The Impact of Racial Concordance on African American Participation in Nursing Research: A Qualitative Descriptive Study

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Dedication

I dedicate this dissertation to Vincent Lamonte Campbell Sr., my dad, for demonstrating courage as a supportive African American father, research participant, and leader in the Good Hope Community located in Silver Spring, Maryland. I want to express my deep and sincere gratitude to God and my family: Avis and Eugene Robinson, Asia Tiffany Thompson-Sampson, Travis Richard Thompson, Pauline R. Campbell, Annie R. Collins, Edward Rhodes Collins, Russell B. Campbell, Vincent L. Campbell, Jr., Danae A. Cotton, Kirsten Ann Collins, Edward R. Collins, Edward E. Statler, Bernadette Thompson, Zyrus Campbell, and Sandra Bennet-Cooper: for their unwavering support.

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Chapter One: Introduction

African American Participation in Research

Research participation is necessary for improving population health, advancing science, and enabling patients' access to novel therapies outside of the standard of care treatment. More urgently, the demand for superior research requires an accurate and balanced representation of minorities participating in research. Yet, despite the known benefits of research participation, African American (AA) participation remains low in the face of disparate mortality rates from cancer. Additionally, AA cancer mortality rates are increasingly exaggerated by the impact of the Coronavirus (COVID-19) (Wang et al., 2021). Furthermore, understanding motivational factors that contribute to AA participation in health research is limited; notably, ascertaining the contributions of African American Nurse Scientists (AANS) in AA participation warrants examination. The emergent findings from this qualitative description approach using thematic analysis, contributes to the body of scientific knowledge by illuminating dimensions of the relationships between AA participants and AANS and accentuating motivation factors contributing to research participation.

Statement of the Problem

Extensive research has demonstrated barriers to AA recruitment and participation rates are a result of historical mistrust, research awareness that includes provider bias, unrealistic study logistics, and the lack of cultural awareness (Luebbert & Perez, 2016; Sheppard et al., 2021; Wolff et al., 2003). Although research examining barriers to research participation among AAs is abundant, it is important to understand how the role of AA researchers contributes to research participation. While preliminary studies examine the importance of diverse research teams and delineate the role of the nurse scientist, there is a lack of preexisting literature on AANS impact on AA willingness to participate and retention rates (Taylor & Mendoza, 2018). Understanding additional facilitators influencing AA participation in oncology research studies is essential to developing effective policy change and strategies for improving AA enrollment in research. More importantly, having an in-depth understanding of how historical maltreatment of AAs has influenced their perceptions of research is needed. While previous studies have shown AAs perceived need for ongoing open dialogue with the research team and closer contact for trust building, in depth analysis about the AA researcher and their dynamic relationship with AA participants, in particular, how this impact research participation is warranted (Robinson et al., 2016).

Examining factors influencing AA participation through social justice and historical lenses, AA are known to suffer from prolonged exposure to structural inequalities from racism, classism, colorism, sexism, and homophobia, therefore, increasing their risk of cancer (Agenor et al., 2015; Beydoun et al., 2016). Social norms of oppression and historical distrust for research negatively impact perceptions and reduced self-efficacy towards health care and health management (Sorkin et al., 2010). Unfortunately, bias practices infiltrate researchers' recruitment efforts. Niranjan and colleagues' study (2020) revealed that implicit bias and racial stereotypes of AA infiltrate researchers' perceptions of AA research participants, negatively influences research designs, and suppresses enrollment opportunities. As a result, AA patients are less likely to receive research opportunities and in-depth discussions about research (Eggly et al., 2015). Moreover, the historical backdrop of many centuries of maltreatment of AA in research exacerbates distrust of the research community. Generational stories passed down about nonconsenting enslaved laborers, including the accounts of Ms. Henrietta Lacks Cells and the

Tuskegee Syphilis Trial, contribute to research skepticism. Improving research strategies that openly acknowledge historical trauma, while publicizing the benefits of research is needed to strengthen AA health outcomes.

This study promotes principles of social justice change on micro and macro levels (Hoefer; 2019) First on a micro level, invoking social changes that promote equal opportunity for the AA research population to receive the psychosocial, financial, and medical benefits from research participation (Whitehead, 1992). Secondly, having uncomfortable conversations that examine the multidimensional historical context promotes self-reflection, and encourages discussions about racial biases**.** Promoting race conversations are essential to prevent a recurrence of mistreatment history by acknowledging the existence of racism. Finally, it is necessary to level the educational racial fields for AA nurse scientists by addressing educational institutional facilitators and barriers to their participation in the research enterprise. This is accomplished by promoting AANS to leadership roles that encourage research critique to identify and address areas of potential bias. Secondly on a macro-level, social change involves assessing research organizations and identifying institutional research barriers (Richardson, 2015). Addressing micro- and macro-level social justice challenges related to research participation will influence organization and policy change that give rise to nursing leaders and nursing organization partnerships with a reputation for policy change. Therefore, this qualitative study was underpinned by Critical Race Theories (CRT).

Study Purpose

The purpose of the study was to understand the bidirectional relationship between the African American Nurse Scientist (AANS) and the African American Research Participant (AARP) and how their relationship influences participation in health research. Examining perspectives of both AA researchers and participants is vital to understanding the strategies to engage AAs in the research system more effectively. An in-depth understanding of the phenomenon can only be accomplished by listening to the unique voices of those who have experienced discrimination (Crenshaw et al., 1995). This analysis attempts to give voice to and listen to AANSs' perspectives in participant recruitment, enrollment, and retention in research, as well as perspectives of AAs who have participated in research, in particular, what has facilitated their participation. A more nuanced understanding of the factors contributing to research participation may shed light on active recruitment, enrollment, and retention of AA participation in addition to strategies that support AANS, thus improving morbidity and mortality rates from cancer.

Specific Aims

This study aimed to:

1. Identify and describe the nature and dimensions of the relationships and shared motivational factors, behaviors, and interactions of AANS and AARP that influence research participation.
2. Explore the impact of shared cultural experiences of the AANS and AARP.

Methodology

This Qualitative Description study obtained a fundamental understanding of the dimensions of the relationship of AANS and AARP. This study included AANS who have conducted research in the AA community and the AARP who have a history of participating in health research. This study incorporated tenets of Critical Race Theory (CRT) with semi-structured interviews providing the basis of data collection. A thematic analysis approach was used to identify themes and an inaugural understanding of the relationships of AANS and AARP and what motivated them to participate in research, as both researchers and participants. It is hoped that this understanding will lead to research destined for improving research participation within AA communities, illuminate the nurse scientist role, and therefore improve population health.

Significance

Disparate African American Cancer Disparities

African Americans continue to experience the highest cancer death rate despite groundbreaking cancer therapies. The US Department of Health and Human Services Office of Minority Health (2021) reports AA having the highest death rate for most cancers than all races. In addition, The American Cancer Society (2019) reports AA men and women experience higher incidence and mortality rates (9% and 22%) in all cancers. For example, AA women with breast cancer have a mortality rate that is 40% higher than their white counterparts (American Cancer Society, 2019). To reduce the cancer disparities gap in AAs, the Senate and House of Representatives of the United States of American Congress passed the 21st Century Cures Act, of 2016, in turn, providing additional funding towards increasing the inclusion of underrepresented populations in research. The Department of Health and Human Services (DHHS) mandated researchers to examine why minorities are experiencing more disease and to eliminate cancer disparities through research participation (DHHS, 2011). More importantly, the Department of Health and Human Services Initiative to Address the Disparate Impact of COVID-19 of African Americans and Other Racial and Ethnic Minorities commissioned to improve data collection of the disparate AA communities that include cancer patients (DHHS, 2020). In addition to federal mandates, substantial incentives from the National Institutes of Healths' (NIH) Health Care Systems (HCS) Research Collaboratory grants, and Healthy People 2030 are aimed at supporting and advancing population-based research (Office of Disease Prevention and Health Promotion [ODPHP], n.d.). Despite these mandates, the African American (AA) community continues to be the most underrepresented population in research within the United States (US).

Low Participation Rate of African Americans

Progress toward AA participation in research remains slow despite known benefits and incentives. AAs make up 13.4 % of the general population; however, they only make up 4% of participation in oncology research (U.S. Census Bureau, 2019; FDA, 2020). Dickmann and Schutman (2018) found AA participation in the United States Food & Drug Administration (FDA) approved cancer drug trials between January 2010 to July 2016 was 2.3%. In the 2020 Drug Trials Snapshots, the FDA reports that 8% of AAs participated in oncology trials (U.S. Food & Drug Administration, 2020). It is significant to mention, in the setting of an acute onset of a worldwide pandemic, AA participation rates in vaccine research trials tripled from 3% to 9.8% for Pfizer and 9.7% for Moderna with increased targeted efforts in the AA community (Warren et al., 2020; FDA, 2020). These irregular statistics reveal AAs are not maximizing benefits received from participating in research. Moreover, research that leads to strategies to enhance AA participation in oncology research is essential for closing the gap of low accrual rates, disparate cancer death rates, and improving population health (Unger et al., 2016). In an era of research scrutiny, the necessity for precise research, which incorporates a factual population representation, warrants a careful examination of the recurring barriers of justifiable mistrust related to the historical maltreatment of AA in research.

Reducing Disparities Through Research Participation

To reduce health inequities, AA participation in oncology research is essential for improving AAs' health. The National Institutes of Health Revitalization Act of 1993 mandated researchers with the support of government funding to examine why minorities are experiencing more disease and eliminate cancer disparities. In additional mandates, the benefits of research participation are abundant. Research participation offers participants additional healthcare and access to novel therapies outside the standard of care therapies. The United States Congress appropriated 6.56 billion dollars to the National Cancer Institute (NCI) for cancer research (National Cancer Institute, 2021). In 2019, NCI reported 69.9 % of its funding went to cancer research, and 5.8% of its budget went to cancer prevention (NCI, 2021). Significant funding contributes to participants not having to pay for medical care or experimental therapies while enrolled on trial at the NCI. Therefore, patients have access to novel therapies, medical oversite, diagnostics care, and hope which cannot be quantified in a dollar amount. While not guaranteed, some patients also experience relief from diseases like cancer through research participation. One such patient is Melinda Bachini, diagnosed with stage IV bile duct cholangiocarcinoma; after participating in several research trials at the NIH, NCI, she is ten years out from her disease and now an activist founder of the Cholangiocarcinoma Foundation. Malinda expressed, “I attribute this to the wonderful advancements in cancer research.” (National Foundation for Cancer Research (2019). As the research nurse on this study that gave Ms. Bachini her immune fighting cells that were part of a research study led by the world-renowned Dr. Steven Rosenberg, this afforded this patient additional lifesaving therapies outside of standard of care treatments. Unfortunately, AA participation in research studies remains low; therefore, deceasing their access to novel cancer therapies, diagnostic screening, and the additional benefits that research provide beyond the standard of care options (Mahipal & Nguyen, 2014).

Understanding Race Congruency in Research

A growing body of evidence supports race matching and race concordance as factors contributing to increased participation and investigator trustworthiness (Frierson et al., 2019; Fouad et al., 2016). Studies conducted in institutions where there were AA investigators and support for minority health reported high enrollment rates (Ewing et al., 2019). While race matching has been studied in the patient-physician relationships in healthcare management, a nuance in need of deeper understanding is how race concordance impacts the researcher-participant relationship (Shen et al., 2018). AANS are at the helm of conducting research within the AA community. Prior to obtaining their PhD in nursing or related health fields, AANS cared for patients suffering from disparate health conditions and provided intimate personalized evidence-based care to patients aimed at improving patient outcomes. Gaps in the literature include the impact AANS have on AA willingness to participate in research studies and the lack of understanding of dimensions of the bidirectional relationship between race matching and racial concordance of the AA research nurse scientist and the AA research participant and how their relationship influences participation, including recruitment and retention. A better understanding of this phenomenon may have implications for future recruitment, retention strategies, and implications for cancer treatment and research policy development.

Impact of COVID on Disparate African American Cancer Disparities

It is critical to acknowledge the context in which this study commenced. During the novel COVID pandemic, social injustice towards the AA community has amplified unjust health disparities affecting AA, including disparate morbidity and mortality from cancer (Minas et al., 2021). Staggering cancer mortality statistics are now compounded by the disproportionate impact of COVID-19 on AA cancer patients. Wang and colleagues' (2021) retrospective study found AAs newly diagnosed with cancer at an increased risk for being hospitalized and dying from

COVID-19. This study reported the overall death from Covid-19 in patients without cancer at 5.61%; more importantly, AA patients with cancer and Covid-19 had an increased morbidity rate of 18.52%, whereas their white counterparts' mortality rate was 14.9% (Wang et al., 2021, p. E6). Therefore, disparate cancer mortality rates in the setting of low AA participation rates that is exacerbated by the disproportionate impact of COVID on the AA community warrant an in-depth examination of strategies to reduce health disparities.

