, we were almost forced to integrate in our own area. Things we did were limited because they weren’t that well organized at that time (impact of Jim Crow Laws). Just 10, 20 years makes a difference. So, I’ve seen a lot of growth in Portland as far as integration is concerned. And being able to participate in all those activities. (Speaker 11)

Integration was a key factor, even though it was limited due to the Jim Crow laws and the residue that continued when the laws were revoked. She continued reflection upon the past, providing a view of maintaining belonging through connection to family and the family goal to obtain a college degree:

> We sort of did our own thing as a family. We did our own. … Berry picking was a big social thing there, picking strawberries as a family. Because we were so few, we were just very close. But the goal my mother and my father had, which they were able to read, was to send all four of us girls to college. Nobody thought we'd be able to do it because when you were a Black family in Portland during those years, there wasn't much money around. But they taught us how to work, and so all four of us girls went to college. There were even bets out that those [family name] girls were not going to graduate from college because it was too expensive. (Speaker 11)

The data shows education was a significant goal for the participants in this study. The importance of education in the Black/African American community dates to the creation of colleges by the Freedman's Bureau, a governmental program developed after the Civil War (Downey, 2009). During this reconstruction period, several colleges were developed for Black/African Americans. Most of the participants believed in the importance of education and had a college degree or at least a few years of higher education. Even though education did not guarantee substantial financial advances or increased mobility, it was another strategy for maintaining belonging (Bhattacharya & Mazumder, 2011; Fox, 2016; Mazumder, 2018). Education provided some opportunities for increased income and upward mobility, yet racism played a role in how far and how much advancement would be achieved.

Other factors also impaired financial advances and mobility, which had a direct relationship to oppressive structures that impact Black/African Americans. Structures like redlining prevented the passing of generational wealth. The Greenwood district in Tulsa, Oklahoma, was a thriving Black Town, also known as Black Wallstreet, and Black/African Americans began developing generational wealth. On May 31 and June 1, 1921, White vigilantes burned and bombed the town, killing several Black/African Americans. Vigilante groups such as these supported anti-Black ideology and sought to maintain control through violence; lynchings, burnings, and mass killings were commonplace before and during the Jim Crow era. Memories of this violence were also mentioned in the focus groups, along with the impact of a hurt spirit:

> They want to have this authoritarian control that doesn’t allow for the kind of expansion [economic/wealth]. If that didn’t work, they burned down the store. [Ku Klux Klan/White supremacy activity of burning things that belong to Black people]. Then, we can go over here. We’re not going to be just down. There’s such an intention to hurt the spirit. That’s what I would say, to hurt the spirit. (Speaker 5)

The violence continues today through the killing of unarmed Black/African Americans and racial stereotyping. This structural impact (racism) also disrupts maintaining belonging. The disruption had an impact on Black/African Americans, which was revealed within the focus groups. The significant point is how this type of disruption affected cultural identity and cognitive decline. The lack of cultural identity impedes the ability to manage the influence of entrenched structural racism. The following section explores the factors that impacted maintaining belonging, causing a disruption.

## Disruptions to Maintaining Belonging

There were times when maintaining belonging was disrupted, and participants failed to see their value reflected back to them; they were labeled as different and felt defined by negative characteristics (othered). Racism was the main cause of disruptions to maintaining belonging. The research participants' responses reflected the impact of structural racism, both conscious and unconscious, as they answered the question, "How has living as an African American or Black influenced your experience of memory loss or caring for a loved one experiencing memory loss?" There were a variety of racial experiences reported, including the impact of social structures (legal, education, financial) and individual racist acts. Those experiences of racism took an emotional toll, and the stress impacted some cognitive functioning due to being forced to constantly need to defend oneself for the right to access to healthcare. This could lead to a reactive response (fear, hyperarousal, racing pulse) and disrupt maintaining belonging.

Racial experiences impact our sense of self, cognitive changes, and how people make sense of their world. Racial experiences also included events where participants had to prove they were Black enough. Even participants who did not use the word "racism" or denied it existed talked about events where disruptions to maintaining belonging due to their race transpired.

> We had to prove to the inner-city kids that we were just as Black as them. (Speaker 2)

> We walked a tightrope. You don't belong in either group, and you step out of line, and they [Black students] be very quick point it out to you. You don't ride the bus with us, so you're not one of us [Black/African American] (Speaker 3)

Common responses from participants reflected a physical and emotional toll when dealing with racism, especially when accessing medical care, which disrupted their ability to maintain belonging. Members of the focus groups discussed negative racial experiences that influenced their decision when accessing medical systems for themselves or people dealing with cognitive experiences. One participant talked about their process to prepare to talk with medical providers. Realizing the amount of stress one goes through to access medical care is significant. The reality of stress was expressed in the following statement:

> So, I feel like I have to be on my guard, like hypervigilant, to make sure that they (medical providers) are listening to me. I even feel like the way that I choose to talk, I feel like the way that I chose to talk I'm careful to speak, enunciate, speak in a way they think I'm educated. (Speaker 6)

Speaker 6 had to move away from their cultural identity that effectively uses English and was forced to explore how their communication would be compared to stereotypical beliefs about Black/African Americans.

Participants also talked about the emotional toll they experience when their physical and mental health is attacked when accessing medical care, which is another form of disruption. Similarly, a participant spoke of their frustration with regular health providers after a job loss. If one does not have job-related healthcare and is not on the Oregon Health Plan, then health professionals can drop one "like a hot potato." Some interactions with the healthcare system were destructive, as expressed in the following quote:

> In the minute I got laid off, and I've been going to these doctors for decades, they dropped me like a hot potato. Even though I got the state insurance that Obama allowed us to get, they were not accepting that. That to me, it was like, you know who I am. You know all the ins and outs about me, my medical. Now, all of a sudden, I'm running through this dry period, and you won't see me? You just cut me off like that? It angered me because I know if that had been someone of their own kind, they would have said, "Oh, yeah. The state takes longer to pay, but yes, of course, come in. I'll write that prescription." [She paused; her face revealed the distress she was experiencing as she talked about this situation. There was a nonverbal, head nodding, and supportive looks on participants' faces as they listened to this story]. So, I was, like, for a whole year trying to scramble and find somebody that would help me, or see me, or whatever. They kept writing the prescriptions [and would not see her] because I had to take several medications because I have lupus. [Through this section, the group provided verbal support and agreement with the experience they heard]. (Speaker 2)

Focus group participants talked about how Speaker 2's experience was directly related to being Black/African American. They talked about how she was othered and denied medical attention, causing a disruption in maintaining belonging. The discussion included how racial stereotypes influence doctors' treatment and disrupt maintaining belonging. The participants talked about how racism influences medical providers' evaluation of their symptoms and the emotional toll as reflected in the following statements:

> This lady, she was so nasty as the ER doctor that I had to get belligerent because she had the nerve to tell me. They took urine for urine test. She go and tell me, "Well, the test came back, and it shows that you have meth in your system." [Verbal and nonverbal expression, of shock, frustration, and reflecting similar personal experiences of this event that is based on social construct of race was expressed by members in the group] …Yes, she did. I looked at her and see I was still working for [name of hospital]. I looked at her and said, "Excuse me?" She goes on, "Yeah. We did random testing. It looks like you have meth in your system." I said, "I don't know where it came from," and I never told her I worked there. I do that on purpose because I want to see how they treat me. I just looked at her. I said, "Well, honey, I don't know where it came from," I said, "Because I have never done meth. I don't do drugs." She kept asking me this over and over. "Have you done street drugs?" I'm thinking, are you nuts? She kept on … So, I said, "No. I haven't." I told my husband (who was with her). I said, "Let's go." He said, "You're all hooked up to this [medical machines]." I said, "I'm ready to

> leave."… After she left, the nurse came in, and it was a male nurse, and I was explaining this to him. He said, "That don't sound right." He said because I had told him I worked there. He said, "Wait a minute." She said … "I'm telling you what this woman told me." I said, "I don't want her. So, when you go out there, get somebody else or else I'm going. Somebody going to get cussed out." I said, "Then, it ain't going to be pretty." So, he went out there, and he talked to one of the other ER doctor guys, and he came in. I talked to him. I told him, "I'm going to report her. This is crazy. I never had nobody treating me like this." (Speaker 4)

The disruption also included navigating intersecting identities, for example, experiencing alliance on a racial level when the medical provider was a descendant from the African diaspora but did not include awareness of sexual orientation. One participant who identifies as gay had a hope of being treated well by a Black provider, but the hope was destroyed when the assumption of the participant being heterosexual was made by the provider, as reflected in the following statement:

> When I had knee surgery, my nurse was a Black new immigrant that got here, got a job at [name of hospital] as a nurse, and she got relaxed with me. Evidently, there was nothing on my paperwork that I was gay. So, she starts saying, "This town is full of gay people," and my mind is going this [derogatory statement] can't work on me because I'm gay. But I didn't say anything. I let her go on because, you know, she was in the kind of her religious gear, and she was being the nurse thing. I let her preach 'cause she thought she was disclosing to me as a straight person. … But what I did was I said, "Get your supervisor; I need to talk

> to her." [There was verbal and nonverbal support from the group]. And she said, "Okay." (Speaker 10)

The focus group participants discussed the mental stress that impacted Speaker 10 due to this and other experiences of racism. Most of the responses that addressed disruption to maintaining belonging due to negative racial experiences increased psychological stress. The impact is expressed through the process a participant goes through to see a medical provider. The anxiety produced by responding to stereotypes based on race (you're Black, so, therefore, you've had exposure to drugs) or sexual orientation bias (gay versus religious beliefs) reduces trust in the medical profession and providers. The following quote exemplifies how one speaker expressed the way that racism added stress when thinking about going to a doctor's appointment:

> When I go to the doctor, I feel like I have to make sure that this is not tied to racism. I have to make sure that I am really alert. I also feel like I don't know if the person is going to be racist, but I know it's a possibility. I find myself thinking that before I go to the doctor. (Speaker 6)

The totality of the discussion explored the negative impact Black/African Americans experience when accessing medical care. Another participant drove home the mental toll Speaker 6 experienced, which most Black/African Americans experience when maintaining belonging is disrupted as people prepare to attend a medical appointment.