Study Importance

Giving a voice to AA and minority participants through their narratives contributes to science and is vital for understanding population behaviors (Borrell, 2018). A review of the science reveals a scarcity of qualitative approaches aimed at subjective experiences. Moreover, the inclusion of AA's historical and cultural experiences is an essential part of holistic nursing care and cannot be omitted (Kenerson et al., 2017). Inclusive descriptive and translational research studies produce findings that contribute to strategies of positive population-health behavior change (Kagawa-Singer, et al., 2010). Persistently low AA research participation rates in the setting of racial cancer disparities requires a holistic nursing research approach that is concentrated in a social justice enterprise (Thurman & Pfitzinger-Lippe, 2017). The significance of this research cannot be overstated as the current worldwide pandemic escalates health disparities in AAs (Azar, 2020).

Key Terms Defined

African American Nurse Scientists (AANS) are self-identified African American or Black Ph.D. prepared nurses who conduct research with African American research participants.

African American Research Participants (AARP) are self-identified African American or Black research participants who have a history of participating in health research.

Black or African American is the ethnicity of the people, community, and participants in this study. These terms are used interchangeably based on the participants' preference as several participants preferred being called Black than African American.

Counterstories are the stories, truths, views, perceptions, and historical accounts provided by people that have a history of being oppressed and marginalized. For this study, the counterstories are the lived experiences provided by the AAs and AARP.

Race concordance or race matching is the shared race between people

Racism is the actions and structural barriers put in place by people or organizations in power that are designed to suppress and disadvantage people.

Microaggressions are the non-exaggerated attacks that occur over time that are designed to put negative pressure on a person of color.

Hypervisibility (21) is when a Black person stands out in a social setting because they are the only person of color in their leadership role.

Summary

The study findings contribute to the illumination of social justice within public health by having examined and advocated for populations experiencing systematic disadvantage (Powers & Faden, 2006; Crenshaw et al., 1995; Lyons et al., 2013). The ever-increasing demand for diverse populations in cancer research to reduce health disparities justifies the need for successful recruitment and retention strategies of AA participants who are disproportionately underrepresented in research (U.S. Food & Drug Administration, 2018; Simon, 2014). By using a qualitative description approach and purposeful sampling, it is hoped that this study gave voice to AA truths and counter stories in a non-biased setting, increased research trustworthiness, thereby adding to the study's representativeness (Elo et al., 2014; Lincoln & Guba,1985, Sandelowski, 2010). In addition to population inclusiveness, this study turned its attention to the contributions of AANS and the nature of their relationships with their participants.

AANS are eager to assist their community in health improvement measures (Gladden-Young, 2020). Unfortunately, 'fewer nurses have held principal investigator (PI) or co-principal investigator (co-PI) roles' (Taylor & Mendoza, 2018, p. 12). Barriers that compound their participation include the small number of AA, PhD prepared nurses and inequities in obtaining adequate research funding (National Institutes of Health, 2019). To

date, there is data scarcity identifying the precise number of PhD-prepared AANS who engage in research. While this study examines AA participants in general, it contributes to identifying factors of the bi-directional relationship of AANS and participants that promote positive behavioral changes within the AA community that will lay the groundwork for future studies. Therefore, a strong effort to recruit as many nurse scientists as possible for this study was made. A deeper understanding of the relationships between AANS and AARP will facilitate the development of strategies to increase research participation, thus impacting more inclusive public health. This is of utmost importance to nursing science. The efforts of this study will provide the basis for moving from micro-level to macro-level social change that supports the AA community.

Organization of Dissertation

Chapter one has provided a brief introduction to cancer inequities in the AA community and AAs' lack of research participation warranting further examination. However, race concordance has shown positive findings towards participants' increased research trustworthiness. In addition, AANS are actively conducting research within AA communities. However, little is known about the dimensions of the relationships between AANS and AARP that motivate research participation. Therefore, Chapter Two will provide the historical backdrop of the study and an in-depth review of the literature surrounding AA participation in research and the theory that underpins the research study. Chapter Three provides an examination of the research design, including the methodological approach. This chapter will also describe the research sample and participant criteria for participation, as well as the data collection and analysis strategies used. Chapter Four will identify and describe the major study themes. Finally, Chapters Five and Six examines the study findings by positioning them within the state of the science and identifying limitations and implications for nursing and future research.

Chapter Two: Literature Review

A Historical Reexamination of AAs in Research: Through the Eyes of a Black Researcher

This chapter aims to provide an in-depth reexamination of history to provide the basis for this study. Three distinct areas of investigation will include: The historical backdrop of the study, the state of the science review of the literature, and the theoretical framework that underpins this study. In this section, I will examine US laws and colonialized social positioning, which contributed to the abuse and lack of agency of AA in research. Furthermore, the historical reexamination will provide evidential factors contributing to the justifiable generational mistrust the AA community has towards the research community. Second, a retrospective and prospective look at AAs in unethical research during the era of enslavement, negative eugenics, and how the U.S. confronted research abuse will be discussed. Finally, Critical Race Theory (CRT), which underpins this study, will be defined, and the rationale for integrating CRT throughout this research will be reviewed.

Historical Context for the Study

Examining factors influencing AA participation through social justice and historical lenses, AAs are known to suffer from prolonged exposure to structural inequalities from racism, classism, and colorism therefore, confounding cancer mortality incidence and mortality rates (Beydoun et al., 2016; Waters et al., 2021; Zavala et al., 2021). Centuries of social norms of oppression and historical abuse have perpetuated negative perceptions of research, contributing to reduced self-efficacy towards research and health care management (Sorkin et al., 2010, Washington, 2006). Moreover, the historical backdrop and generational stories of many centuries of AAs maltreatment in research experimentation exacerbate distrust of the research community. From the era of enslavement to recent revelations of unethical research of AA children in lead research, AAs have been subjected to dehumanizing experimentation, research-related death, deformities, and needless suffering of the body, mind, and spirit. See Appendix A: Historical Context Timeline.

Experimentation in the Era of Enslavement

Building on Critical Race Theory's (CRT) premise that laws have contributed to the subordination of African Americans and others. In the US, certain laws enforced racial policies and by laws underpinned by social ideologies that positioned enslaved laborers as non-citizens, which supported inhumane experimentation. The ACT XII: Negro Women's Children to Serve According to the Condition of their Mother, was a law designed to position Black children in a position of enslavement by means of the mother's slave status and no longer based on the citizenship of the child's father (ACT XII: Negro Womens Children to Serve According to the Condition of the Mother, 1662). Furthermore, government-enforced social order could be beneficial or maleficent depending on where the member fell within the system. A deep historical exploration reveals people of color excluded from the White race were subjected to discrimination, enslavement, poor health, unethical experimentation, and denied citizenship by those in positions of power. Dorothy Roberts (2011) emphasized race was politically constructed by those in positions of power to control those without power. For example, the Judicial Act (1790), officially titled, *A Bill to Establish a Uniform Rule of Naturalization and to Enable Aliens to Hold Lands Under Certain Restriction*, also known as the Naturalization Act, strategically positioned Whites as citizens in the U. S. The House and Senate bill allowed whites full citizenship upon proving two years of residency in the U.S. or native-born in the U. S. Legislator Robert Beverly (1705) provided context found within *An Act Concerning Servants and Slaves*, on the social position of enslaved laborers in Virginia. In his writings, Beverly reported slavery as a lifelong position. His writings even legitimized the murdering of enslaved laborers:

> And if any slave resists his master or owner or other person, by his or her order, correcting such slave, and shall happen to be killed in such correction, it shall not be accounted felony; but the master, owner, and every such other person so giving correction shall be free and acquit of all punishment and accusation for the same, as if such accident had never happened (Chap. XLIX: An Act Concerning Servants and Slaves, 1705, p.459).

Another landmark legal decision that dictated the absence of citizenship for enslaved laborers included the US Supreme Court ruling, *Dred Scott v. Sandford*. Dred Scott, an enslaved AA, unsuccessfully sued his master for his freedom (*Dred Scott v. Sanford*, 1856). The U. S. Supreme Court, December term, 1854, Chief Justice Taney (1860) rendered his opinion, as captured in the Library of Congress:

> But there have been doubts and uncertainties regarding the negro. Indeed, many (perhaps most) American communities have latterly sought to include him in the ranks of citizenship, and force upon him the status of the superior race. This confusion is now at an end, and the Supreme Court, in the Dred Scott decision, has defined the relations, and fixed the status of the subordinate race forever —for that decision is in accord with the natural relations of the races, and therefore can never perish. It is based on historical and existing facts, which are indisputable, and it is a necessary, indeed unavoidable inference, from these facts. (p. 3).

Proceedings such as these provided the legal backing that stripped AAs' self-agency and subjugated them under the authority of their slave owners. Often viewed as property, Thomas Jefferson (1790) cataloged his slaves along with his land records. Keeping careful documentation of slaves, ages ranging from 2 years old to 50 years old, Jefferson attached monetary values to the slaves, reporting some slaves' worth as much as 500 dollars while devaluing others as “of no value” or “worth nothing” (p. 5). Furthermore, the American Slave code promoted the sale and use of infirmed slaves for “medical education and the interest of medical education” (Goodell, 1853, p. 71). Therefore, legislation and social position allowed for abuse of AAs within research settings. This lack of freedom resulted in the absence of participant consent and the slaves’ inability to resist or refuse unethical research experimentation (Noonan et al., 2016, Roberts, 2011; Washington, 2006).

AAs were used in experimentation, often with the approval of their slave owner. Furthermore, the dearth of slave narratives resulted from education prohibitions that further repressed the AA voice (“Important for the Future”, 1862). Fortunately, slave encounters are found within the writings of those that escaped the bondage of slavery. Born in Virginia, John Brown (1855), a slave in Georgia, escaped enslavement to London and carefully narrated the brutal treatment he received as a research subject at the hands of Dr. Hamilton. Dr. Hamilton requested to use John Brown as a research subject as repayment for curing Mr. Stevens, Browns’ slave owner, of a recent illness (p. 45). In search of a cure for sunstroke, Dr. Hamilton used Mr. Brown in various experimentation leaving Mr. Brown in an adverse health state, as Mr. Brown states, “I was in his hands, under treatment, for about nine months and at the end of which period I had become so weak, that I was no longer able to work in the fields” (p. 48). Mr. John Brown (1855), speaking on his inability to consent and his owner’s concerns of the research practices within the research, when Mr. Brown (1855) reported:

> This he did at once never caring to inquire what was going to be done with me. I myself did not know. Even if I had been made aware of the nature of the

> trials I was about to undergo, I could not have helped myself. There was nothing for it but passive resignation, and I gave myself up in ignorance and in much fear. (p. 45-46).

With the consent of Mr. Browns' slave owner, Dr. Hamilton exposed Mr. Brown to various types of heat exposures and invasive experiments, which included inflicting wounds trying to learn "how deep my black skin went" (pp. 46-48). Mr. Brown stated, “He used to blister me at intervals of about two weeks. He also tried other experiments upon me which I cannot dwell upon” (p. 48). After nine months of experimentation, John Brown's body was diminished as his "bodily strength failed daily" from the injuries inflicted during research. Mr. Brown reflected on why his slave owner Mr. Stevenson allowed such treatment when he said, "I don't know what made Stevens so cruel-hearted to us poor slaves. We all led a dreadful life; I did, I know, and this made me more and more anxious to get away" (p. 49). Additional examples of doctors who used enslaved laborers for experimentation included Marion Simms. Dr. Simms, known as the father of gynecology, conducted gynecological experiments on slave women without anesthesia and barbaric closing of Black babies' skulls (Washington, 2006, p. 418). After much protest, the city of New York, recently removed Simms’ statue from New York Central Park in April 2018. It was initially placed as a reminder of his "contributions to science" and stood for more than 100 years to remind the AA community of the inhumane treatment of Black slaves (Marcius & Tracy, 2018).

The Science and Practice of Eugenics

Ideologies from science contributors, in particular, Charles Darwin, his cousin, Sir Francis Galton, and Carl Linnaeus proved to be the foundation for harmful eugenic teachings that influenced societal views and dictated people of colors’ unjust treatment. (Darwin, 1871;

Farber, 2008; Roberts, 2011). This analysis will use the term *eugenics* that Galton coined in 1883. He (1883) wrote the following:

> We greatly want a brief word to express the science of improving stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all influences that end to however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had. The word eugenics would sufficiently express the idea... (p. 25)

Galton's writings laid the foundation for the negative eugenics' movement in the US. Galton's familial relationship with Darwin contributed to the expansion of the eugenics movement (Fancher, 2009). Building on Darwin's theories of natural selection and evolution hierarchy, Galton developed a eugenics program to create a "superior race," which shaped social thinking in the 19th century (Galton, 1883, p. 324; Roberts, 2011, p. 34 & 36). Darwin 's writings characterized Black people by (negative) physical features while highlighting positive attributes of White people. These writings were highly cited and adopted as evolution epistemologies. In the book, *The Descent of Man, Charles Darwin (1871)* attached negative character traits to people of color while promoting favorable White characteristics. Another strong social influencer came from the teaching of Carl Linnaeus, a Swedish (1707) botanist who was known for creating the first human, animal, and plant classification system (Roberts, 2011). Linnaeus (1707-1778) elevated the "superior H. sapiens Europeaus" race with positive attributes of "vigorous, flowing blond hair, blue eyes very smart," while placing blacks in an inferior position by characterizing them as "sluggish, lazy, black kinky hair, and flat noses," (p.29). This way of racial dominance paved the way for segregation laws that opened the door to racial eugenics and the continued harmful treatment of Blacks in research.

The unethical use of Blacks for medical research continued after the Emancipation Proclamation (1863) and the 13th Amendment to abolish slavery, where scientific ideologies shaped social thinking and the treatment of Blacks in research. While enslaved laborers searched for protection under civil rights laws, Jim Crow laws and the animal rights movement were ushered in before human protection, which furthered eugenics practices. Furthermore, Jim Crow laws including Plessy v Ferguson (1895), legalized race separation, and the Marriage Restriction Act of 1895 segregated the races by prohibiting interracial marriage. Segregation laws did not prevent the mistreatment of Blacks. Larsons' book, Sex, Race, and Science described Black patients experiencing worse treatment, "appalling death rates" in hospital settings, and captured the thinking of a White researcher when reporting that Blacks 'tend to resist more than the Whites, which may be due to ignorance and superstition' (as cited in Larson, 1995, p.123 & 156). In addition to poor medical care, social control through marriage restriction and "sexual segregation" laws like the Marriage Restriction Act of 1895, Eugenic Marriage Acts beginning in 1910, and the Racial Integrity Acts starting in the 1920s prohibiting interracial marriage to "control social disorder and create social order" (Kevles, 1985, p. 92; Roberts, 2017, 25:44). Significantly, the protection of animals became more important than protection for humans. During the early 1900s, the American Humane Association moved to protect animals from cruel and unusual punishment. (Lederer, 1995) At the same time, the Progressive Era and Woman's suffrage movement opposed the male-dominated society that groomed males from a young age to harm animals (p.38). The Pennsylvania Society for the Prevention of Cruelty to Animals (SPCA) and Salvation Army pushed legislation and ethical awareness to the forefront.

Nevertheless, scientists were still engaged in unethical experimentation with people of color. These movements did not stop researchers' need for research subject enrollment, and participant consent for participation was often at the researcher's discretion.

Involuntary Use of Cadavers

Eugenics ideologies and the dehumanization of Black bodies continued. Washington (2006) elaborated on the abuses of Black bodies for experimentation that started with the colonial period, when owners either sold or hired their enslaved laborers to medical doctors for experimentation. This continued through the nineteenth century as Black bodies became cadaver research for medical students. By the early twentieth century, birth control of Black reproduction became the aim; and this culminated in the historical abuses of the Tuskegee study, the Holocaust, and the Henrietta Lacks atrocity. The preference for AA bodies over White bodies for medical exhibits and surgical experimentation were abundant and often contained inhumane procedures that lacked regulatory oversight (Washington, 2006). AA vulnerability also existed in death as Blacks could not rest in peace because of the increased demand for cadavers used for medical training (p. 130). Davidsons' (2007) study examining medical schools in Texas revealed unenforced laws to protect the illegal grave robbing to contribute to the cadaver supply. The generational stories of barbaric means to locate research subjects included "disappearing black cadaver" and the "looting of cemetery graveyards" were passed down through the AA community (Washington, 2006, pp. 119-122). These bodies were supplied to medical schools for student practice of medical procedures. These institutions were not concerned about obtaining informed consent from the families as cadavers were often used as spectacles of science and disposed of without a respectful burial (Davison, 2007; Washington, 2006).

Population Suppression

Some within the research community were using their scientific designs to aid in population suppression. Eugenics ideologies penetrated the development of the birth control pill. Dr. Margaret Sanger was known for promoting the birth control pill to poor black women. The detrimental impact on the AA community is rarely acknowledged, while she is often noted for her scientific contribution to contraceptives. In her writings, Woman and the New Race, Sanger (1920) spoke of the “pure native white stock” and the goal of creating a new race through controlling the birth of the undesirables, which included Black people and those with infirmities (p. 38 & p. 88). The renewed scientific quest to prove the races were divided rather than one human race was significantly impacted by the U.S. involvement in prosecuting German war crimes (Roberts, 2011).

Confronting Involuntary Research Participation

The attention towards human subject protection increased in the mid-1900s due to the findings of the trials of Nazi war crimes at the Nuremberg and Tuskegee Syphilis trials. The atrocities of the Holocaust forced the US to bring to justice German war criminals (doctors and researchers) engaged in biological warfare experiments, virology testing, and the killing of Jews in German concentration camps (Trials of war criminals before the Nuremberg Military Tribunals under Control Council law no. 10. Nuremberg, October 1946-April 1949). These crimes resulted in a review of the research process, including voluntary participant consent to research. As a result, The Universal Declaration of Human Rights (1948) document, which promoted universal freedom of all humans and denounced slavery, was created because of the finding of Nuremberg. In addition, the US created Nuremberg Code, which required researchers not to conduct research studies that could cause harm to the participant and gave participants the authority to refuse or vacate research. Ironically, these regulations were not enough to prevent the unethical treatment of AA in the Tuskegee Syphilis research.

The Tuskegee study is often used as the epitome of unethical experimentation of AAs. In 1932, the United States Public Health Service study enrolled over 600 AA males to study and follow the progression of syphilis (Schuman et al., 1955). Unbeknownst to the participants, many were not offered penicillin, which, since 1947, had been an effective standard of care treatment option for the disease. As a result of withholding the curative treatment, AA research subjects passed the condition on to their wives and children, suffered untimely deaths and debilitation, and left the AA community ever convinced not to trust research. Public health researchers did not offer participants informed consent regarding the study's purpose (CDC, 2015). In 1974, Congressional hearings resulted in an examination of the study and ensured regulatory governing bodies the oversite to guide research protection. For example, the government established the Belmont Report and National Research Act passed of July 12, 1974 (U.S. DHHS, 1979) to prevent atrocities like what was seen in the Tuskegee Syphilis Study. The impact on the community was so significant that on May 16, 1997, President Clinton publicly apologized to the five remaining AA clinical research participants.

Unfortunately, the revision of research laws happened too late to prevent the unethical research case of Henrietta Lacks. Henrietta Lacks' story may have gone unnoticed if it was not for reporter Rebecca Skloots' quest for the truth in "someday telling Henrietta's story" (Skloot, 2010, p. 6). In Jan. 1951, Ms. Lacks went to a doctor at the Johns Hopkins University Hospital with concerns of a "lump in her womb." Upon examination of Ms. Lacks' cervix, Dr. Gey obtained a specimen to test for cancer. Unbeknown to Ms. Lacks, her cells were cultured and were found to have replication properties that had never been seen before in the scientific community. Prior to Ms. Lacks cells**,** there were numerous failed attempts by scientists, including Dr. Gey, to grow human cells outside of the body. Surprisingly, Henrietta's cells continued to grow and were divided and used for cell lines to be used in research all over the world. Not only was H. Lacks uninformed of the use of her cells, but the doctor also obtained cells from Ms. Lacks' postmortem body for continued research studies and cell production without the consent of her family. Dr. George Grey renamed the cell line to hide Ms. Lacks as the origin of tissue specimens for a fictitious patient, Hellen Lane and distributed them for scientific research. The contribution from Ms. Henrietta Lacks' cells includes thousands of patents which include Nobel Prizes and Covid-19 experimentation and development (Wolinetz & Collins, 2020). Moreover, HeLa cell lines are available for purchase online to this very day. Even though Ms. Lacks' cells aided in many medical breakthroughs, such as polio vaccines, growing cell cultures and the study of cancer, mass production and financial gains were made from a vulnerable patient who gave no consent and received no benefit.

As reported by members of Ms. Henrietta Lacks' family, prior to Ms. Skoots' inquiries into Ms. Lacks' family, multiple reporters and doctors prodded into the Lacks' lives for selfish gains. Unfortunately, the family expressed their complete mental and physical exhaustion from the invasions of their privacy. The events surrounding Ms. Lacks' life and cells increased the family's mistrust towards the medical community. The family was aware of the money being made by the cells' medical advances while they themselves lacked adequate health insurance and it was all done without Ms. Lacks' consent. As a result, the Lacks family, its members which had multiple health problems, were refusing to have, or delaying necessary medical treatment as members lacked adequate health insurance. An example, Ms. Lacks' husband, Day Lacks, refused to have his gangrenous foot amputated because he did not trust the doctors. Skloot

(2010) reported Mr. Lacks saying "His feet hurt too much in regular shoes. Gangrene was spreading from Days' toes to his knee; his doctor said his toe needed amputating, but Day refused. He said he didn't want doctors cutting on him like they did Henrietta" (pg. 163). Skloot (2010) quoted Lawrence (Ms. Lacks' son) saying "Hopkins say they gave them cells away," Lawrence yelled, "but they made millions! It is not fair! She is the most important person in the work and her family is living in poverty. If our mother is so important to science, why can't we get health insurance?" (pg. 168). The fundamental purpose of the cells was used to help the health of millions, but the basic humanitarian needs of health care were not provided to her family, who were without insurance. Presidential and institutional apologies to family members of the Tuskegee men and the Lacks family do not repair the impact unethical has had on the AA community (CDC, 1997; Hudson & Collins, 2013).

Today, Institutional Review Boards (IRB) provide the checks and balances which allow researchers to conduct research that prioritizes the research participant over the research. Lederer (1995) asserted that before legislation and regulatory oversite, the medical community contemplated varying levels of informed consent of their research participants. Therefore, obtaining patient consent for experimentation ranged from no consent to informed consent before enacting ethical laws. Unfortunately, scientific eugenics teachings positioned people of color as those lacking decision-making capacity and compounded the generational impact AA mistrust of the research continued in the AA community.

An undeniable historic stain from US laws that facilitate the normalcy of racism as demonstrated by the inhumane treatment of AA research subjects over the centuries, remains a barrier to research participation despite regulatory oversight designed to protect research participants; consequently, aligning with the Critical Race Theory (CRT) that underpinned this study and will be expounded on in the proceeding section. This deep historical exploration supports AAs justifiable distrust for research and demands attention to rebuild trust between the research and Black communities. Researchers neglecting to have a deep understanding of the unethical treatment of AAs in research will only contribute to research that lacks empathy and awareness as to AAs protective behaviors of self-empowerment to avoid and prevent future abuse at the hands of the research community. The chain of events surrounding this deep lack of trust contributes to proximal factors that exacerbate health disparities that ultimately impact worldwide health, as seen in the most recent worldwide Covid-19 pandemic. More importantly, without an in-depth historical review, there is the danger of repeating the past. As philosopher George Santayana remarked, 'Those who cannot remember the past are condemned to repeat it' (Flamm, n.d.).

Integrative Review of the Research Literature

African Americans' participation in groundbreaking oncology research is low despite having the highest mortality rate in breast, prostate, and colorectal cancers and lowest survival rates of most cancers within the United States (US) (American Cancer Society, 2019). In the 2019 Drug Trials Snapshots, the FDA reports that 4% of AAs participate in oncology trials (U.S. Food & Drug Administration, 2019). Moreover, population marginalization, racism, and social positioning have accelerated and exacerbated poor health outcomes for AA with cancer (Anderson et al., 2019, Braveman & Gruskin, 2003; Colon-Otero et al., 2011; Farr et al., 2015; Link & Phelan, 1995; Strissel, et al., 2016). Conversely, research has potential to reduce cancer disparities by developing scientific knowledge and effective cancer treatments; therefore, understanding strategies to promote and include AA in research participation is vital to improving population health (Health Equity Research, 2021).