> How exhausting is that. You're already sick. You just can't go in there and be yourself. You got psychological [anxiety/depression/mentally prepare when

> seeking medical care]. You got to work yourself up. Okay, how am I going to articulate dah-dah-dah. That's adding on to your stress and your sickness. (Speaker 2)

Across the narratives, participants expressed the feeling of being unheard, ignored, stereotyped, or ghosted by medical providers. Being ghosted occurs when people dismiss/ignore comments or questions from Black/African Americans. Being ghosted includes being denied basic humanity, othered, and defined based on racist stereotypes and beliefs. Participants discussed a variety of examples of being ghosted when seeking medical care. One example of being ghosted is when a Black/African American is ignored and left in the emergency waiting room instead of being taken to the medical exam rooms:

> There was another situation with my dad again. He had gone into the ER. He was very sick to his stomach and having trouble keeping anything down. So, they finally went over to the ER about 9:00 at night. I got there. So, I was probably about 30 minutes from that particular hospital. So, I got there walking. He's sitting in a chair in a waiting area, so number one. The chair he was in was one of those ones that really reclines all the way back. So, he was kind of there, in and out of sleep. I'm like, "They don't have a bed for him or anything?" They had him out there from … I finally got to his house from the pharmacy at around 2:00 a.m. They didn't give him a room until around midnight. They finally got him into a room because, by that time, my dad's 93. (Speaker 3)

Another example is when family members have to advocate for their loved ones to receive standard care and are denied medication to address stroke, as expressed below:

> When my father had a stroke about 13 years ago. He had [name of insurance], which is a good insurance. They got into the hospital quickly, like within 30 minutes. They [medical team] didn't want to give him the clot buster. … I had to fight for them to give him that drug which is the gold standard for treatment for somebody who's had a stroke. They'd give it to him, and it helps the brain repair. So, that was the first thing, so we got them [medical team] to give him that. (Speaker 3)

Being ghosted also occurs when the medical provider refuses to talk with the person who is seeking services and speaks to the caregiver because they align with their racial identity. This example is reflected in the following quote:

> The times I've found myself in situations where they're more trying to interact with him [referring to his partner who is White] 'cause there's that immediate connection cause, usually, they are White, too. So, they go straight to [partner's name]. … It seem like I'm not going to communicate or can't communicate or whatever. A number of times it's gotten to the point where I might really speak up and take over. But I think, if anything, I'd like to do is just figure out ways to make them aware of what they're doing. … It really doesn't hurt my heart. But sometimes, I do find it mildly irritating. (Speaker 9)

These experiences of ghosting negatively impact being part of a whole and not being reduced to an object and drive the socialization that being Black/African American is bad and that you do not matter. It has a profound impact on maintaining belonging and hinders Black/African Americans from accessing medical care, specifically in regard to cognitive health.

Another disruption to maintaining belonging was from the past. It was the busing of students, which is another form of ghosting, or abruptly changing school communities without including students or their families in the process. School busing in Portland occurred in the 1970s, forcing the burden of integration on Black/African Americans (Serbulo, 2019). Busing, as told by the participants, was the process where mostly Black/African American students were bused from Northeast Portland to schools in the southern parts of Portland and sometimes to North Portland schools. The students usually came from schools deemed of lower SES. The participants talked about the impact of busing and their relationship with other Black/African American students who were bused to their school. The impact left several participants feeling not seen, not Black enough, and reduced to an object. The participants talked about how the impact of busing caused a division between Black/African American children who were bussed and who were not bussed but attended the same school.

> My experience growing up in Portland in grade school. We were like the third Black family in the neighborhood. So, it was only really three Black families in our school. We went to [name of school]. We were okay until they decided to have busing. So, that meant taking the kids out of inner Northeast and elsewhere and busing them into North Portland because that’s where we grew up. … We understood the subtleties when you’re not the same, Black and White, but within

> your own race, that was so hard for us to accept or understand. I feel that since our mother was from Saint Louis, she was used to segregation, “separate but equal.” She was able to help us grow as adult and understand both sides. So, I feel that we were more well-rounded than some people out here. So, we had to prove to the inner-city kids that we were just as Black as them. So, the struggle wasn’t so much with the White kids. The struggle was with our own race. So, that was very hard because it was as if we just couldn’t get a break. We couldn’t understand what’s wrong with them. Why are they treating us like this? (Speaker 2)

> This is what we did in school. I grew up in Southwest Portland, the exact same situation. I think seventh and eighth grade was just before busing. Then when I got to high school, is when busing started. We walked a tightrope. You don’t belong in either group, and you step out of line, and they’ll be very quick to point it out to you. You don’t ride the bus with us, so you’re not one of us. [members of the group made audible sounds of agreement]. (Speaker 3)

These experiences of not being seen, forced to act in ways to prevent being hurt, challenge one’s cultural identity. A sense of loss and a stressful struggle to fit in and exist. This disruption pulls away the protective factor that occurs when sustaining one’s connection to their cultural community.

Another disruption in maintaining belonging occurs when diversity within the Black/African American community is unacknowledged and/or when the Black/African American community is seen as a monolith. The data reflect that when we acknowledge diversity within the Black/African American community, members are not expected to act the same, which allows for various ways to express their cultural identity. When diversity is denied, the impact causes a disruption in maintaining belonging, as expressed in the following quote:

> Then I moved here as an adult, and … it took me years to have any sense of being a part of a Black community and even working at [name of a community college] with other Black faculty, and I distinctly remember having an experience where … because you're in a predominantly White environment. The primary way of interacting was you try to be professional because I was hired to do a job there. Then, I felt like there were a lot of times where there were some Black faculty who I felt like, or faculty or staff, who I felt treated me like somehow, I was not acting, again, Black enough. I distinctly remember one person saying because I was talking in a group and I said, "You know … as a Black person blah-blah-blah." He looked right at me and said, "I didn't know you have a Black side." It was that kind of thing where … I felt I was trying to do this function as a Black woman in a predominantly White world and trying to interact in both ways. (Speaker 6)

In employment, the disruption included lack of diversity, lack of Black/African American leadership, the participant feeling isolated, and the participants needing to negotiate how to present themselves when there is an expectation to perform because of one's cultural identity. Participants talked about the racial experience that one participant called Straddling, which is where one is simultaneously attempting to function in multiple worlds, such as White, Black, gay, and straight communities, at the same time.

Straddling is a byproduct of structural racism, causing a disruption to maintaining belonging. It harms people from the African diaspora who are forced to live in multiple worlds simultaneously, as reflected by the previous quote of Speaker 6. Participants discussed the emotional toll this causes and reflected on the amount of brainpower needed to deal with racial bias and stereotyping and how straddling can hinder the sense of maintaining belonging. The impact of straddling was heightened when participants' racial identities included intersections of gay, lesbian, or transgender communities. Some effects are not feeling entirely accepted in either the LGBTQI2-S or Black/African American communities and constantly negotiating one's existence. Living in multiple worlds influences one's identity and the process of making sense of their worlds and causes a disruption in maintaining a connection to the Black/African American community.

Another significant finding that disrupted belonging is the actions of White people boldly defining Black/African Americans' experiences of racism. The participants talked about the boldness to discount or minimize the existence of racism and discounting racial experiences through the stereotyped "angry Black person."

> I've had white people tried to school me [on racism and discounting lived experiences] that they read in a book. (Speaker 6)
>
> So, you're always seen as an angry Black person, they're not listening (to statement about racism), first they saying it is an angry person … We have the right to be angry, and we need to discuss how we cannot make me and the rest of the world [Black people] not angry (Speaker 10)

These experiences reinforce the belief that their cultural meaning making does not matter and invalidates who they are. These experiences also reinforce Black/African Americans’ beliefs that White care providers have little interest in their well-being. Maintaining belonging is a critical component of sustaining a healthy cultural identity. Maintaining belonging is significant in enhancing one’s ability to navigate through biased behavior that aligns your identity with the worst of society. Cultural identity is an essential component in developing coping strategies to reinforce the maintain one’s humanity. Because of the significance of developing coping strategies to maintain belonging, these strategies will be explored in the following section.

## Strategies for Maintaining Belonging

This section explores the different techniques the participants employ to sustain their connections to their Black/African American community and maintain their humanity and cultural identity, including building resilience against structural racism. The techniques are expressed in four categories, family formation, mentorship, social movements and speaking up.

### *Family Formation*

The need to acquire advocacy skills to navigate racial bias and stereotyping is strengthened through maintaining belonging to community. A significant strategy for maintaining belonging was expanding the family to include biological and non-biological members. An example is when a research participant talked about the care team for his mother, who was experiencing cognitive decline. After the focus group, it was revealed that the sister was not a biological sister. They became a part of the family due to the father, who was her mentor throughout dental school. The relation grew to the point that the family considered her an extended part of the family. This extended family reflects the communal aspect of the Africana worldview. We first see extended familial connections during enslavement, when families were separated since African people were seen as commodities devoid of human existence. The extended family (kinship) was a survival skill used by those who were enslaved (Berlin, 1998) and continues as a survival skill to navigate living in racialized societies. Intergenerational kinship provides social support and is a protective factor against racism and its associated insults (Green, 2007).

Social workers and other social scientists have provided a view that most Black/African Americans have strong anti-gay attitudes and expel family members who identify as gay (Boykin, 1996; Green, 2007; Icard, 2008; Icard, 1986). The research further states that Black/African American gay males rarely find support within the gay community where their cultural identity is respected or honored (Boykin, 1996; Green, 2007; Icard, 1986). One key factor in this research is that the participants who are members of the Black/African American gay male community did not follow this trend of losing their connection to the biological family and were, in fact, leaders within the Black/African American community. Even though they maintained their connection to their biological families, they also still created an extended family. They developed the extended family to support members of the Black/African American gay male and broader community who did lose their connection to their biological family.

The results of maintaining biological family connections for Black/African American gay male members in this research seemed to have a positive impact on their identity. They had a strong cultural identity (Black/African American and gay) that provided resiliency to rise above racist and homophobic events. They were able to stay connected to the Black/African American community and develop cultural support within the queer community. Maintaining belonging was evident when they reflected on the activist work of their parents, which influenced their activities to fight for racial justice and expanded it to include gay rights.

> Second generation, so my really light-skinned mama who had to go through all those ordeals gave us our training, and then the little arts community … having fierce mentors. … My house was a house full of artists [Black/African American], and all the artists came to our house and all of that, but the mentoring was fierce. It's like being a preacher's kid. Do this, don't do that, do this. … This is how you do…" And so that training from the mentor standpoint just gave us really thick skin [the ability to deal with racism/homophobia] and, oh no, you didn't moment, to somebody who did shit wrong to you. Specifically, if it was to you…. But that's because I'm from here. (Speaker 8)

> My mother going to DC to listen to Martin Luther King deliver the speech. Parents who are actively talking and doing things in the community. And they're also telling you yes, nothing you can't do. You can be anything [participant's name]. They drilled day and night, so much until I realized there's nothing going to stop me from doing what I want to do. Nothing. No, nobody's going to stop

> me. And if you, if you get White on me, I can show you how to get White tough.
>
> (Speaker 10)

These social justice activities were strategies that strengthened belonging because their activist work supported both communities: Black/African American and the queer community. Supporting both communities caused experiences of affirmation for all members. Participants drew strength to fight against structural racism and homophobia from their connections to their families and their parents' activist work.