Scope

To encourage research participation, the Department of Health and Human Services (DHHS) mandated researchers to examine why minorities are experiencing more disease and to develop research to eliminate cancer disparities (DHHS, 2011). Furthermore, federal mandates, substantial incentives, and initiatives from the National Institutes of Health (NIH) and Healthy People 2030 aim to support and advance population-based research (ODPHP, n.d.). Unfortunately, African American participation in research remains low; therefore, non-participants miss the benefits research provides beyond the standard of care treatments, including novel cancer therapies, diagnostic testing, and positive psychological benefits of continuing cancer therapy (Mahipal, & Nguyen, 2014; Sheridan, 2020). An examination of the literature identifies known barriers and facilitators to African American participation in oncology research.

Organization

This review was designed to examine empirical evidence that identifies barriers and motivators amongst AA research participants in oncology research. A comprehensive synthesis of primary sources was analyzed to reveal common themes identified among AA research participants, therefore, providing an enhanced understanding of the factors contributing to low research participation rates. The aim of this review was to examine the current state of the science on African American participation in oncology research, summarize barriers and facilitators for research participation into themes, synthesize the literature for strengths and weakness, and explore implications for future research strategies, including setting the stage for this study.

Method and Design

This review was guided by Whittemore and Knafl's (2005) approach to identify African American barriers and facilitators to research participation in oncology research. Whittemore and Knafl's (2005, p. 549) five stages of an integrative review are as follows:

1. Problem identification
2. Literature search
3. Data evaluation
4. Data analysis
5. Presentation

The reviewer identified relevant publications in PubMed, Web of Science, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. Medical Subject Headings (MeSH) terms used to identify scholarly publications included: African Americans, Blacks, clinical research, clinical trial, perception, attitude, participation, willingness, enrollment, barriers, cancer, and oncology. Each article was critically appraised for quality using the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2018). Duplicate publications and articles that did not meet eligibility criteria were excluded from the review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram is found in Figure 1: African Americans' Research Participation Barriers and Facilitators.

Eligibility Criteria and Study Characteristics

Eligibility criteria included empirical and non-empirical studies published within the past ten years. Articles that included non-African Americans, non-peer-reviewed, comparison studies, greater than ten years old, and duplicates were excluded from the review. Two hundred and sixty-three articles were appraised and screened by one reviewer to meet the eligibility criteria.

Twenty-one articles (n=21) were included in this review, including ten quantitative, six qualitative, and five mixed-method methodologies. Seven studies assessed the effectiveness of interventions (Banda et al., 2012; Colon-Otero et al., 2011; Fouad et al., 2016; Holt et al., 2012; Kenerson et al., 2017; Smith et al. 2018; Yeary et al., 2018). Six studies employed theoretical frameworks that guided the study (Frierson et al., 2019; Holt et al., 2012; Kenerson et al., 2017; Kikut et al., 2020; Roger, 2018; Yeary et al., 2018). Six salient themes were placed under the central theme of research barriers and facilitators.

Identified Research Participation Themes

Barriers to Research Participation

Historical Mistrust

An analysis of the literature continues to reveal the ever-present historical mistrust and distrust barriers to African American participation in research. Overwhelmingly, fourteen of the twenty-one studies directly acknowledged African American participant distrust of research and research institutions. AA participant mistrust is related to historical mistreatment, research exploitation, guinea pig phobia, and research misrepresentation (Ahaghotu et al., 2016; Banda et al., 2012; Brown et al., 2013; Colon-Otero et al., 2011; Ewing et al., 2019; Farr et al., 2015, Frierson et al., 2019; Kenerson et al., 2017; Owens et al., 2013; Smith et al.; 2018; Sprague-Martinez et al. 2017, 2020; Kikut et al., 2020 & Roger 2018). The historical remembrance evokes feelings of fear and uncertainty (Owens et al., 2013; Sprague-Martinez et al., 2017). These findings are consistent with prior studies on AA participation barriers (Huges et al. 2017, Rivers et al., 2013; Luebbert & Perez, 2013).

An examination of the literature revealed additional barriers beyond the historical research abuse. McDonalds' (2012) study found participants fear exploitation and misrepresentation of their data within the research setting. In addition, the fear of being treated like a “guinea pig” or “guinea pig syndrome” is consistent with other studies (Sprague-Martinez et al., 2017, p.1098; Quinn et al., 2007, p. 191). However, in one study, despite this fear, AA participants acknowledged the value of participating in research and proceeded with participation (Kikut et al., 2020). In the final analysis, the literature continues to support historical mistrust as a salient barrier to AA participation in oncology research. A nuance that remains is the lack of breadth and depth of the impact fear has on AA’s self-agency to engage in research and self-advocate within the healthcare community. AAs' dearth of research knowledge and education compounds this barrier.

Uninformed or Ill-informed Research Participant

Nine of the seventeen studies determined that African American participants lacked pertinent information to make an informed decision to participate in research. Study findings reported that participants were unaware of study availability and not offered to participate in research studies for which they were eligible (Ahaghotu et al., 2016; Colon-Otero et al., 2011; Smith et al., 2018). Key findings included the lack of awareness of research study availability and poor health management by the primary care physician (Sprague-Martinez et al., 2017; Ahaghotu et al., 2016, Alhajji et al., 2020). A contributing factor to a lack of knowledge was physician bias of AA compliance or willingness to participate, resulting in decreased trial referrals and identified as an area for future research (Ahaghotu et al., 2016; Roger et al., 2019). The Niranjan (2020) qualitative study found similar biases and stereotypes within other members of the research team. Another congruent area among a few studies was patients’ concerns and lack of information about the randomization process (Ahaghoaltu, 2016; Frierson et al., 2019).

Logistical Barriers to Participation

In addition to a lack of knowledge, personal barriers contribute to a lack of participation. An analysis of the studies found participants who were contending with psychosocial, socioeconomic, and logistical barriers to participation. Several studies support AA cancer patients experiencing feelings of uncertainty and being overwhelmed by their disease process. Often these feelings are exacerbated by financial pressures and concerns of placing additional burdens on their family members (Alhajji et al., 2020, Banda et al., 2012; Brown et al., 2013; Sprague-Martinez et al., 2017; Owen et al., 2013). Logistical barriers included research time constraints, a lack of transportation to get to research venues, and variables related to living in lower socioeconomic neighborhoods with minimal resources (Banda et al., 2012; Fouad et al., 2016; Frierson et al., 2019; Yeary et al., 2018, Owens, 2013). Additional barriers found among a few studies included strict qualifying blood levels and comorbidities eligibility criteria that excluded participants from participating (Holt et al., 2012; Vastola et al., 2018). Understanding logistical obstacles are essential to developing research strategies to support AA participation in research. Conducting a needs assessment of and preemptively solving logistical barriers pre-study has been found effective in participant retention (Fouad et al., 2016). Despite the barriers, several studies demonstrated key strategies that facilitate AA participation in research.

Facilitators to Research Participation

Community Engagement

Community engagement strategies were identified in 19 of the 21 studies and found to be a critical motivator for increasing AA participation in oncology research (Fouad et al., 2016; Smith et al., 2018; Yeary et al., 2018). Demonstration of community involvement included research studies that utilized community outreach to identify and prioritize the needs of the AA oncology community (Farr et al., 2015; McDonald et al., 2012). Additional community involvement consisted of participant inclusiveness in research designs and study oversight (Banda et al., 2012 & Colon-Otero et al., 2011). For example, Kenersons' (2017), included AA women in the planning phase to customize the research intervention to meet the participants' cultural and linguistic needs. Furthermore, researcher visibility and longevity within the community were found to be vital to AA participation and trust building (Frierson et al., 2019).

Moreover, conducting research within well-known organizations with solid reputations that are embedded in the community has been found to be a facilitator (Yeary et al., 2018). Smith and colleagues (2018) used community members to recruit AA participants from events that were well attended by AA, including oncology support groups, cancer centers, and cancer awareness events. Furthermore, researcher presence and longevity in the community contributed to trust-building and avoided leaving the community feeling exploited (Frierson et al., 2019). Another facet of the community was the vital role churches played in promoting and conducting research (Colon-Otero et al., 2011). Pastor informants were found to be effective gatekeepers in engaging the AA community in research (Haynes-Maslow et al., 2014). Holt and colleagues' (2012) randomized control study increased AA perception of cancer screening by delivering cancer prevention education via a spiritually based message. It's important to mention, a closer examination found that AA women appreciated the spiritual-based approach more than men. Community inclusiveness within all phases of the research process has been shown to be successful in increasing AA participation and promoting positive research perceptions.

Interpersonal Communication & Educational Needs

Along with community presence, there are intrinsic factors that strongly motivate AA to participate in oncology research. Upon review, six quantitative and qualitative studies advocated for overeducating and personalized education as successful strategies for AA participation in research. Studies that delivered research education through workshops and oral presentations with increased researcher visibility had increased participation rates (Colon-Otero et al., 2011; Smith et al., 2018). Found et al. (2016) found patients' recruitment and retention rates increased through patient navigators that provided ongoing education and informed consent, and therefore, increased retention rates. One study found the use of a question prompt tool useful in guiding participants' decision making and discussions with the research team (Brown, 2013). Word of mouth and oral communication were also seen as important and aligned as an effective research strategy in a prior study (Jones et al., 2009). One emergent theme in an intervention feasibility study was that AA women wanted the educational audio card to reflect an AA woman's voice (Kenerson et al., 2017). Additionally, studies that employed educational workshops to educate and increase research awareness reported increased enrollment and recruitment rates (Banda et al., 2012; Smith et al., 2018). Effective communication is needed to build trust in the AA community (Hansen et al., 2016).

Culturally Tailored Research

Seven of the twenty-one studies used culturally tailored research strategies as a successful motivating factor among AA research participants. One example is the use of culturally tailored education and videos to simplify research consents and openly acknowledge historic mistreatment (Banda et al., 2012; Kenerson et al., 2017). The contributions from recruiting and producing research at minority-serving institutions were identified in the literature. For example, one study conducted at Howard University Cancer Center surveyed 200 AA participants and collected biospecimens from 79% of the participants (Ewing et al., 2019, p. 471).

Another promising area is using racially diverse research teams or race matched investigators (Fouad, 2018; Smith et al., 2018). Race matched patient navigators were used in a study to assist participants with their research needs (Frierson et al., 2019). A more nuanced understanding is needed regarding the impact of race concordance of AARP and AANS. A negative case revealed participants voicing concerns of using a ‘race concordance front’ and then finding out the research team did not authentically include diversity. The participant in one qualitative study reported feeling the study was devoid of transparency (Frierson et al, 2019). Overall, studies that used culturally tailored interventions and race matched research team members as facilitators to African American research participation illuminated positive results.

Discussion

A summation of evidence revealed salient themes of AA barriers to participation in oncology research related to historical mistrust, uninformed research participants and logistical barriers to participation. Moreover, there are facilitators that contribute to successful participation efforts, which include community engagement strategies, interpersonally tailored education, and culturally congruent research teams. When mapping out educational barriers to research participation, the review revealed inequities within the patient-provider relationship as well as the importance of personalized educational delivery as a mode of building trust within the AA community. Understanding the impact providers have on research participation warrants further exploration.

Strengths and Weaknesses

A review of the literature revealed strengths and weaknesses that will fortify research aimed at implementing effective strategies that support AA research participation. The literature search revealed five of the twenty-one study studies incorporating qualitative methodologies, and of those studies, all five used focus groups. Therefore, this lack of qualitative studies representing the individual subjective experience in research is limited and needs amelioration.

There is a need for participant narratives and counterstories from this population that seeks to have their voices heard due to population marginalization and oppression.

Moreover, very few studies (n=9) used a theoretical framework or a conceptual model to guide the research. The use of theory is pivotal, especially in nursing research as theory is used as a lens to conduct the research based on tested and proven theories. Several studies included in the review report AAs' mistrust and distrust towards the research and health community, and these findings are congruent with previous reviews and research studies. While some studies acknowledge the history of AA research abuse priori, several omitted the historical roots of AA mistrust of research. It's vital for researchers working with the AA community to be educated on the depth of this mistreatment to guide the study's design with cultural awareness and humility. While there are clear barriers in the context of historical mistrust, several studies had success in institutions with long-term reputations of being embedded in minority communities and using culturally matched investigators. This warrants further examination for a deeper understanding of these dynamics.

Strengths of the integrated evidence demonstrated that several researchers implemented community participation in various aspects of the research. Furthermore, community inclusion is essential to building the trust between the research and AA community. Future research on the impacts of community engagement on social behaviors is warranted. In addition, several studies acknowledged African Americans' justifiable mistrust and distrust towards the research and health community. However, the significance of how the distrust impacts the AA community outside of low enrollment and accrual rates lacks elaboration. These findings are congruent with previous reviews and research studies.

Implications for Practice

Several studies found race matching and race concordance as factors contributing to increased participation and investigator trustworthiness (Fouad et al., 2016; Frierson et al., 2019, Ewing, 2016). In addition, studies conducted in institutions where there were African American investigators and support for minority health reported high enrollment rates (Ewing et al., 2019). While race matching has been studied in the patient-physician relationships in the context of health care management, a more nuanced understanding of how race concordances impact the relationships of African American research patients would amplify our knowledge (Shen et al., 2018). Upon review of the authors of the study conducted in this review, we do not know how many researchers in review are Black people of color and of these studies. Furthermore, while African American nurse scientists are actively conducting research within the AA community, there is very little literature that examines their contributions to the body of science. This dissertation study aimed to identify and describe the nature and dimensions of the relationship and shared motivation factors, behaviors and interactions of AARP that influences research participation in the US that is inclusive of a historical reexamination of the context of AA in research participation through the eyes of a Black researcher.

Critical Race Theory (CRT)

Critical Race Theory (CRT) is of great significance to the pursuit of social justice and includes an activist agenda that recreates societal truths, pursues meaningful social change, eliminates inequities, and empowers marginalized populations. Furthermore, this critical epistemology aligns itself with a qualitative assessment of the narratives of AARP and the experiences of AANS. Ironically, this theory’s recent popularity and politicization warrant a detailed exploration that reveals an accurate understanding of CRT and delivers a compelling rationale for its significance in this study (Exec. Order No. M-20-37, 2020; Exec. Order No.

13950, 2021). Therefore, this section will describe CRT's origin, social development, central tenets, and its importance to the conceptualization for this study.

Critical Race Theory Defined

CRT is a social justice emancipatory epistemology that rejects historical and contemporary colonialism and politically constructed paradigms and creates new realities inclusive of culture, intersectionality, and gender differences (Crenshaw et al., 1995; Denzin & Lincoln, 2000). More specifically, surrounding the topic of racism within the Black community, the CRT premise is that the elimination of structural racism cannot occur without fully acknowledging its historical, political, and economical contexts (Delgado & Stefancic, 2012). In fact, CRT begins with the reexamination of history through Black eyes and interpretation also known as "new interpreters" that takes a non-neutral position and creates a renewed understanding of historical factors from a lens often erased by colonialism (Crenshaw et al., 1995, p. 319). Moreover, this action-oriented stance encourages racial challenges to recreate societal truths that contribute to meaningful social change and eliminate inequities identified within marginalized populations. Therefore, the tenets of CRT, which are often encountered in law and education, were used to underpin this nursing research study.

The Origins of CRT in the United States

CRT had its earliest beginnings in the 19th century within Foucault-Marxism critiques of social oppression and power dynamics (Alirangues, 2018). For this study, the focus was on CRTs beginnings in the United States (Bell, 1987). The critical turn in epistemology is grounded in historical and social events that evolved after the post positivism feminist movement in the mid-twentieth century and is an epistemology that aligns itself with social justice, human rights, and social revolution (Crenshaw et al., 1995; Lincoln & Guba, 1995; Power & Faden, 2008).

The 1960s was a time of civil activism by the AA community. As a result, organizations like the National Association for the Advancement of Colored People (NAACP) were engaged in changing segregation laws (Crenshaw et al., 1995). However, the 1970s efforts to change oppressive laws slowed because of neoliberalism and presidential pressure (Smith, 2019). During this time, Harvard lawyers Derrick Bell, Alan Freeman, Kimberle Crenshaw and others were black scholars who led CRT's new movement in the United States (Delgado & Stefancic, 2012). Their activism against racism was often seen as radical efforts. As Black intellectual students of law, they found their legal education emphasized traditional teachings from White men that lacked an in-depth examination of AA culture and truths (Bell, 1987; Crenshaw et al., 1995). In 1989, the theorists convened a study group to take a non-traditional, subjective approach to examine how racism dominates law within the United States (Delgado & Stefancic, 2012). Furthermore, these students took an activist approach to reexamine history through Black people's eyes and eradicate structural discrimination through activism (Crenshaw et al., 1995).

Major Principals of CRT

Attributes from CRT can be used to critique and create transformational changes in nursing research. While CRT was initially developed in the judicial and educational disciplines, the tenets can be used in other specialties to expose and eradicate inequities of marginalized populations. Delgado and Stefancic (2012) highlighted the six principles of CRT:

1. The normalcy of societal racism; therefore, the lack of awareness makes it difficult to abolish.
2. Society lacks interest in the abolishment of racial discrimination as it supports the psychological and material benefits of the privileged class.

3. Race assignment is a social construct and not a result of biological-genetic characteristics.
4. Stereotypes evolve with the political and social climate.
5. The voices of people of color are unique.
6. The intersectionality of identities presents unique challenges.

These tenets provide a framework that guides researchers to conduct research that will produce findings used as the basis for an activist strategy for meaningful policy development and social change. The tenets also allow for a profound historical reexamination of the context of AARPs in the United States. Critical race ideologies also underpinned the design, implementation, and dissemination of the findings for this study.

CRT's Conceptualization in This Research Study

Using principles of CRT, the researcher started the study with an extensive historical reexamination that revealed truths of AAs' situated context in research participation. This reexamination of history aligns with CRTs' first tenet, which acknowledges the ordinariness or normalcy of racism within the settings of AA research participation. Through the eyes of the Black researcher, a deep historical dive revealed counter stories of slaves and experiences of AAs in research that go beyond the repetitive exposure of stories encircling the Tuskegee study. This historical immersion has revealed a new written history that is inclusive of the AA population that has often had its history oppressed and erased.

Along with a historical review, the researcher used a qualitative descriptive approach that aligns with CRTs' inclusion of the subjective experience. Face-to-face interviews provided the data from AARP narratives and highlighted the contributions of AANS, which cannot be overstated. CRT premises elevated the AARP and AANS voices, guided by interview guide questions that explored the impacts of racism on the participants' health and participation behaviors (Crenshaw, 1995, p.63; Delgado & Stefancic, 2012). In addition, open-ended questions allowed for the examination of participants narrative for facets of racism within research, which allowed for structural racism, oppression, and subordination themes to be revealed during the data analysis (Crenshaw et al., 1995; Borrell, 2018). (See Chapter 3 for a detailed presentation of the Methods.)

The researcher analyzed the data from a critical stance and equity lens using an inductive approach while sticking close to the data; therefore, emergent themes that provided an in-depth description and a fundamental understanding of the phenomenon were identified (Braun & Clarke, 2006). The rich and nuanced data were possible with the integration of CRT into data analysis. The AA researcher conducted the analysis using an equity lens and from a space of shared experiences of racism. Moreover, taking a CRT's emancipatory approach to research, the findings from this study will be used to develop mentorship programs for up-and-coming AANS, create meaningful strategies to encourage sustain research participation, and guide new areas of research within the AA community.

Chapter Three: The Methodology of Qualitative Description

Introduction

Chapter Three presents the qualitative description methodological approach and examines the research methods utilized in this study. Therefore, a detailed examination of the study design, including the research setting, participants selection, data collection and analysis, research trustworthiness, and study limitations, will be discussed.

Research Methodological Approach: Qualitative Description

Qualitative description (QD) is the methodological approach for this study. The single-phase study design allowed for an essential historical exploration, contextualization of relationships, and detailed descriptions of new areas that answered the who, what, and why of a phenomenon (Green & Thorogood, 2018; Neergaard et al., 2009; Sandelowski, 2000). This methodology also aligned with the critical race epistemology in that it elicited the subjective experience and counter storytelling through participants' narrative interviews and integrated participants' historical accounts (Ford & Airhihenbuwa, 2018). Furthermore, the inductive six-step approach to thematic analysis guided data analysis (Braun & Clarke, 2006). Finally, the findings will be presented to the AA community and used for research strategy development, AANS doctoral student mentorship programs, and advocacy for social justice change (Graham et al., 2011). Before discussing the study design, it is vital to understand the impact the researcher may have had on the study.

Researcher’s Positionality

The researcher was the tool used to allow the participants to redefine their truths (Weaver & Olson, 2006). It was, therefore, crucial for the researcher to make a careful examination of their situated positionality by engaging in reflexivity to recognize their potential influence on research activities and participants. As an AA female nurse scientist with extensive oncology research experience at the National Institute of Health. I acknowledged the challenges of having the dual role as an insider, in relation to participants by the shared color of our skin and as an outsider, related to the ever-changing power differentials found within the researcher-participant relationship (Aluwihare-Samaranayake, 2012). In addition, I acknowledged my lived experiences with generational oppression, discrimination, and racial inequities. My reflexivity practices included engaging in reflexive writing, discussing researchers' reflections with committee members, and constantly considering how my biases and situated contexts may have affected the research process (Denzin & Lincoln, 2005). The researcher positionality awareness and reflectivity practices contributed to the depth and breadth of understanding how racial concordance impacts research participation.

Research Setting and Context

For this dissertation, the research was conducted in the context of a global pandemic. While it would typically be research conducted in settings of the participants' choice, it was of necessity conducted in virtual space. Moreover, all researcher-participant interviews were conducted and recorded using the Zoom cloud-based videoconferencing platform, employing COVID-19 social distancing restrictions to protect participants from undo COVID-19 exposure. Participants without computer technology available had the option of a telephone interview. Participants were encouraged to choose a quiet place for the discussion to provide confidentiality, participant privacy, and minimize distractions during the virtual or phone interview—allowing the participants to select the interview site attempted to level researcher-participant power differentials (Blackstone, 2012). The researcher conducted all interviews from a private office that was free from distractions and maintained the confidentiality of the participants.

Research Populations

The participants in this study were obtained through purposive sampling of AA across the United States. The researcher recruited two major human participants groups. Participants enrolled in the study were (1) African American Nurse Scientists (AANS) and (2) patients who have participated in health research, identified as African American Research Participants (AARP). Participants were asked their country of origin to ascertain differences in historical and cultural experiences that may impact their research perspectives. Therefore, the researcher did not exclude AA participants that self-identify as AA but not natives of the United States, as valuable information was learned from this population. In addition, the researcher decided not to exclude participants who chose not to self-identify their gender, therefore promoting gender sensitivity. There were no participants that expressed a refusal to the gender eligibility criteria question during this study.

Participants were excluded if they were unable to understand the research or consent process or if they were a member of a vulnerable group, including prisoners or pregnant women.

Eligibility Criteria for African American Research Participants (AARP).

1. Adults male or female
2. Age 18-85 years old
3. Self-identify as African American (AA)
4. Had a history of participating in research studies in the United States.

Eligibility Criteria for African American Nurse Scientist (AANS).

1. Adults male or female
2. Age 18-85 years old
3. Self-identified as African American
4. Held a PhD in nursing or a related field
5. Experience working as a principal investigator or co-investigator on a research study that has included AA participants in the United States.

Since the research question had to do with the recruitment of participants in research, race matching (the shared AA race between participants), and the scarcity of AANS, the study took a nationwide, non-categorical approach related to specialty focus of research for nurse scientists' recruitment for added protection of their confidentiality. Taking a non-categorical approach meant the researcher did not target nurse scientists from any particular specialty area like oncology for recruitment. This approach was used to protect their anonymity because the number of nurse scientists per specialty is small and thus, they could be identifiable. This non-categorical approach was used to recruit nurse scientists who have studied patients with chronic, life-limiting conditions.

Sample Size

Given the qualitative descriptive design, the researcher estimated that approximately 20 participants in each group would be sufficient to provide a robust data set. However, data were collected until thematic saturation was reached in each participant group (Glaser & Strauss, 1967; Malterud et al., 2016; Moser & Korstjens, 2018). A total of thirty-three participants were enrolled in the study, and thirty-three participants participated in semi-structured interviews. In addition, fourteen of the participants were AANS, and nineteen participants were AARP.

Participants who decided to use the phone dial-in option due to limited technology or personal preference only had access to the audio conferencing, which didn’t allow the speakers’ face-to-face visualization during the interview session. Giving the participants the option of web conferencing platforms increased participants' comfort and confidentiality, and reduced power differential barriers.