### ***Mentorship***

Mentorship was a strategy to maintain belonging When participants were living in multiple worlds. This strategy to maintain belonging was pivotal for this Black/African American queer community in developing a strong cultural identity because it allowed people to heal from structural racism and homophobia. The support created an internal belief that they matter, despite living in an anti-Black and anti-gay country. Having a strong Black/African American queer cultural identity enables one to live in multiple worlds (White/Black, queer/heterosexual, etc.), embrace intersecting identities, and build social networks and kinships that honor one. The participants spoke fondly of these connections and how mentorship was an extremely important survival tactic for the Black queer members of the focus groups. They discussed the power of one of their strategies, which was attending a culturally specific group and how it was healing. Connecting to the culturally specific Black/African American queer group was significant to receive mentorship, and it reinforced the many intersections of cultural identity (Black/African

American and queer). The following quote is from a participant who talked about the life-changing and empowering impact of this strategy:

> I mean the thing about those guys, even where we would have the Amani group [gay/bi/lesbian/transgender people of color], is that you could be in a room full of people, and everyone's from all these different parts of the country, and you come together, and you're astounded that there's this common culture [Black queer]. It's almost like you start speaking in languages that other people don't understand. You put on music that brings up a certain thing in people. You bring the Uncle Jack chicken wings; you sit at the table, and you play cards. The saddest part about it is it's hard to say that any one time is more in need than any other time. Every time we've done it has been much needed, but now it really does seem like now is the time we need to do more of it because we really don't know who's silently going crazy somewhere because of this [dealing with structural racism/homophobia]. … It's serious. (Speaker 9)

Another participant talked about how attending an event for Black/African American gay men was a strategy to maintain his connection not only to the gay community but to the Black/African American community as well. It was also the foundation for advocating for the rights of Black/African American queer people within White queer spaces.

> I also think, too, what you brought up about being Black and gay. I share this when I'm in rooms I see with White gay folks or Black gay folks. It's like I stand on your guys' shoulders (the shoulders of Black Gay men) because there was a time at your house, off of Multnomah, the first time I went to a brother-to-brother meeting

> (Black Gay men meeting), and I walked in there. I'm dealing with my own sexuality. I walked in and saw these Black gay men, and I knew just listening to you guys, I'm going to be okay. And we forget that. (Speaker 7)

> I feel the same way, and it really makes me think back to the time that a few of us were wanting to have gatherings like this for queer folks (Black/African American queer folks). And one of the things I really liked about those gatherings is they were men and women. And you're right. I really feel as if we keep not having in the forefront of our minds how healthy this is for us. (Speaker 9)

This connection was significant for Speaker 7 because this strategy of mentorship enhanced his ability to maintain his connection to two communities. It provided protection from the impact of racism, regained his dignity, strengthened his cultural identity, and increased his resilience. These cultural mentorships are also important for heterosexual Black men and women. It is through mentorship that people can find perspectives to deal with racism, a person to talk with, and not have to explain the Black/African American experience, as expressed in the following quotes:

> For me to try to find a perspective [ways to deal with racism] in the streets or basketball, that wasn't enough. So, some of these people, one of the managers, we called him Colonel King [Black/African American male]. He was a sergeant, a master sergeant in the Army. He used to be something else. I forget. He was a manager at the apartment. So, I've hanged out with him quite a bit. (Speaker 1)

> It makes it less an isolating experience. To me, that seems like the most important thing, to be able to talk to somebody else and have them understand what you're saying, and just to acknowledge sometimes. I feel like one of the things that Black people do is we can laugh about some of the most horrible things, and sometimes it gives you the energy that you need to move forward. (Speaker 6)

One member talked about the teachings they received from their mother and how these led to developing a community and the experience of mentorship within this community that reinforced maintaining belonging and cultural identity:

> I think my mom was very strategic about putting me into certain areas, getting me involved in certain things, process and exposing me to things that, yeah … You a little Black boy. You're going to have these problems [racial]. But some of the stuff she taught me, I use to this day. It's like you need to be able to talk to these people in the board room and still be able to talk with your homeboys on the street, and you know you're going to have these problems [racism/homophobia]. Now what happens is I've gotten older; I've created my own community [Black/multicultural/gay], and so there are certain people that have helped me navigate the way. (Speaker 7)

### ***Social Movements***

Another strategic activity to maintain a healthy connection is to engage in a social movement and help to buffer the impact of racism on others. A strong connection to the community leads to a strong cultural identity and is a significant factor in developing and maintaining resiliency when there is a threat to Black/African American well-being. The participants discussed sustaining their connection to the Black/African American community through social movements, including the Black Lives Matter movement. A few participants expanded the conversation on social movements and included the significance of continuing the fight for freedom and the humanity of Black/African Americans. One participant reflected on the current events rooted in the Civil Rights Movement and how the barber shop is still important:

> We've seen what was happening, what was going on in your neighborhood [violence towards Black people], what was going on in the world, and what's going on in your community by going to those places (supportive places where discussion that impact Black/African Americans occurs-fight for equality). I think those were the best outlets that we had growing up. Not just in Portland, I think that was a cultural thing everywhere because Dr. King went to the barbershop. (Speaker 2)

In the discussion about healthy connections, one participant talked about the NAACP, a social and political organization that also created safety. The fight for equality strengthens the connection to the community, increases a sense of self, and keeps their humanity while enhancing resilienc*e* to have an impact on changing policy, engage with community leaders, or government agencies

The data reflected the diversity within the Black/African American community that expands connection points to the community and decreases the struggle in constructing a healthy cultural identity. The diversity and connections are critical when there are low populations of Black/African American Oregonians. Maintaining belonging builds a healthy Black/African American identity and reinforces cultural identity. The Black/African American and cultural identity is a foundation for resilience.

Resilience is a crucial component to navigating through structural racism and a significant strategy that provides a buffer against the stigma of not being Black enough. Not being Black enough occurs when people consciously or unconsciously align with the type of classification in the one-drop rule: “any person with one drop of Black ancestry as a Black person” (Lujan & DiCarlo, 2021, p. 647). Resilience against not being Black enough increases the ability to sustain a connection to the Black/African American community. It is the process of being grounded in one’s cultural identity no matter what Black/African Americans experience, and it enhances safety. As previously mentioned, belonging enables one to remember one’s humanity and ward off racism’s negative effects. One participant talked about how attending an event for Black/African American gay men was a strategy to maintain his connection not only to the gay community but to the Black/African American community as well.

### ***Speaking Up***

As previously mentioned, resilience is a product of maintaining belonging and was discussed across all the focus groups. It is a source of power that causes one to speak against structural racism. Speaking against racism is a protective factor, affirms one’s connection to the Black/African American community, and is an act of resilience. It is imperative to speak against a racist event due to “the totality of ways in which societies foster racial discrimination” (Bailey et al., 2017, p. 1453), leading one to lose one’s cultural identity and connection to the Black/African American community. The following quote reflects the underlying expectation that most Black/African Americans have of others when dealing with racism:

> Yeah. If what you're experiencing is an overt or covert act of racism, don't let it go unnoticed. And don't let that person believe that they slipped it by you. Share with them what you saw and what you felt and how you feel and what you want to see in the future, so they know your expectation. Take the risk. If you think you're going to lose them by doing that, by confronting them, then it's not a loss at all. It's really not a loss at all; it's a gain. You get that trash out of your life and go on with your life. (Speaker 13)

The sense of directedness in the previous quote is an example of the Africana worldview teleology. The communication has definite ends, the ultimate purpose, and a strategy for maintaining belonging. The quote had two purposes: to encourage and affirm group members as they deal with racist events and to confirm their membership in the Black/African American community by taking a stance against structural racism. Participants in all the focus groups talked about their experiences using their voice when facing social structures that allow people to use racial epithets. This act of sharing experiences is the Black/African American social symbolic interactionism. The action of sharing maintains the balance, highlighting the interdependence of the members with the environment. The specific environment is the societal environment of structural racism, which influences the participants' lived experiences. These shared experiences were expressed when a participant shared her story with the group, establishing her connection to the community and speaking against racism, which is a strategy for maintaining belonging and interacting with the group:

> I remember, my freshman year, a couple of the students said, “We got a [racial epithet] on campus.” And I thought to myself, “I heard it. They didn’t direct it at me, but it came to me.” And I thought, “How am I going to handle that?” So, remember afterwards, maybe about an hour or 2 later, I saw that person by themself. I went up to them, and I said, “I’m [participant’s name], and I am not a [racial epithet].” The person’s face turned beet red, and I said, “Can you say that?” I said, “No, I’m not asking for an apology. I’m asking for you to repeat my name.” He said, “Okay [participant’s name], I’m sorry, I’m sorry.” And he just stood there and looked at me. His face was as red as a beet. And I looked him right in the eye for about 2 minutes. And you know that can be a long time, and I turned around, and I walked away. He never called me a [racial epithet] again. But the funny thing about that, I still remember, [gallows humor was used to ease the pain] it was so long ago. But it seemed like every time I walked by him, he turned red. His face, it was like he had a light bulb in it. (Speaker 11)

As Speaker 11 told her story, there was action between her and the group. In the interactions of all the focus group members, meaning developed through the process of interpretations. The meaning was expressed in group action through their support and continual verbal and nonverbal communication while Speaker 11 told her story. Throughout the focus group meeting, she shared her exposure to racism with other members, creating awareness of a collective experience. Her story affirmed her membership within the group and the Black/African American community. This story and the support of the focus group members reinforced safety because their experiences of racism were not minimized or discounted.

Sharing racial experiences is a strategy for maintaining belonging and reinforces collective and individual experiences. As one participant stated, "I'm down for the cause," meaning the connection to the community is maintained because they fight for the humanity of Black/African Americans, which is anathema to most White Americans. Participants did not ignore, minimize, or discount the experiences of racism. It is an attack on the humanity of Black/African Americans when their experiences of racism are denied, minimized, and shamed for bringing racism into the conversation.

The participants talked about several techniques for maintaining belonging, including creating a biological and extended family that supports one's humanity and cultural identity. In addition, techniques include finding or providing mentorship and using social movements to strengthen cultural identity, increase one's strength to live in multiple worlds, build resilience, and speak against racial oppression. The participants also shared diverse ways that they used their voice to address structural racism and cognitive changes. The collective experience of the focus group was an example of cultural meaning making Black/African Americans use to understand memory loss and dementia, which is explored in the following section.

### Maintaining Belonging in the Midst of Cognitive Changes

In addition to the importance of maintaining belonging in regard to experiences of racism, this theme was also important in the context of cognitive changes. The section presents challenges to the connection to one's cultural group, family, and friends while experiencing cognitive changes, as well as ways to sustain the connections. The section begins with dignity, focused on sustaining dignity despite barriers due to cognitive decline and structural racism. The next section describes threats to belonging caused by cognitive changes. A later section discusses hiding and minimizing cognitive losses and humor, focused on multiple techniques people use to maintain their connection to community, family, and friends and protect loved ones against racist events. A section on fear follows and focuses on the fear of substandard care and cognitive losses. The section ends with useful steps to address cognitive losses.

### ***Dignity***

As previously mentioned, maintaining belonging is a crucial component for Black/African Americans to maintain dignity in support of their cultural identity. Memory loss and forms of dementia impact the connection and one's dignity. There were several ways participants worked to maintain the dignity and cultural identity of the person living with cognitive decline. A common focus was to mitigate the loss of connection to the community. They express the loss of connection to people experiencing cognitive decline that impacts cultural identity through statements such as, "They're not coming to church anymore, they're not attending, or they're not visiting anymore." First is the observation of the person suffering from memory loss beginning to miss regularly scheduled events, visits to family or friends and other breaks in community connection. The loss pulls the person away from the situations that reinforce their cultural identity. It then leads to a loss of self and dignity. Yet to maintain dignity, family members minimize the change with the loved one with memory loss. They will act as if it was the first time the loved one with memory loss asked a question, as expressed in the quote below:

> Trying to act very calm. This is the most normal thing in the world, and yet you feel like I've heard this story 12 times today. It's the same story you told the last that was here, 12 times. (Speaker 6)

Sustaining one's dignity also includes normalizing the way a person dresses even when they put their clothes on incorrectly:

> About that time, she comes up the hall, and she has changed clothes. She put on a sweatsuit, and my mother loved her adult diaper. She put the adult diaper on top of the sweatpants. So, she walked there with the sweatsuit and adult diaper with dignity. (Speaker 5)

People do several things to maintain the dignity of the person with cognitive decline. For example, one participant talked about how they told people they were busy and planning to return their call. The statement was to maintain their dignity and hide their memory loss.

### ***Strengths and Limitation***

Across the narratives, people had similar experiences where the person living with cognitive decline forgot who the caregiver, family member, or friend was. It was evident through the participants' body language and facial expressions [affect symbolic imagery] that this was a painful experience. Participants provided verbal and nonverbal support and tried to ease the pain while drawing attention to the impact on one's quality of life. There was majority agreement that the quality of life was important, as expressed below:

> Eventually, she just thought I was a nice lady. I remember when she couldn't remember my father's name, and they were married for almost 50 years. They had known each other their whole lives. There's a quality-of-life element to it. I have a real issue with Alzheimer's. People who have gone so far that you know that I have. They're not going to have those glimpses of life (memories that sustained one's life, memories of loved ones) coming back. (Speaker 5)

At the same time that participants emphasized the importance of those connections, they also expressed the complexity of the impact of memory loss on the caregiver as well as the one living with cognitive decline. As one participant shared,

> Well, it's frustrating [his partner]. Because I've gone through what everyone has talked about in terms of keys, but for me, it's so many different things. … It's just the worst. Yeah, it's really hard. It is really hard. It affects [name] because his thing is, the minute I say I've lost something, he's zipping around trying to find stuff. And all that. Even the energy of that, the way he looks for things. I say, "Oh, I shouldn't have told you." I don't want to be in the middle of all that chaos. I calmly try to look at places. He's just opening doors and stuff. (Speaker 9)

Both quotes talk about the difficulty in maintaining containing connections due to cognitive changes.

### *Hiding/Minimizing Cognitive Losses, and Humor*

The perception of cognitive impairment is how participants described memory loss (forgetting days, names, misplaced keys). At times, memory loss had multiple meanings and different ways to mask it and its severity. The meanings on the surface seem mild, align with aging, and most medical providers potentially consider memory loss as normal aging or extremely mild cognitive impairment. However, the meanings of participants' memory loss reflected the beginnings of severe cognitive impairment that causes life-changing events. The severity of the impairment was clear when participants talked about where they found their keys or the length of time (a week or more) before they found the things they were missing. As participants and I explored the misplacement of the keys, we found there was a moment of a potential cognitive change:

> And then I noticed, even in my own case at 70, there are things that I can't remember and don't recall. And, to me, it's a signal. It's a sign of things that's going to happen as you get older. You know, you can't find your keys for weeks. They're in the house, but I don't know where they are in the house. You've got this fancy dish that you bought [to hold keys, wallet] and so you could see stuff, but then I go look in it, and it's not there. I put them somewhere, where did I put them? And go upstairs, like one time it was in the refrigerator. [People laughed in the way of acknowledging their experience of loss of memory about the placement of keys] (Speaker 10)

Through the discussion, participants shared the depth of their cognitive decline. Using humor to lighten or hide the impact, participants expressed their concern that cognitive changes were beyond normal aging. The laughter was also a strategy that sustained their connection. Participants laughed and joked about Speaker 10 not using the fancy dish for the keys or other objects. Speaker 10's delivery of his experience in misplacing his keys was given in a joking manner and engaged the participants, which minimized the seriousness of the experience.

Even though serious cognitive decline was occurring, participants shared their ability to maintain work schedules and other obligations. The participant expressed the fact they were fearful and significantly struggling to remember and did not want to lose connection to the community because of the cognitive decline. The joking was a way to keep connection and gently let people know of their concern about cognitive decline. As the discussion on cognitive impairment continued, Speaker 10 expressed his fear when responding to participants' acknowledgement of their fear of memory loss by stating, "I'm right there with you." There were multiple meanings for cognitive decline when participants joked about placing the keys in the refrigerator or unrelated locations, as seen below:

> They ended up being in the bathroom drawer [participant was laughing as well as the group members], and I don't know how they got there, or I'll be talking, and I'll say, didn't I already say this? [Group members said wow, and responded with concern, several jokes expressed, gallows humor] (Speaker 7)

Another meaning through joking is apparent when talking about subtle and blatant racist acts, structures that support racism along with cognitive decline, and how to deal with things one cannot control. Participants used gallows humor when discussing health issues, the hidden impact of racism, and stress leading to memory changes. Laughter is an essential coping strategy that potentially signifies severity that goes unnoticed. Jokes and gallows humor seems to soften the impact of service providers who do not listen or do not ask the right questions during appointments. It is often said that one laughs to keep from crying; participants laughed along with each other about losing keys or misplacing other items around the house. However, memory loss is real. Along with losing keys, there is the fear of losing connections with one's environment.

The following quote is a participant's beginning experiences of cognitive decline and process of hiding rather than admitting cognitive decline and trying to normalize the experience:

> Well, my memory loss is just beginning, really. I sense it. I do forget people's names if somebody has called me, and if I don't write it down right away, then I forget. They'll say, "You know, I called you a couple of days ago, and you didn't return my call." And the last thing you want to say is, "I didn't remember." So, the response is, "I intend to call you." That covers it up. When you get to be 90, you're just going to lose some memory, and that's where I am. In fact, I'm lucky that I remembered the question you asked me [she laughed, and participants joined in the laughter]. (Speaker 11)

Even though the discussions had the air of being lighthearted, the more profound meaning was the fear of cognitive decline, which will be explored in the following section.

### ***Fear***

Participants mentioned three main types of fears in regard to cognitive decline: substandard care due to racism, loss of protection from family against racism, and fear of losing one's memory. The fear of substandard care because of one's race led to various strategies to avoid going to a care facility. The strategy of hiding memory loss helped to avoid being moved to a care facility or requiring care from someone outside of family members or community. It allowed aging in place, as people remained in living environments ranging from residential settings to surrounding neighborhoods and communities (Epps et al., 2018). Across the focus groups, participants talked about how they hid the cognitive changes from most people to prevent being forced to move from their homes to a care facility. Being removed from the security of home would reduce the supports that enhance resilience and protection from possible mistreatment by strangers. It was also important to participants that they have a Black/African American person to provide in-home care services to enhance maintaining belonging as their loved ones struggle with memory loss. Having a Black/African American caregiver provide another layer against racist events.

Participants reflected on losing memory; however, they were able to recall long-term memory. Most memories recalled included segregation, different treatments due to Jim Crow laws, and a variety of racial events. As noted by participants, family or a person from their culture will maintain the humanity of the loved one and understand the racist history impacting Black/African Americans. The participants stated that caring for a loved one protects them from structural racism. One participant shared the following:

> I feel like it's more of a family thing, so we'll do it as long as we're able to. Because we may not trust others as much as we would trust other African Americans. Once the family can't do it anymore, I would look for an African American to provide care … because they understand. They have the history.

> They've gone through some of the same things. They have a deeper understanding of the person, so I think that being Black is important. I would just first seek out another Black if I couldn't do it myself. But I think the family is very strong, usually. And, so, different members of the family will take turns and come together to try to care for the older person. (Speaker 12)

This fear included not being able to trust the government in providing care and what people did to ensure their loved ones received effective care.

> We can't rely on the government or anybody else to be there for us. (Speaker 2)

> We'd get the chance to go out there [care facility for a family member living with cognitive decline], and it's close to the airport, and I traveled a lot. … This was 1-2 weeks a month, so I'd always stop there on the way out and on the way back. He was always pleased to see me, and I was always pleased to see him. It sort of kept them [caregivers in the facility] on their toes, too, the people at the hospital, in terms of making sure they gave correct care. [Concerned they will not receive adequate care because of racism and the impact of Jim Crow era]. I never found him wet, I never found him in need of anything. They didn't know when we would arrive, so they were always on their toes. (Speaker 13)

The importance of maintaining belonging and protecting against racism for loved ones experiencing cognitive decline was consistent across the focus groups. The families' experience in maintaining belonging was crucial in this study. It expanded the meaning of memory changes through family dynamics and continuing the family roles. Participants focused on maintaining their quality of life, community connections, and the dignity of their loved ones struggling with cognitive changes. They focused on the connection, not the symptoms. The participants expressed grief over losing a loved one to dementia and the pain of watching a family member or oneself struggle with cognitive decline. This extension of grief includes fear, guilt, and one's own awareness of the family and extended family caregivers' eventual cognitive changes. The following example expresses the complexity of the fear and the mental challenge of dealing with cognitive changes from a caregiver's point of view:

> It's frustrating. It's crazy. Then there's days where it's hopeful. I don't know. It's a lot of different feelings. It's a lot of different things. I think one of the main things is I want for her health and her well-being to be as good as it can be. On the other hand, I'm looking and I'm saying, "What happens 5, 10, 20, 30 years if this shit happens to me?" Who's going to take care of me? I don't have kids but even if I did, that doesn't mean they're going to want to take care of me? (Speaker 1)

As the group processed this statement, the discussion revealed a general fear not only of losing memory but also of being forced to move to a facility and potentially being mistreated for being Black/African American. The following statements underline the fear that the participants felt about declining memory and the self-awareness of their cognitive changes. The tone of his voice in the first quote showed his fear, and the second connected memory loss to terror. The other quotes highlight the fear where they are entertaining the thought of suicide as a way to deal with AD and other forms of dementia.

> Or someone saying, you know, you told me that the other day. And I'm like, "Oh, okay." And, so, that's what frightens me [voice intense] because with my

> grandfather having memory loss, I think am I experiencing memory loss at 52. That's scary. (Speaker 7)
>
> Plus, the fear and the terror. They say, "You don't have any fear." Well, shit. When you can't remember stuff, I'm scared of that. I don't want to lose my memory to these degrees where I can't remember what I did an hour ago or yesterday. (Speaker 1)

> I remember that so clearly (cognitive decline due to cancer). That was in the '70s. I always say, if that happened to me, I'm going to do what I got to do for me, [suicide] because that was it for me. I was so upset. (Speaker 4)

> I'm finding myself being secretive about it [suicide]. So, I'm answering what other people think about it. I don't tell them. What happened [AD] with my mother scared me to the point of I'm going to hide some pills [ to end her life] and hope I can remember where I put it because I don't want my quality of life to be like that [mother who had AD] because you don't know how long it's ... I don't know how long. How many years it's going to last? [AD; therefore, suicide as an option] (Speaker 5)

On the surface, the responses from Speakers 1, 2, and 13 reflect their concern about losing memory or caring for a loved one living with cognitive decline. An undercurrent of each response was the concern about receiving substandard care or mistreatment for being Black/African American. Sub-standard care and mistreatment were ongoing conversations across all the focus groups. The discussions did not rest on the fear but explored strategies to address the fear of cognitive decline, fear of losing protection against racism, fear of losing memory and ways of maintaining belonging.