Research Participants

The recruitment period started in February 2021 was completed in October 2021, and the researcher recruited all participants. There were four male participants and twenty-nine female participants. Recruitment strategies were targeted towards the participant population, and researcher flexibility demonstrated attentiveness towards participant needs. For example, one participant could not access a computer to view the consent; therefore, per the participants' request, the researcher mailed the participant a paper copy of the consent for review. In addition, the researcher observed a few participants' email correspondence was written in large font; therefore, the researcher increased the font of email correspondence to these participants, increasing the visibility of the email. In addition to population-targeted recruitment strategies, both participant groups were recruited using snowball referral strategies as selected participants were asked to refer potential participants. Goodman reports these 'respondent-driven' techniques are helpful in 'hard to reach populations' (Goodman, 2011, p. 348, Goodman, 1961). Once potential participants were identified, an email invitation was sent, inviting the participants to participate in the study. According to their time zone, the email invitation was sent (8:00 am – 5:00 pm) during regular business hours using the duo method using University of Virginia’s provided email account and following the UVA-IRB-SBS patient recruitment requirements. Furthermore, in the era of a worldwide pandemic, research strategies had to be adapted to protect the participant's safety and research (Kim et al., 2021). Therefore, the researcher conducted all interviews in the virtual setting or via phone to protect participants from undue harm of coronavirus exposures.

Recruitment Strategies for AANS

AANS were identified and recruited through online searches, word of mouth peer networking, and email correspondence. An extensive online search and ‘mass email’ recruitment was used for AANS (Kim et al., 2021, p. 3). First, the researcher conducted an extensive internet search of the top ten research-intensive PhD nursing programs in the United States for potential research participants. Furthermore, additional internet searches included historically black colleges and universities (HBCU) with PhD nursing programs and various other Ph.D. nursing programs in the United States for additional AANS. Once the institutions were identified, a careful examination of the universities’ PhD nursing program staff and faculty web pages (which often contain faculty photos and bio-sketches) was conducted to select potential nurse researchers of color with PhD credentials. (Note: While visual inspection of photographs is a judgment call and potential participants may be misidentified, potential participants were then asked to self-identify their race and ethnicity to determine their eligibility). Also, their online profiles and curriculum vitae for published work, research, and relevant work experience with AA populations with cancer and other chronic diseases were reviewed. In addition, AANS scientists were identified and recruited using word of mouth strategies and snowball strategies. Word of mouth recruitment strategies were effective in AA recruitment (Jones et al., 2009). Additionally, the researcher approached nursing colleges to advertise the research study, which yielded additional research participants. The initial email correspondence began the multi-step consent process. Additional information is found under the consent process subheading. Furthermore, population-targeted research interventions will be discussed.

Recruitment Strategies for AARP

Community recruitment opportunities, social media recruitment, and snowball strategies were used for patient participants. A recent study revealed that AA research populations find increased trust in community organizations that are visible in their communities (Frierson et al., 2019). Through an extensive online search, the researcher identified the Healthier Black Elders Center (HBEC) in Detroit Michigan. This organization has a twenty-year history of improving the health of AAs, supporting research-participant partnerships, and is affiliated with local universities, Wayne State University, University of Michigan, and Michigan State University. After the HBEC community advisory board screened the researchers' research study, the researcher was granted access to 1200 potential patient participants from their participant database, see Appendix F and Appendix G. Participants that are part of the AA participant pool have given their contact information to the HBEC for possible contact by a researcher seeking to conduct research with AA participants. Research participant pool recruitment was a successful recruitment strategy to reach potential AARP participants from across the nation during a world-wide coronavirus pandemic when other strategies were unavailable due to the need to maintain social distance. In addition, to access the participant pool, the HBEC sent out flyers to all their participant pool members advertising the research study. As a result, a few participants called the researcher eager to hear more about the study and agreed to participate after consent.

In addition to the participant pool, the study was advertised using the Facebook advertising tool to disseminate research information. The potential participants contacted the researcher through the Facebook advertisement manager to inquire about the research study. This research strategy yielded 3 research participants. Challenges using this strategy were the increased number of potential participants interested in participating, but not eligible because of not having a history of participating in research. For more information about Facebook, advertisement see: Appendix L. Social media advertisements included the study's title, brief study overview, eligibility criteria, enrollment directions, PI contact information, IRB-SBS protocol number, and compensation information. In addition, the researcher also networked with former researcher colleagues for potential participant referrals.

Snowball techniques were employed to recruit participants from enrolled participant referrals (Kristensen & Ravn, 2015, Goodman, 1961). Research has shown that participant referrals effectively recruit AA participants (Otado et al., 2015). Therefore, at the end of each interview, the researcher encouraged participants to recommend other AA individuals they know who have participated in research studies (Noy, 2008).

All potential participant and participant-guided referrals were added and tracked on a spreadsheet for a detailed review before initiating contact. Recruitment followed the UVA IRB-SBS guidelines. The PI contacted all potential participants for eligibility screening by phone or email. Overall, participants enrolled in the study lived across the United States as no specified region was selected for participant recruitment.

Ethical Consideration and Human Subject's Protection

Approval for the study was obtained from the Intuitional Review Board for the Social and Behavioral Sciences (IRB-SBS) at the University of Virginia see Appendix E. The study was designed with minimal risk to the participant and attempted to maximize the potential benefit and contribution to science. The researcher used the following guidelines to optimize participant protection. The proposed study was reviewed and approved by the UVA-IRB-SBS outside reviewers to ensure study subject protection. The research followed UVA Zoom Security Best Practices to protect patient confidentiality during Zoom interviews. For more information on the UVA Zoom policy. This included creating a passcode required for all interview meetings, admitting all participants into meetings, turning on the "only authenticated users can join" setting, removing uninvited participants, and not sharing Zoom meeting links.

Additional measures were implemented to protect this AA population. The researcher emphasized the research study's voluntariness and omitted any potential coercive language in the consent process. The researcher made every attempt to display cultural humility throughout the study by openly acknowledging the history of trauma in the AA community. Participants were allowed to self-identify their race and ethnicity. The researcher consented all participants after full, transparent disclosure of study goals and potential psychological risks. All participants were provided the principal investigator's phone number and email address if they had additional questions before, during, and one year after the study.

Informed Consent

Following IRB approval, the researcher consented all eligible participants using the following consenting process:

1. Each participant was provided a comprehensive verbal description and full disclosure of the research study, including its risks in the written consent. See Appendix H and Appendix I. Due to the in-person COVID restrictions, the UVA-IRB-SBS oral consent process was followed for Zoom web conferencing and phone interviews as participants could not provide an electronic signature for the written consent.
2. Participants were informed that their participation was voluntary, and they could withdraw from the study at any time.

3. Participants were advised that the study included 60-90 minutes of recorded one-on-one interviews (in-the virtual setting or via telephone) with the researcher and may consist of a follow-up interview and member checking.
4. All interviews were de-identified to protect the participant's confidentiality.
5. Participants were advised that the potential risks from participating in this research study included the potential for emotional distress of recalling past negative or traumatic experiences during the interview, fatigue, inconvenience, and loss of privacy. Participants were advised that they may refuse to answer any questions or stop the interview at any time should they become distressed or fatigued; the interview may be split into two sessions if needed to address fatigue; the interview was scheduled at a time that was convenient for the participant and every effort was be made to maintain participant confidentiality by de-identifying all data and taking care not to use data examples that could potentially identify a participant. The researcher also provided additional counseling resources offered by Call Black Line as necessary (https://www.callblackline.com/) 1-800-604-5841. This is a black counseling hotline designed to meet the needs of Black people.
6. Potential participants were made aware that there were no direct benefits of the research to the participant; however, their perspective added to scientific knowledge and informed strategies to improve the research experience for others.
7. Each participant was provided a copy of the consent through email or mail for review, the researcher's contact information and advised to contact the researcher to answer questions that might not have come up during the consenting process.

After full, transparent disclosure of study goals and potential risks, the researcher consented eligible participants on to the protocol. For more information about the written consents see Appendix J and Appendix K. Every effort was taken to protect patient confidentiality and build trust between the researcher and AA participants.

Participation Compensation

All AA research participants (from both participant categories) who were enrolled in the study received a $25.00 electronic Amazon gift card for their time and participation. Funding that assisted with participant compensation was provided by the generous contributions from the Ann Taylors' Foundation from the University of Virginia (UVA).

Data Collection Procedures

Data Sources

Data were collected from semi-structured interviews and field notes from observations during each research encounter. All participant semi-structured interviews were conducted using either Zoom cloud-based web conferencing or telephone for participants who lacked access to technology. Zoom was selected for its multilayered security features and its user-friendliness for participants (Archibald et al., 2019; Nehls, Smith, & Schneider, 2015). In this research study, minimal technical problems related to connectivity difficulties were experienced during the interview. Turning the camera off to reduce the bandwidth usage seemed to correct and video freezing that occurred. Despite conductivity challenges, Archibald, and colleges (2018) found the use of Zoom for qualitative research an effective tool for interviews.

Semi-Structured Interviews

The interview was driven by the participant-specific interview guide using open-ended and probe questions and took approximately 1 to 1 ½ hours (Turner, 2010). Interview topics for

AANS included factors influencing career choice, personal commitment to research with AA participants, aspects of implementing protective measures for AA participants, their perspective on the impact racism has on AA participation in research, and how they manage their relationship with the AA participant. Interview topics for research AARP included motivational factors for research participation, storytelling on overcoming historical barriers to research participation, self-efficacy towards research participation, and impacts of race concordance research see Appendix H and Appendix I interview guides. Furthermore, the flexibility of the interview guides encouraged the exploration of topics and areas presented by the participant that were not part of the guide (Charmaz, 2014).

The researcher conducted interviews by phone and zoom conferencing. Given the COVID context, interviews via Zoom in the virtual setting prevented undue COVID exposure to the participants. The UVA Zoom security policy was followed to protect the participant's privacy. Moreover, measures to protect participants' privacy included the researcher conducting the interview in a discreet and quiet office, a closed door, and a white noise machine to maintain participant privacy. The respondent was asked to select a private room of their choice to proceed with the interview conversation.

Rapport building is essential for researcher-participant trust-building, therefore, the interview was started with casual introductory questions to balance power differentials and encourage participants to feel comfortable engaging in discussion. The researcher had a heightened awareness of the potential for the emotional distress of recalling past negative or traumatic experiences (surrounding the topic of race) and racism during the interview. In the present era of racial and political strive surrounding the events of the murder of George Floyd, the researcher was particularly vigilant to watch for participants' behaviors surrounding questions of personal experiences with racism so as not to cause additional emotional trauma. The researcher carefully observed the participant's body language for signs of distress (crying, sighing, and change in mood) to limit evoking emotional stress, preventing undue emotional harm to the participants. If the participant exhibited signs of emotional distress, the researcher would pause the interview and ask the participant if they would like to continue the discussion or move to a different question. For more information about the interview guides see Appendix H and Appendix I.

Interviews were digitally recorded and transcribed verbatim or by the Zoom transcription service. If the transcript was not available, the researcher deidentified and transcribed the interview verbatim. All recorded data was downloaded and stored in the My Passport for Mac portable hard drive storage device. The My Passport hard drive provides five terabytes of storage and is encrypted with password protection to protect the electronic codebook. A combination of interview transcriptions and field notes from observations provided data that captured the emic experiences of AA culture and participants' points of view, aligning with the study's aims to identify their relationships' nature and dimensions (Olive, 2014). All written materials were stored in a locked file cabinet located in my home office. All phone recorded interviews were recorded using the Zoom web conferencing platform. All phone recordings were deidentified, downloaded to the external hard drive. All Zoom web conferencing recordings and transcripts were erased by the platform 180 days after the recorded interview. Following UVA’s retention of research records guidelines, all records will be retained for a minimum of five years. All electronic records will be erased, and all paper records will be shredded and recycled, not before the 5-years retention period.

Participant Observations

Observations during the virtual encounter allowed for another dimension of data collection (Sandelowski, 2000). Observing participants' situated context, verbal, and nonverbal behaviors added to the breadth and depth of data collection by visualizing power and reciprocal dynamics (Denzin & Lincoln, 2013; Spradley, 1980). The observational data were captured in the form of written field notes. The field notes were brief notes taken before, during, and post participant interactions, including detailed descriptions of the interview setting, participant-research interactions, participant mannerisms, power deferential, and participant-researcher roles (Phillippi & Lauderdale, 2018).

Data Analysis

Braun and Clarke's (2006) approach to thematic analysis guided the data analysis. The researcher followed the following process for identifying, analyzing, and reporting themes:

1. First, the researcher became familiar with the data by manually transcribing and coding the interviews and field notes verbatim or by reviewing the Zoom-generated transcripts. Transcripts were reread multiple times while listening to the recorded interviews which allowed for data familiarity.
2. The data were expanded the using an inductive approach to generate and attach initial codes identified in the data.
3. By constantly comparing codes across interviews and codes with similar characteristics were grouped into categories and eventually, this process revealed early themes. To maintain a detailed audit trail, codes were traced by developing a codebook to track code and category lists, as well as analytic decisions.
4. A comprehensive review of the themes by the researcher and committee members led to decisions about the salience of themes and provided thematic verification. In addition,

participants selected as key informants were involved in member checking to review and provide feedback on salient themes for additional elaboration, clarification, and verification.