***Strategies to Address Cognitive Losses***

Participants expressed the need to develop strategies to address the fear in the discussions about future care, financial planning and outliving one's earnings. One focus group that included caregivers discussed the strategy of planning for one's future before experiencing cognitive decline by ensuring financial resources, as expressed in the following statement:

> So, jumping back on what you said [name], you have guilt, and you do have concerns about whether that's going to happen to you. … Now that you see, and that's your mom [cognitive decline], you really have to plan for yourself and make sure you have the retirement, that insurance. I mean, because if you don't have any kids and that's saying that they would take care of you because I don't either. You have to make sure that you have yourself situated if that was to happen. Not just memory loss, any type of health issues. (Speaker 3)

As the groups processed the fear, the discussion landed on the hope that the participants would not lose their connection to their community and negatively impact their sense of maintaining belonging**.**

Finally, the discussion around cognitive decline, loss of connection, and substandard care or exploitation was present across all the focus groups. The participants' focus was on how cognitive decline and racism could disrupt maintaining belonging. As previously mentioned, racism related to substandard care or mistreatment is stressful, leads to the activation of the sympathetic nervous system (Bailey et al., 2017; Menakem, 2017; Rothschild, 2017), and affects cognitive functioning (Bailey et al., 2017; Rothschild, 2017; Van Der Kolk, 2014). These discussions highlighted Black/African Americans' experiences of the impact of structural racism in Oregon's healthcare systems and the emotional toll that occurs. The discussions brought forth the question, are the high rates of cognitive impairment within the Black/African American community a byproduct of the stress of racism?

An aspect of cognitive decline is expressed in the term "slipping away," which came from a discussion with the coding team. As reflected in the focus group discussions, "slipping away" defines moments in which it appears that the spirit/personality/essence of the person living with cognitive impairment is gone while the body of the person is still alive and physically present. Lindauer et al. (2015) capitalized on the shift in the person living with cognitive impairments through the caregiver's point of view using the phrase "changed, but still here." They focused on the preserved capabilities and personality traits still present. Our participants and coding team focused on the fact that they were losing their loved ones. They were struck by the impact of losing a loved one, the stress it brought, and finding ways to live with this loss. The change in the loved one was noted by blank facial expressions and/or behavioral changes. Slipping away also meant the loss of life-giving activities, including loss of choice, forgetting names, and losing family connection with the person living with cognitive impairment, as expressed in the participant's comment below:

> Yeah. That was the very first time I had to deal with somebody with memory loss. And I think, at that age, trying to understand and having this strong Black man who was a father figure for me, that was always there. It was hard to see him slip away from me because he didn't know who I was. Yeah. That was [he paused, and the pain was visible on his face]. It was difficult. Even when we had to finally put him into the hospital and going up there, and you know, I never called, my grandfather, grandfather, I called him daddy. I was like, "Daddy, it's me." He was like, "Well, who are you?" I'm like, "I'm [participant's name]. It's [participant's name]." I was like, "I'm the first one. I'm your first grandson." And, you know, trying to explain to him. It was hard, very hard. (Speaker 7)

Participants discussed several strategies to address cognitive decline that resulted in maintaining belonging. The strategies ranged from sharing and playing music, creating photo albums to share, and spending time to normalizing repetitive behaviors or questions. The following are strategies participants used for loved ones with cognitive decline.

> I made photographs for her to look at. I'd bring those, and we'd talk about them. … We'd call long distance to her friends when I was there, and we'd talk to them and talk to the family here. So, I did take care of her in that way. (Speaker 2)

> Trying to act very calm. This is the most normal thing in the world, and yet you feel like I've heard this story 12 times today. It's the same story you told the last that was here, 12 times. (Speaker 6)

> Listen [to people experiencing cognitive decline]. They need to be heard. (Speaker 3)

Participants also talked about strategies they used to maintain belonging and memory that allowed them to organize past experiences, which strengthened their cognitive functioning, as expressed below:

> Those things. I operate from a kind of therapeutic position because, first of all, I've been working on these projects that really do involve memory and looking at the past, and I get so much joy from it. Writing their history. Well, recently, what I'm doing is writing about the history of my comic strip, and that's kind of gotten me in this mode where I really appreciate looking back and putting things almost in a kind of order. And I think whenever you work on something that's biographical, you started looking at your life, your time. (Speaker 9)

In this section, we learned through the lived experiences of the research participants that whether a person was living with or without cognitive decline, most participants strived to sustain connection to the community and position in the family, community or with their loved ones. Maintaining belonging was important and a protective factor against the vicissitudes and ravages of hostile racist environments. They included strategies to address blatant racial incidents, substandard care, or mistreatment and isolation that helped them retain dignity and self-worth and affirm their honor. These strategies reinforced resilience in managing cognitive decline and racism. The section presented the significance of cultural identity in managing cognitive decline and maintaining connection to one's community. The historical impact of structural racism and its influence on cognitive decline was also expressed.

In this chapter, we discussed the lived experiences of Black/African Americans as expressed through maintaining belonging. We explored disruption to the connection to the community due to structural racism and strategies to sustain connection to the community. The strategies included family formation, mentorship, social movements, and speaking up. Then, we explored the impact of cognitive decline on maintaining belonging, including maintaining dignity, hiding, or minimizing cognitive decline and three types of fear related to memory loss and cognitive impairment. We ended the section with strategies to address cognitive losses and techniques to sustain connections.

# Chapter VI Discussion

From the conception of this research, there were two goals for this study. The first goal was to demonstrate the use of the Africana worldview, also known as the Africana paradigm, as an important cultural framework in social work research. The second goal was to answer the two research questions: (a) What is the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans, and (b) What are the different ways this worldview aids in the interpretation of Black/African Americans' understanding of memory loss, dementia, and AD? Aligned with the tenets of the Africana worldview, multiple ways of knowing occurred from this research. Hence, the variety of understandings of maintaining belonging was a critical discovery from this research. To stay true to the tenets of the Africana worldview, I here provide my understanding of maintaining belonging and its influence on the field of social work as one of the many views that can occur. First, I discuss the significance of maintaining belonging by exploring the power of connection, which includes the cultural nuances and significance of a culturally responsive methodology. Second, I explore cultural meaning making, which focuses on the first research question. Then, I extrapolate the relevance of the Africana worldview/paradigm. The chapter continues with implications for social work practice and education, strengths, and limitation, and ends with ideas for future research.

## The Power of Connection

Using a culturally specific methodology is essential because it draws on the significance of connection, which is critical within the Black/African American community. A critical part of the connection was the double consciousness. Participants drew on their cultural identity as they created a connection to each other by learning about people's relationships to the Portland Black/African American community. The questions were both direct and indirect. An example of an indirect question was asking where people went to school. One participant attended a predominantly White school in the Southwest hills of Portland. Because of the location of the school and its negative reputation regarding Black/African Americans, the attendee's connection to the Black/African American community was suspect. The discussion revealed that another participant had a family member who also went to that school, which brought to focus the cultural identity used to manage structural racism. The discussion reinforced the connection to the Black/African American community, strengthened cultural identity, and eliminated doubt about the participant's commitment to the community. The discussion was a way to see oneself reflected in others, which is a significant part of double consciousness. Through double consciousness, one understands the influence of racist ideology on identity yet chooses a cultural lens when developing one's Black/African American identity.

Another aspect of double consciousness in this study reinforced the multiple positive identities Black/African Americans experiences when effectively navigating structural racism's dehumanization. Multiple identities include Black/African American, Black/African American LGBTQI2-S, Black/African American and Muslim, Black/African American teacher, or Black/African American artist. The identities reinforce belonging in the United States despite racism and White supremacy. Because of these positive reinforced aspects, participants sustained harmony with each other and the Black/African American community. They acknowledged everyone's experience of racism without challenging or minimizing the impact. Through the discussion, participants understood the power of White stereotypes, removed them from the group, created a place of belonging within mainstream society, and decreased the internal conflict between Black/African Americans and Americans, as expressed in W.E.B Du Bois's double consciousness.

The double consciousness was evident in the focus group, where all participants were members of the LGBTQI2-S community. In this focus group, they talked about their struggles navigating the Black/African American and queer communities. The struggle included addressing rejection from the queer community because of one's race. Therefore, the participants sustained their connection to the Black/African American community. However, the discussion explored integrating sexuality and racial identity to participate in both communities effectively. Through mentoring from queer Black/African American men, participants strengthened their self-worth by seeing themselves reflected, creating resilience. Therefore, these different experiences reinforced the importance of the cultural aspect of maintaining belonging to strengthen one's dignity and humanity. The mentoring and the significance of cultural identity were married across all focus groups.

Intersectionality impacted how participants viewed cognitive impairment and how a solid Black/African American identity was the key to their success in maintaining belonging in both communities and the reality of the interdependence of all living things.

Interdependence is significant in this research because it is the lifeline for most Black/African Americans navigating through systemic racism while managing the nuances of cognitive decline. Interdependence also demonstrates the significance of supporting and maintaining the humanity of Black/African Americans. The most robust evidence of humanization was through the participants' and the coding team's process of maintaining belonging. The humanization is significant for it countered how participants mentioned being stereotyped, ignored, or treated as less than a human using European and Western methodologies grounded in the philosophy of a supreme race and the justification of the demonization of Black/African Americans (Carroll, 2008; DeGruy, 2005; Washington, 2008).

Humanization is also essential because participants can maintain confidence in self-advocating their needs, feel connected to their community, trust care providers and make any needed transition as a caregiver or person with memory loss. By recognizing and centering the humanity of Black/African Americans with memory loss, care providers can counter bias, correct the causes of health disparities, and move toward equity in services. The research participants and the coding team discussed the impact of structural racism and its power to interrupt making genuine connections with the Black/African American community. This study found that type of interruption can erode essential supports needed to counter racist stereotyping, mistreatment, and the emotional impact of cognitive decline. When people constantly battle systemic racism, there is a mental toll that impairs cognitive functioning. The study shows that staying connected to the Black/African American community prevents interruptions caused by structural racism, restores resiliency, and buffers the mental toll and cognitive decline. An important finding in this research was that all discussions around experiences of racism ended with the development of strategies to resolve or attend and respond to racist events as they occurred.

Research participants discussed the power of their ability to move through racist situations individually and collectively. This shared communal experience of managing racist events occurs because of maintaining belonging, which is the foundation of resilience. The resilience is effective when individuals see themselves reflected in the Black/African American community and the cultural community reflected in themselves. Through the communal experience of maintaining belonging, people develop the advocacy skills to speak up, resist, or collectively fight against structural racism. The process of harnessing this support that, at times, is unspoken builds individual and collective strength. This act of building strength is a global phenomenon seen throughout the history of members of the African diaspora as they persevere through colonialism and other dehumanizing atrocities. Maintaining belonging to the cultural community builds strength as one lives through adversity, including managing cognitive decline. This study showed the importance of maintaining one’s position in the community and family for the person living with memory loss. These connections gave the person purpose and the will to live. For example, one participant talked about suicide as an alternative to experiencing AD. Connection seemed to slow down the progression of cognitive decline and maintain happiness.

Research shows that social engagement with others is a factor that potentially protects against cognitive decline, which is supported in this study (Fratiglioni et al., 2004; Haslam et al., 2014). However, this study showed that it is not just social engagement for Black/African Americans. It is a specific socialization the participants discussed that had a protective impact. The positive impact on people living with cognitive decline occurred when the cultural identity was reflected by the people with whom they socialized. The participants reflected on how over-explaining, defining, and performing did not occur when they were with other Black/African American people as when around European Americans. Being with members of their community decreases racial stress, which also has a protective impact on cognitive decline. Again, the person living with cognitive decline was able to access long-term memory through stories, pictures, and music. The acknowledgment of cultural identity was found to be essential for cultural meaning making and managing life.

## Cultural Meaning Making

First, personal identity is a self-concept that involves acquiring attitudes, feelings, characteristics, behaviors, and identification with a larger group. The experience of exclusion and racialization supported by society and the larger world has forced Black/African Americans to the social construct of race in their identity. Most Black/African Americans living in Portland have used group identity to create culture. The culture is broad and diverse and used to cultivate the self’s core. Parham et al. (2011) state that this cultural identity has three functions: (a) anchors and provides meaning to one’s existence, (b) connects to the Black/African American community in the US and globally, and (c) protects against racism that continually bombards the psyche with non-affirming and dehumanizing messages. For the participants in this study, cultural identity was critical and was used to make sense of life challenges and memory changes. This meaning making process is the framework most Black/African Americans use to make sense of their world when living in a racialized society. Cultural identity also strengthened self-worth and enhanced the ability to deal with life changes. It provided a buffer from internalized racism (believing the racist ideology/internalizing racial oppression) as participants sustained connection and made meaning by engaging in conversations with others.

Portland has a view as a progressive city that embraces diversity. However, every participant talked about experiencing different treatments due to the color of their skin. They also talked about the constant reminder of race. Furthermore, this constant reminder took a toll on one's mental health. Therefore, cognitive decline is understood through cultural identity in that maintaining belonging to the Black/African American community is critical for a healthy identity.

Communication occurs through ascribing meaning to the language, facial expressions, and tone of voice. We interpret these symbols and ascribe meaning (symbolic interactions). Ascribing meaning is grounded in one's life as one experiences one's environment (Blumer, 1986). Because we live in a racialized society, the experience of racialization and cultural identity is incorporated into the meaning making process. It was apparent that affect symbolic interactions were critical, causing one to pay attention to both verbal and nonverbal expressions of the participant's responses, knowing that there is an impact of historical racism. The attention to affect symbolic imagery is a critical part of the methodology I employed.

The congruency of participants' cultural identity, acknowledgement of experiences of racism, and commitment to the Black/African American community provided diverse ways for cultural meaning making to occur. Cultural meaning making occurred when participants talked about busing because race was the key factor in who was bussed. It also occurred when participants talked about cognitive decline in terms of maintaining belonging and keeping one's place in the community. They also talked about this topic in terms of being denied services or ghosted because of their membership in the Black/African American community.

Cultural meaning making was evident when participants used strategies to access each other by expressing their commitment to the Black/African American community by claiming their cultural identity, shared experiences of racism, and their family's role in supporting the community. These assessments created safety for the participants to share their lived experiences with health issues and cognitive decline. Participants' individual commitment to the Black/African American community created space for trusting, in-depth discussions, and maintaining belonging continued after the group time ended. The depth of discussion was also a byproduct of framing this research in the Africana worldview, which centers the Black experience and does not shy away from discussing racists events

## The Impact of Africana Worldview

In traditional research approaches, we facilitate a refocus when group participants stray away from the research topic. Researchers (grounded in the Eurocentric worldview or dichotomous logic) experience discomfort when participants move away from the order of the research format. However, actualizing this methodology centralized the importance of not shifting and interrupting participants experiencing cognitive issues beyond "normal aging" as the discussion moved away from the focus group guide. In utilizing Africana methodologies, by sitting with the discomfort that occurs and not refocusing, participants better understand the research. It allows room for the rhythm within the language style that moves in stories and concepts and does not align hierarchically. It forces researchers not to categorize the conversations and choose what they think is essential and missing the participants' vital points. In the focus group process, I did not interrupt and realized the context of the entire conversation provided insight into how people made sense of cognitive decline. Throughout the discussion, group members talked about experiences of racism that included practical steps to manage racist events and cognitive decline. These discussions were critical as they showed how intertwined racist events are with everyday living for Black/African Americans and their impact on cognitive decline.

By actualizing the Africana worldview, I was able to think critically about the role of cultural meaning making in understanding memory loss and dementia among Black/African Americans. I paid attention to the subtle cultural nuances that addressed historical information that increased meaning in participants' responses when they talked about racial incidents. Asking questions led to a deeper understanding of the impact of cognitive decline, the cultural ways participants dealt with impairments, and the reasons they were reluctant to seek support from healthcare institutions.

The Africana worldview draws attention to the cultural element that leads to expanding the meanings of Black/African American responses. This worldview draws attention to exploring cultural nuances, which is the foundation for resilience. One of the strategies for developing resilience is learning Black/African American history, reinforcing one's cultural identity and strengthening cultural meaning making. Black/African American history is rarely taught in schools. History from a Eurocentric education deemphasizes Black/African American people's contributions to American history beyond enslavement. Learning of one's cultural history that does not begin with enslavement is a strength that protects against the impact of hostile racial environments supported by structural racism (Schiele, 1996). Through actualizing the Africana worldview, one becomes aware of the diversity within the Black/African American experience and highlights the multiple meanings taken from the participants' responses grounded in cultural meaning making. Understanding the diversity within the responses allows the researcher to grasp the impact of memory loss and loss of connection to the community that participants expressed in the focus groups.

Using Africana methodology, I learned how cultural meaning making helped to highlight the effects of racism in a way that led participants to talk about memory loss or accessing healthcare. It led me to ask questions of participants who reported racial influences leading them to try to hide their fear of cognitive decline. The fear of losing one’s memory was more about the potential of experiencing racial harassment or substandard care for being Black/African American. More importantly, using this worldview highlighted the meaning of fear, which was about losing one’s connection to the community that brings healing from racism and cognitive decline. The fear of separation from their community or supports to survive racism was also why most participants were reluctant to discuss their concerns about their experience of memory loss with a provider or family members. The matter included the possibility of a person with cognitive decline living in a healthcare facility and the potential of mistreatment without protection from the family or advocacy from community members to reinforce the person’s humanity.

Using the Africana worldview also influenced how I explored the collective experience of racism living in Portland, Oregon. Because of the small Black/African American population, racism was different. The difference is that racism is more subtle, with few blatant acts. For example, racism is expressed through compliments about a person’s hair, followed by touching or running hands in that hair. It is also expressed in “Portland Nice,” where people present as kind but gentrify a Black/African American neighborhood by force. The community has also been impacted by gentrification and displacement. To build a hospital in the Black/African American community, African American area residents were offered below market value for their homes. If they refused to sell, their homes were seized through eminent domain.

The culturally specific worldview also reinforced acknowledging the importance of resiliency. Focus group participants embodied resilience through social action, supporting each other and fighting for the needs of the Black/African American community. Resilience showed up through the discussions about overcoming racist events, sustaining one's position while experiencing cognitive decline, and supporting each other when talking about difficult life experiences. Resilience aligned with Baldwin et al. (2011) in that consistent exposure to unfair treatment led to developing successful adaptation to cope with racist events. All participants moved beyond talking about racial experience to coping strategies and the importance of racial integration. The coping skills included sustained connection to the Black/African American community that honored, encouraged, and reinforced one's humanity.

The discussion also covered resilience regarding the need for a strong cultural identity. Advocating for racial justice and fighting against the Jim Crow laws enhanced cultural identity and strengthened resiliency. Racial socialization and positive racial identity (double consciousness) buffer against racism and enhance Black/African Americans' ability to bounce back from adversity (Baldwin et al., 2011). Every participant talked about their experience of racism and the ways they bounced back. As previously mentioned, if a discussion around racism occurred, it included ways to manage the racist events.

## Practice

Findings from this study have significant implications for social work practice and other helping professions and people directly or indirectly working with Black/African American clients and communities. First, the social work profession has a long history of exclusion practices that harm Black/African Americans. The profession focuses on the deficit approach, which aligns with the racial views that came out of enslavement and anti-Blackness. Therefore, the profession struggles to incorporate the diverse voices of Black/African Americans when developing policies and programs and addressing the impact of aging. Even though there are several Black/African American authors, they have to work within the Eurocentric framework, preventing incorporating multiple ways of knowing and interdependence. Addressing this complication requires a culturally responsive clinical practice and an understanding of how to reinforce the significance of maintaining belonging. It is vital to have a working knowledge of both local and national history of racial policies and practices, like exclusion laws, and the emotional toll that racism causes. If practitioners know this history, it can be easier to develop effective ways to engage Black/African Americans living openly and honestly. Knowing the history will also enhance awareness of the cultural nuances. The cultural nuances aid in the Black/African American decision-making process.

Second, social work practice needs to address issues around racism. Every participant knew someone or had lived experience of racial trauma during the Jim Crow era or read about trauma (lynching, beating, violence in school) Black/African Americans experienced. The discussion of racism occurred in all of the focus groups. By allowing the discussions to run their course, they ended with strategies to manage racism and build resilience. This knowledge is noteworthy because of the discomfort when discussing racism; there is an urgency to shut down the conversation or switch it and move closer to comfortable discussions. This information is critical because shutting down the conversation increases the risk of potential reinforcement of racial trauma Black/African

Americans experience when denied aging services. Many Black/African Americans in Oregon are aware of the negative impacts of structural racism like redlining and the impact of gentrification in predominantly Black/African American communities in Portland, Oregon. It is beneficial to incorporate knowledge about structures that support racism, the history that led to structural racism, and how it impacts social work practice. The information becomes more critical for social workers whose clients are older Black/African Americans.

These lived experiences are part of the long-term memory that occurs over the years (Banich & Compton, 2018). As we age, long-term memory remains longer than short-term memory, even when experiencing cognitive decline, dementia, and AD (Banich & Compton, 2018). Explicit semantic long-term memory is knowledge gained through experiencing life, the world, and interaction with people they know (Banich & Compton, 2018). For example, participants experiencing cognitive decline found it easy to remember the life-changing childhood experiences but struggled to remember situations that occurred within two weeks or a couple of hours. In the focus groups, participants could quickly recall racial trauma events in the Jim Crow era, which everyone connected to because of their own experiences of racism. This knowledge can guide social workers in direct services as they engage with older Black/African Americans. Knowledge of the history of racism and exclusion in Oregon and resiliency becomes vital when the ethnic/racial identity is not congruent between the social worker and the client/services user. The knowledge can also guide social workers in developing equitable policies and working for equity.

Third, the profession can enhance the skills of social workers working with Black/African Americans living in Oregon by learning the covert expressions of racism used locally. It means focusing on institutional racism in Oregon and going beyond individual racist acts. Structural racism impacted every research participant, and the history of Oregon's exclusion laws means there is a high chance that most Black/African Americans living in Portland experienced some form of racial bias during service delivery, poorly implemented equitable policies, or culturally unresponsive practice.