5. Throughout analysis, analytic memos were written to define codes, categories, and themes, adding context, and ultimately naming the definitive salient themes that crossed interviews.
6. Finally, the study findings were created and summarized to incorporate salient themes into diagrams that were reflective of the study aims (dimensions of the research relationship and shared motivational factors between researcher and participants that impact research participation) and inclusive of striking participant statements in the form of data illustrations.

The thematic analysis approach produced evidence that provides the framework for developing interventions directed towards increasing AA participation in research, designing mentorship programs to increase the number of AANS, and laying the foundation for policy development.

Study Rigor and Trustworthiness

The researcher implemented the following strategies that contributed to the trustworthiness of the research. To promote credibility (Lincoln & Guba, 1985), the researcher entered each interview with the goal of actively engaging participants to contribute to the depth and breadth of the data. The researcher conducted weekly debriefing sessions with the dissertation chair that elicited feedback on study progress and analysis. To verify themes, member checking was performed by asking selected participants to participate in follow up interviews to review and provide feedback on identified themes and data representation (Whitmore et al., 2001; Candela, 2019).

To ensure dependability, the researcher maintained a detailed electronic codebook, including a detailed audit trail of codes, categories, and themes with related analytic memos to track the researcher's analytic decision-making process throughout the entire study (Birks et al., 2008). The codebook included transcribed interviews, all coding, analytic memos, observational field notes, researcher reflexivity notes, and methodological notes on study logistics. Prolonged engagement displaying sensitivity to African Americans' historical mistreatment in research was necessary. The researcher reflected on potential personal biases by understanding her position and being careful not to sway the interview, data collection, and analysis process. This was actively undertaken as reflexivity practice (Gentles et al., 2014; Berger, 2013).

Findings were confirmed through discussions with dissertation committee members, other experts in the field, and member checking (Morse, 2015). The final analysis included salient themes with the inclusion of negative cases that reflects cultural difference from participants that self-identified as AA and were born outside of the United States. Transferability and applicability were examined by engaging the literature on similar studies for theme comparison and examining findings' congruence with prior studies. The establishment of the researcher's trustworthiness and credibility led to authentic and significant findings that may be used with confidence to guide further research, practice, and policy.

Study Limitations

This study reports the dimensions of the relationships of AANS and AARP and their shared collective commitment to improve AA public health. Moreover, this study included individual qualitative interviews that magnified AA participants' voices and subjective experiences in research. Many AARPs came from an AA participant pool; therefore, the findings may not be representative of the general AA population. The study included three male participants and 23 female participants; therefore, the study may be limited to the intersectionality experiences of AARP and AANS women. Despite these limitations, this is highly likely the first study to illuminate the role of the AANS in AA research participation.

Summary

Chapter Three adopted QD as the methodological approach for this study (Sandelowski, 2000). This approach allowed for a deep exploration of the subjective experiences of AANS and AARP and was inclusive of the CRT social positioning that underpins this study. Furthermore, Clarke and Brauns' (2006) six steps of thematic analysis provided the strategies used to analyze the thick, rich data from thirty-three AANS and AARP that led to the development of salient themes that described the dimensions of the relationship and explored the impact of shared cultural experiences of AANS and AARP.

Chapter Four: African American Research Participants (AARP) Findings

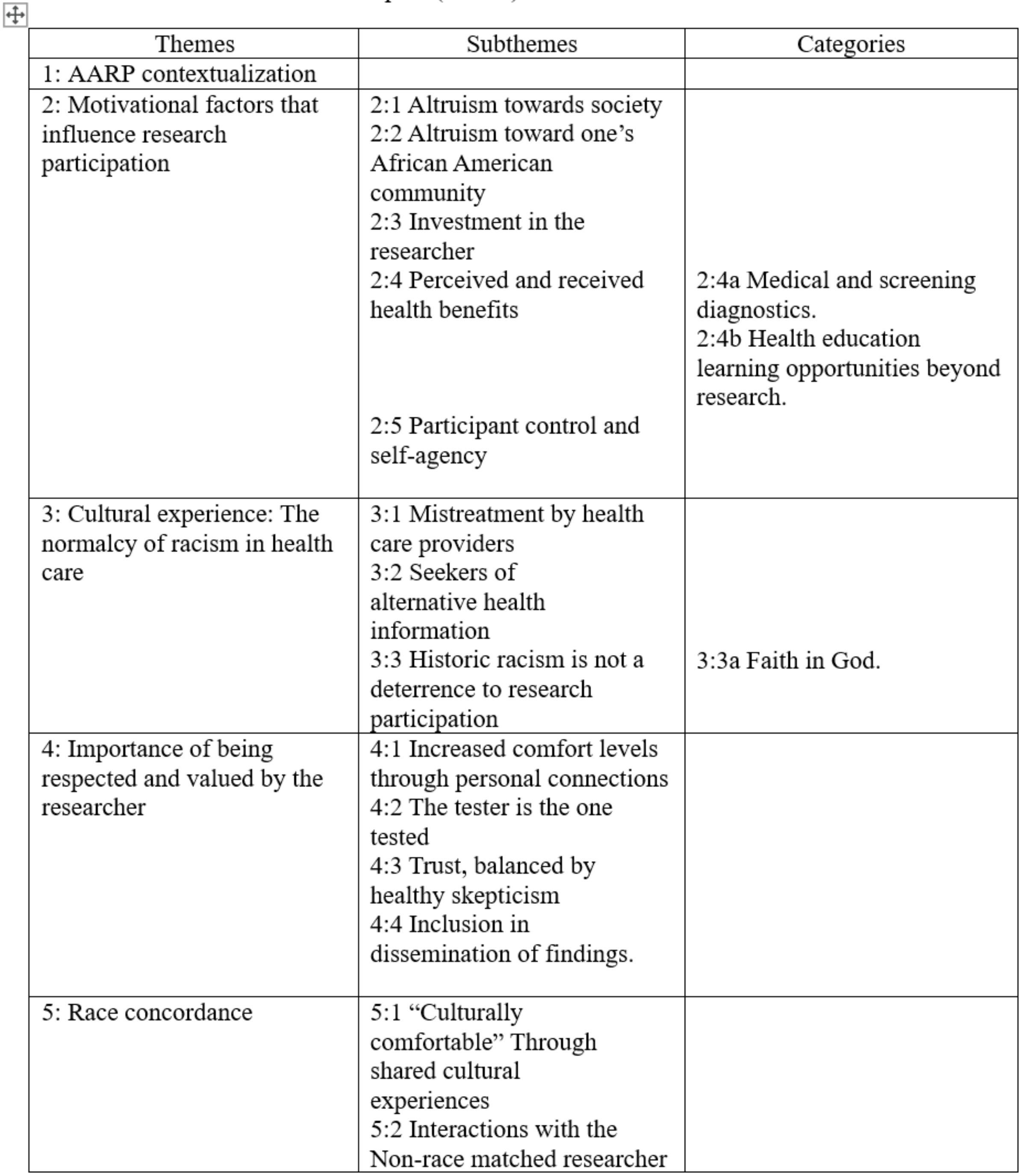
Chapter four describes the motivational factors of African American research participants (AARP) that facilitate their participation in research and the dimensions of the relationships between AARP and their researchers. The robust interviews generating 18 participants' narratives and observations provided the deep descriptive data for this study. In this section, I will discuss the context of the AARP and the powerful themes found within the data. See Appendix B.

A nationwide sample of eighteen AARPs who have participated in health research were enrolled in this study. Thematic saturation was met at around fourteen AARPs after conducting semi-structured interviews and taking an iterative approach to data analysis. Four additional interviews were included for thematic verification via member checking. After an exhaustive examination of the data, salient themes that motivated AARPs to research participation and dimensions of the relationships with their researchers that contribute to participation in health research were revealed and included:

1. AARPs' contextualization
2. Motivational factors
3. Cultural experience: The normalcy of racism in health care
4. Respected and valued by the researcher
5. Race concordance

Table 1:

African American Research Participant (AARP) Themes



Themes	Subthemes	Categories
1: AARP contextualization		
2: Motivational factors that influence research participation	2:1 Altruism towards society 2:2 Altruism toward one's African American community 2:3 Investment in the researcher 2:4 Perceived and received health benefits 2:5 Participant control and self-agency	2:4a Medical and screening diagnostics. 2:4b Health education learning opportunities beyond research.
3: Cultural experience: The normalcy of racism in health care	3:1 Mistreatment by health care providers 3:2 Seekers of alternative health information 3:3 Historic racism is not a deterrence to research participation	3:3a Faith in God.
4: Importance of being respected and valued by the researcher	4:1 Increased comfort levels through personal connections 4:2 The tester is the one tested 4:3 Trust, balanced by healthy skepticism 4:4 Inclusion in dissemination of findings.	
5: Race concordance	5:1 "Culturally comfortable" Through shared cultural experiences 5:2 Interactions with the Non-race matched researcher	

Theme 1: AARP Contextualization

A nationwide sample of adult AARPs participated in this research. Each participant self-identified as African American (AA), resides in the United States (US), and has a history of participating in health research. AARP were recruited using Facebook advertising, word-of-mouth, snowball sampling, as well as recruitment from the research collaboration with Michigan Center for Urban African American Aging Research (MCUAAAR), Healthy Black Elders' research participant pool located in Flint, Michigan. The AARPs' ethnicity included AARPs born in the US and born outside of the US. Their ages ranged from 18 to 85 years old. Interviews of AARPs were conducted from February 2021 – October 2021 during a national pandemic and in an era of racial strife in the US. In addition, all AARPs had participated in research that involved researchers or research team members who were AA.

Moreover, the AARPs who participated in this research study are experts in research participation and graciously shared their research experiences in health research as evidenced by a few participants who reported participating in over 20 research studies (29, 24), while other AARP participants reported participating in longitudinal health research that has spanned more than 2 decades (23, 27). Another AARP reported participating in research in the 1960s when researchers went “door-to-door" to recruit research participants (20). Therefore, their experiences and perceptions provided a robust data set that included their perceptions and lived experience surrounding their research participation.

AARPs awareness of research opportunities originated from their actively seeking out research studies or recruitment efforts by researchers who used various research strategies that included recruitment participant pools, research registries, higher education research, and word-of-mouth recruitment from family and friends in their close social network. Participants who reported actively seeking research searched for research using the internet, including Facebook (7, 8) and YouTube advertisements (7). Several of the AARPs were members of research participant pools, university, and national research registries. While the pandemic halted in-person research for several months, AARP reported research participation during the pandemic reduced research challenges related to travel (27) and increased their desire to participate as many found participating in research during the pandemic to be a way to combat isolation from social isolation and national COVID social distancing mandates. One AARP expressed,

> *"The one I did last year, around this time. I mean that was a great relationship between the researcher and I, you know I really enjoyed speaking to her on a weekly basis and discussing my issues, and you know she had a lot of good ideas, and I think the idea of just someone to do this. Okay, I think that's very, very important for someone to listen, sometimes you don't always need someone to throw out advice, sometimes you just need somebody to listen, and I think that was really important, you know with that particular study that she listened. And that's what I needed at that particular time, was someone to share and listen to my feelings, and I can just pour out what I was feeling. You know, after being stuck in the house, I think that was already a month into the pandemic "(31).*

The AARP came from various educational and social backgrounds including those with high school to graduate level educations. Several AARPs held leadership roles in Black communities, including leading groups that provided emotional support, access to resource opportunities, and supplemental health information to their members. In addition, several of the AARP reported coming from large families where they took on long-term caregiver roles, including the elderly caring for multigenerational family members.

Theme: 2 Motivational Factors That Influence Research Participation

Motivational factors that influence AARPs to research participation are the interactions, behaviors, and research relationship dimensions that encourage AARPs to participate in research. These factors also contribute to AARPs' willingness to enroll and self-efficacy to participate in health research. Factors that motivate AARPs to participation in health research included altruism towards improving population health in the community, altruism towards one's own race, investment in the researcher, perceived and received health benefits, and the participants' control and self-agency to participate in health research.