Enhancing culturally responsive practice when working with older Black/African Americans requires the ability to have open discussions about racism. It is important to be able to manage negative behaviors that may be directly linked to prior mistreatment or other forms of cultural ignorance. For example, being present and not minimizing a person's lived racial experience is important. Practitioners must be able to acknowledge and affirm the hurt and other difficult emotions experienced. The practitioner should increase their skills to speak about ethnic differences and their potential impact on the therapeutic relationship, their working relationship, or policy development. The culturally responsive social worker is aware that ethnic differences potentially cause discomfort and loses the urgency to ease the uneasiness. The skill includes assessing when to bring up the discussion of ethnic differences/racism or follow the lead of the client/services user/patient. This skill is critical when collaborating with older Black/African Americans explicitly experiencing cognitive decline. As previously mentioned, long-term memory (episodic memory, semantic memory) is grounded in the generational trauma of Black/African Americans due to Jim Crow laws, enslavement, and racism. A critical factor in addressing this is maintaining belonging. It will be beneficial for practitioners to enhance clients' connections to the Black/African American community and increase knowledge of the diversity within that community.

The social work field needs to maintain belonging for Black/African Americans with cognitive decline remembering the process of hiding or minimizing cognitive losses. As previously noted, the minimization or hiding is a protective factor preventing a move to establishments that increase their risk of experiencing racism. Because clients will not reveal the cognitive decline, social workers are encouraged to explore the hidden meaning behind the laughter and minimization.

Additionally, minimization or hiding is a way to keep the family together and maintain the roles or humanity of the person living with cognitive decline. It reflects the fear of being removed from protection against racism and from the people you trust and who honor your cultural identity. It is important to find culturally responsive care facilities and culturally congruent care providers. Also, aging in place may be particularly critical for Black/African Americans. Aging in place maintains the connection and role in the community and protects from structural oppression. Epps et al. (2018) posited there are challenges to successful aging in place for Black/African Americans, such as resource inadequacy, financial constraints, improper housing, and transportation concerns. All of these challenges have connections to structural racism, and the social work field has a responsibility to address these issues based on our code of ethics.

## Social Work Education

Education is broad and incorporates all forms of learning, including the previous sections. To narrow the focus, I explore four areas for social work education to consider when working with aging Black/African Americans and cognitive decline. The first consideration is that social work education will benefit by increasing potential social workers' skills to address the three main fears presented in this study: fear of substandard care due to racism, fear of losing family protection against racism as one ages, and fear of losing one's memory. Addressing these fears includes incorporating knowledge about structural racism's impacts on Black/African Americans and their access to healthcare facilities.

Understanding the impacts of structural racism might increase one's knowledge about the relationship between racism and cognitive decline. The knowledge could lead to effective interventions and practical steps for positive change. This knowledge about racial impacts is important because most participants had a racist experience when engaging with medical professionals. These racist encounters reinforced the fear of healthcare establishments and were extremely stressful. Stress is a contributing factor that can impact some cognitive functioning. It is vital that Social Work Education addresses these issues within the educational system and enhance the skill of students to address and dismantle racist barriers.

When increasing the knowledge and skill set to dismantle racist barriers, understanding the power of cultural identity plays a significant role in advocacy work within Black/African American communities. Cultural identity is enhanced by a sustained connection to Black/African American community that supports and honors the individual. Cultural responsiveness means sustaining connections to the community in ways that honor the individual. Part of the sustaining connection is finding adequate ways to address some of the challenges impacting Black/African Americans' ability to age in place. Redefining the family unit and expanding the definition of family to include non-biological family members increases the chances of sustaining connection to the Black/African American community and resources.

Including basic Black/African American history, social movements, and the connection to the cultural needs of aging adults experiencing cognitive decline in social work education, prepares social workers to work with this population. Therefore, a counter to the impacts of structural racism is by providing the positive contribution Black/African Americans have made to the field of social work. Another counter is to focus on the assets of Black/African Americans and the community, even when addressing social issues.

The second consideration focuses on using teleology and diunital logic in the education system. This research confirmed the literature around Africana teleology, where components of directness with definite ends are part of the communication style of most Black/African Americans. Awareness of Africana teleology shifts how we interpret conversation and avoid stereotypical views that Black/African Americans are aggressive or defiant when they ask or answer questions. Furthermore, this research found that Black/African Americans respond directly to research and participant questions. The directness was also noticeable as participants questioned people's commitment to the community and talked about experiences of racism and their resistance toward the healthcare system. However, the conversation never stopped at the racist experience but included resolution techniques and reinforced resilience. In addition, the conversation consistently incorporated ways to manage and move beyond racial events. Incorporating actual acts of resilience and ways to move beyond the racist event is a critical component of education when dealing with structural racism.

Fourth, using diunital logic opens the doorway to multiple ways of knowing and is the most challenging to understand. It causes everyone to move outside the academy's foundation grounded in dichotomous logic. This concept of "this and that" requires accepting multiple ways of understanding and is critical when learning about Black/African Americans. The basic foundation of diunital logic evokes the realization of the diversity in the Black/African American community, including cultural diversity within this collection of people. This reality challenges everything traditionally taught in the academy and is essential when addressing aging issues within the Black/African American community. It highlights the reality that Black/African Americans are not a monolithic group. Even the term Black/African American evokes the reality of diversity and challenges the traditional stereotypical views expressed in the academy, one type of Black/African American community.

Diunital logic embraces intersectionality, highlighting the diversity and the multiple dimensions within the Black/African American community. Incorporating diunital logic embraces multiple ways Black/African Americans define family and extended family. Daniel Moynihan's study, previously mentioned, would have a different result that incorporated structural racism as a reason for the struggle of Black/African American families instead of blaming Black fathers or single mothers. The acknowledgment of the diversity in the families causes a focus on various ways to advocate for access to quality health services based on past racial harms and for practitioners to understand their community's history.

**Strengths and Considerations**

While strengths and limitations are a common way to evaluate research, it is important to name that this framework does not fit with the Africana worldview. In particular, this way of thinking is dichotomous. In contrast, within the Africana paradigm, we can see that this research, as well as future research, shows multiple sides of the research questions, and subsequent studies will bring similar and different understandings, and the different meanings are all meaningful. However, for this dissertation, I will highlight some key strengths of this work as well as considerations and implications for future research.

First, Africana methodology, focus groups, and Africana phenomenology were strengths of this research. A salient strength was centering the Black/African American experience and staying open to the multiple ways the experience was expressed. For example, some focus group members' experiences mirrored the coding team's lived experiences. As team members talked about their experiences of bussing, accessing medical care, and racial experiences, they provided the cultural context to the participants' experiences. They also provided a variety of experiences and multiple ways of understanding. The mirrored experiences of the coding team were significant because of their membership in the Black/African American community. Having the same cultural identity as the participants, the coding group understood the cultural nuances.

A cultural understanding provided several different ways to examine the data, including the double meanings of the participant's responses. For example, the coding team understood and discussed the struggle of living in multiple worlds. The team felt the experience of the members of the Black/African American queer communities as they talked about being forced to live in the gay and straight world. The coding team brought their experience of living in the White and Black world and double meaning, which is the struggle of not having full membership in both worlds.

Another strength was using focus groups because it allowed the exploration of the individual and collective experiences. Using groups connected to the tenets of the Africana worldview, such as interconnected and interdependence, where all things in the universe are interconnected and interdependent. The value of relationships built in the focus groups and the research team is a part of maintaining belonging in action! Using the focus group provided multiple experiences creating a deeper understanding of the research questions. The social relations while living in Portland impacting the research questions were revealed, particularly the racial dynamics influencing Black/African Americans in accessing care for cognitive decline.

As we explore limitations, we might instead think of them as different ways to approach future research based on learnings from this project. One consideration is that the study focused on a small group of people living within a 50-mile radius of Portland, Oregon. The findings were specific to the history and sociopolitical context of this region. However, if we expand the area and include more Black/African Americans, the data could expand and yield different results. In addition, the participants in this research had a high education level. Some researchers may argue that this sample's education and economic levels are not representative of most Black/African Americans. That argument is grounded in the deficit approach as well as a stereotypical view. The argument ignores the educational drive for Black/African Americans during the reformation period and the Civil Rights movement. I would suggest that future research may include participants with less formal education and more varied socioeconomic class backgrounds to better understand how these factors shape Black experiences with memory loss. Another consideration previously mentioned is the impact of COVID-19. The pandemic prevented continuing with a few more focus groups. Future research may consider utilizing more focus groups and/or individual interviews to gain more community perspectives.

## Implications for Future Research

Applying the Africana worldview provided a profound awareness of the multiple ways Black/African Americans living in Portland use cultural meaning making to understand memory loss and dementia. The new awareness inspires further exploration of the different ways Black/African Americans use cultural meaning making to define health issues. An area of interest is whether different locations or a higher number of participants would provide additional forms of cultural meaning making. Based on the tenets of the Africana worldview, a different direction would add to this study, supporting the multiple-ways ideology (diunital logic).

As I reflect on my inquiry, there are six future research interests. First, future research should increase the number of participants to determine whether new information emerges. In this expansion, a focus on LGBTQI2-S would address the lack of cognitive decline research involving this community. Second, I am interested in finding whether regional locations influence how the Africana worldview aids in interpreting Black/African Americans' understanding of memory loss, dementia, and AD. One could explore whether different Oregon regions influence cognitive resilience through maintaining connections in the Black/African communities. A third interest would be to explore the strategies used to increase access to standard medical care for Black/African Americans with cognitive decline and related cognitive issues. A fourth goal is to understand why racism has such a significant impact on cognitive impairment and function. Fifth, future research should explore the influence of economics on maintaining belonging and cognitive decline impacting Black/African Americans. Sixth, it is essential to explore strategies that help to diminish disruptions to maintaining belonging.

In this chapter, we looked at a few ways to interpret the data through the power of connection, cultural meaning making, and the impact of the Africana worldview, ending with implications for future research, social work practice, and education. The information expressed in this chapter and the entire dissertation can lead to a deeper understanding of Black/African Americans' unique needs as they make sense of cognitive decline. It is one view, and the Africana worldview encourages us to stay open to other views. Staying open to multiple views will also enhance social workers' effectiveness, providing direct services, community and policy work, and advocacy. It holds space for opposite views and is not basing decisions on right or wrong ways.

This study did not intend to generalize ways to work with Black/African Americans living with cognitive decline or memory issues. Highlighting the lived experience of 13 Black/African Americans in Portland provided different views of cognitive decline and life in Portland due to using some tenets of the Africana worldview. Incorporating the other tenets might stop the ongoing destruction of Black/African Americans due to White Supremacy, colonialism, and dehumanization. This worldview causes an exploration of a cultural approach when addressing dementia and AD and healthcare for the Black/African American community. It causes one to center the community's assets and address systems such as structural racism that evoke health disparities. It reminds us to stay hopeful and use a holistic approach that acknowledges and upholds the wholeness of Black/African Americans.

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## Appendix A: Consent to Participate in Research

| | |
|---|---|
| **Project Title:** | Does Structural Racism Influence the way Black/African Americans Define Memory Loss and Cognitive Impairment: An Africana Phenomenological Study |
| **Researcher:** | Andre Pruitt – School of Social Work<br>Institution-Portland State University |
| **Researcher Contact:** | Email address: apr2@pdx.edu<br>Phone number: 503-860-1213 |

You are being asked to take part in a research study. The box below highlights the main information about this research for you to consider when making a decision whether or not to join in the study. Please carefully look over the information given to you on this form. Please ask questions about any of the information you do not understand before you decide to agree to take part.

**Key Information for You to Consider**

- **Voluntary Consent**. You are being asked to volunteer for a research study. It is up to you whether you choose to take part or not. There is no penalty if you choose not to join in or decide to stop your involvement.
- **Why is the study being done?** The reason for this research is [This research is part of my dissertation. The purpose for this study is to learn about people's lived experience as Black/African Americans living in Portland. I am also interested in Black/African Americans lived experience or providing care for someone living with memory loss.
- **How long will it take?** Your participation should last 1-2 hours
- **What will I be expected to do?** You will be asked to participate in a focus group and to share your lived experience or caring for someone living with memory loss. You will also be asked to share your lived experience as a Black/African American living in Portland Oregon.
- **Risks.** Some of the possible risks or discomforts of taking part in this study include feeling some distress as you share your story. Some feelings of sadness or anger when talking about being Black/African American living in Portland or your lived experience living with or providing care for someone living with memory loss.
- **Benefits**. Some of the benefits that may be expected include a sense of helping the Black/African American community by sharing your story. A sense of belong and honoring based on being a Black/African American. Being seen and respected based on your ethnic culture.

- **Options.** Instead of taking part in this study, you may leave without judgement and still receive the $15.00 stipend

**What happens to the information collected?**
Information I collect today is part of the result section of my dissertation. A summary of the results without identify information is included. The identifying information will be kept separate from the consent and will have a number so it cannot be traced to demographics you shared.

**How will my privacy and data be protected?**
We will take measures to protect your privacy including storing all information in a locked file cabinet that I will be the only one who has access to the data collected.

To protect all of your personal information, we will the consent will not be kept with the demographic information. Despite these precautions, we can never fully guarantee that all your study information will not be revealed.

Individuals and organizations that conduct or monitor this research may be permitted access to inspect research records. This may include private information. These individuals and organizations include [the Institutional Review Board that reviewed this research and the dissertation chair.

**What if I want to stop my part in this research?**
Your part in this study is voluntary. You do not have to take part in this study, but if you do, you may stop at any time. You have the right to choose not to take part in any study activity or completely stop at any point without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to join in will not affect your relationship with the researchers or Portland State University.

**Will I be paid for being in this research?**
By showing up to this focus group you will receive $15.00 compensation whether or not you participate in the record semi-structured focus group.

| **General Counsel / Office of the President** | **Office of Research Integrity** |
|---|---|
| PO Box 751—POF<br>Portland, OR 97207-0751<br>(503) 725-4419 | PO Box 751<br>Portland, OR 97207-0751<br>(503) 725-5484<br>1 (877) 480-4400 |

A law called the Oregon Tort Claims Act may limit the amount of money you can receive from the State of Oregon if you are harmed.

**Who can answer my questions about this research?**

If you have questions, concerns, or have experienced a research related injury, contact the research team at:

Andre Pruitt
503-860-1213
apr2@pdx.edu

**Who can I speak to about my rights as a part of research?**

The Portland State University Institutional Review Board ("IRB") is overseeing this research. The IRB is a group of people who independently review research studies to ensure the rights and welfare of participants are protected. The Office of Research Integrity is the office at Portland State University that supports the IRB. If you have questions about your rights, or wish to speak with someone other than the research team, you may contact:

Office of Research Integrity
PO Box 751
Portland, OR 97207-0751
Phone: (503) 725-5484
Toll Free: 1 (877) 480-4400
Email: hsrrc@pdx.edu

**Consent Statement**

I have had the opportunity to read and consider the information in this form. I have asked any questions necessary to make a decision about my taking part in the study. I understand that I can ask more questions at any time.

By signing below, I understand that I am volunteering to take part in this research. I understand that I am not waiving any legal rights. I have been provided with a copy of this consent form. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to provide consent before I continue in the study.

I consent to join in this study.

| | |
|---|---|
| **Name of Adult Participant** | **Signature of Adult Participant** |

**Date**

**Researcher Signature** (to be completed at time of informed consent)
I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

_______________________________ ___________________________________ ___
**Name of Research Team Member** **Signature of Research Team Member**
**Date**

## Appendix B: Demographic Survey

### A few questions about you…

1. What is your age? ___________
2. What is your household income from all sources?

☐ Less than $ 10,000
☐ $10,000 to $15,000
☐ $15,000 to $20,000
☐ $20,000 to 25,000
☐ $25,000 to $ 35,000
☐ $35,000 to $ 50,000
☐ $ 50,000 to $75, 000
☐ $ 75,000 or more

3. How many people are in your household, including you? __________

4. What is your gender?
   ☐ Male
   ☐ Female
   ☐ Transgender male
   ☐ Transgender Female

   ☐ Your terminology: __________________________

5. How do you racially identify?

☐ African American
☐ Black
☐ Bi-Racial African American/White
☐ Bi-Racial Black/White

☐ Multi-Racial African American and ___________________________________ _______________________________________________________________

☐ Multi-Racial Black and ______________________________________________ _______________________________________________________________

☐ Your terminology: - __________________________________________________

**Education**

6. What is the highest grade or year of school you completed?

☐ Never attended school or only attended kindergarten
☐ Grades 1 through 8 (Elementary)
☐ Grades 9 through 11 (Some high school)
☐ Grade 12 (High school graduate)
☐ College 1 year to 3 years (Some college or technical school)
☐ College 4 years or more (College graduate)
☐ GED (Did not graduate high school, instead obtained a GED)
☐ Graduate School (Received master’s degree or higher)

**Income**

7. Are you currently employed?

☐ Retired
☐ Employed for wages – full time
☐ Employed for wages – part time
☐ Self-employed
☐ Out of work for 1 year or more
☐ Out of work for less than 1 year

- ☐ A homemaker
- ☐ A student
- ☐ Unable to work
- ☐ Your terminology:__________________________

8. What kind of work do you do? (For example, registered nurse, janitor, cashier, auto mechanic). If retired, what work did you do before you retired?

________________________________________________________
________________________________________________________
________________________________________________________

9. Would you say that in general your health is?
   - ☐ Excellent
   - ☐ Very Good
   - ☐ Good
   - ☐ Fair
   - ☐ Poor

**Home Ownership**

10. Do you own or rent your home?
   - ☐ Own
   - ☐ Rent
   - ☐ Other: _________________________________

*End of Survey*

*Thank you for responding to these questions!*

# Appendix C: Focus Group Discussion Guide

**(Total Session Time: 128 Minutes)**

**Dissertation research:** Does Structural Racism Influence the way Black/African Americans Define Memory Loss and Cognitive Impairment: An Africana Phenomenological Study

**Introduction (One-minute timeline)**

"Welcome participants." (Facilitator introduces self and other assisting with the focus group; hand out $15 cash or gift card and invite people to get a snack.)
(Facilitator explains purpose of focus group:)

- "We are here today as part of a research exploring Black/African Americans lived experience in Oregon"
- "We are conducting these focus groups with Black/African Americans because we want to understand their experience living in Portland as a black/African American and their lived experience dealing with memory loss or taking care of a loved one experiencing memory loss."

**Consent and Media release** (Seven minutes)

But first, I would like to answer any questions about the consent form that you previously during our initial meeting that gives information about your participation today. (Review the consent form and allow time for responses to questions.) (Hand out the Media consent form and explain participants do not have to have their picture taken.) [The form allows them to agree or not to have them identified by name if/when pictures are used.] *Note that we will keep consent forms completely separate from the surveys and record the discussion to protect confidentiality. (Collect signed consent forms.)
The information gathered is confidential and yet I cannot guarantee that other member of the focus group will maintain confidentiality.
"If at any point during the process you are uncomfortable or need to take a break, you can leave at any time. If you do stay, that means that you fully understand what I have just read and agree to participate in the survey and discussion. Please sign the media consent."

"I would like to continue by hearing a bit about you. Can you provide your first name or the name you would like us to use and let us know how long you have lived in or brought you to Portland [or another town if group is conducted outside of Portland?] (Facilitator starts) "My name is [first name] and I have lived in Portland for XX years or since [year]."

STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

"During this focus group, we are interested in learning about your own lived experience or loved ones experiencing with memory loss and dementia. We are also interested in your lived experiences as a Black/African American living in Portland.

**Focus Group Discussion (120 minutes timeline).**

"Now, we are ready to begin the recorded section of the focus group. I would like to go over some guidelines." (Facilitator reviews guidelines for the sessions.)

- Everyone participates- all opinions will be heard.
- Confidential please reframe discussion what people said outside of this group
- There are *NO* wrong answers.
- You want to answer questions from your own personal experience or from your general understanding of the topics we are asking about.
- Sessions will be recorded
- Sessions will last about 90 minutes.

**Experience living in Portland (45 Min)**

I would like to continue exploring your lived experiences in Portland as a Black/African American

1. You previously mentioned how long you lived in Portland or what brought you to Portland. I am wondering
    a. How has living in Portland impacted your life?
        i. Prompts
            1. Think of an experience in which you were aware of your race and tell me what was it like? What happened? How did it affect you?
            2. How has connection to Black/AA community impacted your ability to deal with racism/racial situation How has race/racism influenced your experience of accessing medical care for memory loss or other medical concerns?
        ii. Prompts –
            1. What have you done when race created barriers in getting care?
            2. How have you navigated experiences of racism (if people talk about racism)?
            3. Who assisted you when you experienced barriers to medical services?
            4. When race was a barrier to medical care, how did it impact or influence your identity?

**Cognitive Impairment (45 - minute timeline)**

STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

Thank you for sharing and next let’s move the discussion to memory loss

1.) “How has your experience dealing with memory loss or taking care of a person living with memory loss affected your life?

STRUCTURAL RACISM INFLUENCES BLACK/AFRICAN AMERICAN DEFINITION OF COGNITIVE IMPAIRMENT

**Prompts**

- For those of you who are yourselves experiencing some memory loss, how have your friends, family and community responded to these changes in you?
- "Thinking about people you know who have had problems with memory loss, confusion, or dementia [or other words participants used], how have you known that they were experiencing problems?" (Clarify specific behaviors or activities of concern.)

**Bringing it Together (30 Minutes timeline)**

(The is the section that we bring together – experiences of racism + cultural identity + cognitive impairment)

1.) How has living as a Black/African American influenced your experience of memory loss or caring for a loved one experience memory loss, cognitive impairment, dementia, or Alzheimer's disease?
    - What is one thing you would share to support someone Black/African American experiencing memory loss?
    - What is one thing people should do when experiencing racism?
    - What recommendations do you have for African American/Black community members who may be experiencing memory loss or caring for someone with memory loss?

**"That is all the questions we have. Do you have any questions for us or any comments you would like to make?"**

*Thank people for attending.*