Subtheme 2:1 Altruism Towards Society

Altruism towards the community drives the willingness to participate in research studies with the goals and hope that the research will add scientific knowledge to improve population health. Dimensions of altruism in this study involved a process in which the AARP acknowledges historical maltreatment in research and then, has the ability to put personal feelings of fears and disabling skepticism toward research participation aside, which allows them to actively participate in health research as a way to improve population health for the "greater good." Furthermore, it includes the possibility that the participant may not benefit from actively participating in research but continues out of their hope that their research contributions will not be in vain but will help people in the future. One AARP described focusing on the greater good of helping others despite not seeing immediate results when she stated:

> *"We can't always have instantaneous results, but we have to realize that it could help your children, your grandchildren great-grandchildren, or is it just people that you don't even know and the whole thing in this world is to help someone as the song says, if I can help someone on the journey, then my living*

> *will not be in vain and that's what I try to live each day, I want to make sure that I've helped somebody, down the road because somebody helped me at one point." (24)*

Another participant described the ability to put fears of participation aside to focus on the importance of participating in research when she said,

> *"I really don't want anyone cutting a piece of my hair. I really didn't want a needle stuck in me because I told her I bruise easily, but I said, well, okay if it's going to benefit, you know how one person can make a decision, but it affects and benefits so many, so you were looking at the bigger picture. This is going to benefit more people than I could ever know about, so that's why you do it." (22).*

Another participant shared the same sentiment,

> *"So, either you still participate and forget about my feelings, you know just look at the bigger picture, because now, I have a son, you have young people under you. So, you want it better for them, so you look toward the future. Yes, that's why you participate." (22)*

Despite the skepticism and fears related to historical research mistreatment, AARPs' desire to help future generations elevates them to participate in health research. This form of healthy skepticism is discussed later in chapter 4 under the subtheme entitled trust, balanced by healthy skepticism.

Subtheme 2:2 Altruism Toward the One's African American Community

An additional dimension of altruism towards the great good of the community is participating in research to specifically improve the health of the AA community. Dimensions of this attribute are AARPs' awareness of the health disparities experienced within their families and the health conditions that impact their AA community. Overwhelmingly, several AARPs spoke about the devastating impact and death from diseases such as cancer, diabetes, hypertension, multiple sclerosis, and the acute onset of COVID-19 had on their families. As a result, many AARPs spoke to their roles of contributing to their AA community through research participation. One participant said,

> *"Well, I wanted to do whatever I could do to help any cause that would benefit my race. As a senior, whatever needs to be done to assist us and whatever might be available to us. So, I just decided to do my part and whatever I could do to assist and, if I can make things better for others who are like me, I'd like to do that." (19).*

Several AARPs spoke to the greater good of helping future generations' health despite the awareness of historical maltreatment in research and encounters of racism in the health care system. When asked how she overcame the fear of research participation, one AARP stated,

> *"I trust in my Father to maintain. I guess I'm just positive and see the glass as half full all the time. You know. I try to look at things from a positive perspective, but with common sense. I looked at if we don't have researchers if we don't have people who try to help find cures and medicines and whatever else, how are we ever going to accomplish what we need to accomplish in this life. And I feel like God gives these people researchers, such as yourself, they give them the knowledge to go in to learn and listen, and I think that that's what I look at and so any kind of way that I can help. I'm always available." (24)*

AARPs altruistic feelings and behaviors contribute to their participation in research studies on a weekly and monthly basis, and for others to participate in long-term research studies that span over decades. For several research participants, their participation demonstrates their leap of faith in God that is coupled with “common sense” (24) that enables them to engage with the research community.

Subtheme 2:3 Investment in the Researcher

Investment in the researcher is the altruistic sense of responsibility for the success of the AA researcher, including AANSs. A dimension of this investment in the researcher is that AARPs decide to participate because they view the researcher as the necessary link towards their primary goal of improving the community's health or the health of the Black community. In addition, several AARPs expressed feeling proud to witness the AA researcher in spaces in which they were not allowed historically. This investment includes participating in the AA researchers’ study and verbalizing the AARPs contribution to the researcher’s research, which will improve the researcher's life. One AARP spoke of the investment in the researcher when he said,

> *“Well, I think I'm like you. Is this for your graduate studies, right? Yes, now the information you're getting from me, I don't know if you have other people participating all so. You can do your comparison, and whatever it is, you know your statistics, or you're whatever, so you know I just feel like I'm contributing to helping you get your education, and you know your quality of life is going to be better also. I was getting my master's in education when I was doing my master's thesis in my study, so you know it's just something that I don't mind helping people with at all.” (11)*

The AARP feels a sense of obligation to ensure that the researcher is successful, which is verbalized by both the AA researcher and the participant. The success of the AANS is vital as the AARP knows their participation will be linked with the AANS completing their educational goals of doctoral degree attainment, which contributes to the greater good of improving the health of the AA community through research participation. Another AARP expressed,

> *"I felt good about doing it in the first place, I did the research, and they are usually they're really excited. Okay, I help somebody get their grades together or you know get the papers done. Basically, my hope is that they are able to do something good with the information they collected from all of these individuals"* (28).

Another research participant expressed, *"I enjoy it (research) because I feel that I'm helping you know the researcher meet their goal"* (11).

Subtheme 2:4 Perceived and Received Health Benefits

Another solid motivational contributor for AARP research participation is the perceived and received health benefits that the participant described while enrolled in the research study and the continued benefits to health after the research is complete. Two dimensions support the added health benefit received by AA participants of research: diagnostic tests and procedures and health knowledge used to promote health post-research. One research participant spoke about how her mother benefited from research when the research diagnostics scan found a tumor. She said,

> *"Like I said, that's one thing that really, really helped my mom in terms of finding that tumor. You know, she's one who always kept up with her doctors' appointments, and you know that sort of thing, but it was something that there were no symptoms, no pain, nothing even to indicate that there was something there. You know, just that was not something they were actually looking for, they*

> *just did a lot of scans and stuff as part of the study. And that's how they found it."* *(31).*

2:4a Medical and Screening Diagnostics. Some of the invasive health research require medical and health screening therefore participants that participated in research that provided medical and diagnostic studies received the added benefits of access to additional specific health care. Examples of medical and screening included obtaining serum blood specimens that required medical-researcher oversite and diagnostic therapies. One AARP reported appreciating the benefits of dental care when she said,

> *"I don't do a lot of invasive if it's invading my body, I don't, but I did do a dental one at one point, and that worked out very well for me, you know, I got a lot of free dental work done. And then it helped them to keep track to see how this medication was affecting me as an individual and as an African American." (24)*

Another AARP spoke of the blood work done during research that provided valuable research and information about their current health status,

> *"Because you know, based upon studies or evidence there's no cure for us, so the study that I signed on first was a natural history study where they would study you, because I didn't have any symptoms, they would study, like the pathway of the disease with minimal intervention. I was not on any medications or anything I would do like every six months, I would do labs, and they would follow the trajectory of my disease." (6)*

Another AARP spoke about the medical benefits received from participating in a hearing research study,

> *"I did a hearing study with another university. It was a very comprehensive hearing examination, and we discovered that there was just a slight hearing loss in my right ear. I had no idea, you know, and I wore a device for almost two months that enhanced your hearing. I took the results to my doctor, and it's something that we're monitoring to you make sure it's not getting any worse, but you know you never know unless they did that comprehensive testing again, but it was just something that helped me." (31)*

Several AARP spoke to the additional medical information received from research diagnostics studies and medical procedures surrounding research that motivated their participation in research. It is important to note there were no AARPs that reported using it as a primary source of health care but rather an added benefit.

2:4b Health Education Learning Opportunities Beyond Research. Health education learning opportunities are additional benefits that AARPs received from participating in health research. Furthermore, the benefits gained from research health education exceeded the boundaries of the research study as many AARPs reported incorporating health exercises, health care management strategies, and utilizing tools provided during the research study into their daily practices. Health management skills and tools came in the forms of written literature, follow-up health information delivered on phone trees, health videos, health safety tips, self-care tips, and health technology which contributed to motivating AARP to continue participating in research studies (23). Participant (31) spoke about how she filed research literature in her file cabinet to reference. Another participant talked about the importance of receiving daily exercise information, which encouraged her to increase her exercise,

> ***"****Okay, because I participated in the survey. The people called me, and this is what they said to me, you are not exercising enough, and I was like what? And someone said that's because you filled out the survey, and it just so happened just before they call I had just started increasing my exercise, so I feel good, then I said, well, I got them because I started before they called and said that Okay, I guess they read my responses and said she's not including enough exercise and I try to do it every day, I try to do it when I'm flipping pancakes, I try to do it while I'm waiting for the washing machine. You just find any and every kind of opportunity, you can even at the bus stop do your exercising, and I feel better because they said it releases those happy hormones."* (22)

Another AARP explained how the health information received from the research encouraged her to recenter and focus on her health when she expressed,

> *"The study was about two months, and we were given a handbook. And in that handbook, we discussed different types of exercise, for example, Chair exercising, walking, swimming and also things that could influence us too. Just perhaps do other things that would enhance the exercises, for example, meditating, deep breathing, recording our steps… things like that, so that was my most recent research project. You know what it did for me? Put me back on track, because I, I still work, and my work is very stressful, and it takes a lot of my time. More than an eight hour my workday is generally around 16 hours yeah, and so it kind of put me back on the path to put more attention on me, because everything is outpouring, and nothing was going in. So that was yeah, and so it kind of put me back on the path to put more attention on me, because everything is outpouring,*

> *and nothing was going in. So, that was my motivation to participate, and it didn't fail me because I would get weekly phone calls and then these weekly phone calls or check-ins, I would share what I had done for myself to get some exercise and I would read a chapter in the book and share my thoughts on the chapter and talk about. They would give suggestions and different links on how music can influence exercise, exercising inside, like chair exercise videos, and walking with safety tips-- it just really put me back on track to take a little bit of time out for myself to get back into you know, providing some physical movement in my life so that's what I enjoyed and that's what it did for me." (23)*

The exponential benefits provided by research motivated several of the AARPs to participate in research. Benefits included those received from medical treatment and diagnostics and, more importantly, those skills and encouragement acquired from health opportunities designed to motivate participants to be active in improving one's health.

Subtheme 2:5 Participant Control and Self-agency

A detailed examination of the data revealed that AARPs are motivated to participate in health research because of their ability to control the decision-making process and have the self-agency to decide to whether or not to participate, therefore directing how they contribute and assist future generations. Dimensions of the participant's control and self-agency are their ability to exercise their freedom to choose the type of research they participate in and their freedom to give their opinions in health research as they are considered the experts of their lived experiences. One AARP reported, *"My decision to participate was actually my decision. I thought it was something interesting and the fact that I was able to give my opinion and be compensated for it."* (7)

Several of the AARPs appreciated exercising their abilities to choose the type of research they would like to engage in, therefore having control over how they decide to help future generations through their research participation. In addition to exercising their choice to participate, several AARPs expressed deciding to participate in health research on their own without including others in their decision-making process. As one AARP said,

> *"My husband, I was married for 48 years, and my husband passed away two years ago. He and I did a couple together. One about financial things, and he even enjoyed doing it, and usually, men don't want to do stuff like that. But he did, and he was surprised at how well he did and how well he came out. So, no, I make my own decisions about that." (30).*

The participants want the freedom of expression without judgment. A part of choice within research includes the participant freedom to give their opinion even if it doesn't agree with the researcher.

Theme 3: Cultural Experience: The Normalcy of Racism in Health Care

Cultural experiences that impact AARP lives and health include the normal culture of racism in health care. Participants described this culture as the repetitive, multifaceted, and all-consuming impact of racism on the AA individual and community's health in the United States. It's important to acknowledge the impact of racism on AA health is synergistic with other forms of racism (income, education, housing, employment, and social position) that are experienced by the AA in the United States, which includes the justifiable distrust AA have towards participation in research. As one AARP expressed,

> *"I don't think Black people get the same care that Caucasians do. It's so much systemic racism it's culturally built into the system. Even when it's staring*

> *you in the face it might just seem normal because this has been how it's always been done. But there's been an awakening and there's a gap in race as it is in economics" (28)*

Participants were eager to discuss the pervasiveness of systemic racism in their health care experiences as they discussed their research participation. There were numerous accounts of AARP experiences of mistreatment at the hands of their health care providers. It's important to note the connection that health care providers have with research as a few AARPs verbalized viewing healthcare and research as one entity. As one AARP explained,

> *"In the Black community, we have a lot of trust issues. When it comes to this medical stuff that you are doing this research stuff. We think it's medical, ok. And because of the lack of medical attention or needs that we've gotten throughout the years and not getting the right information or the full information, there's a lot of mistrust." (12)*

Navigating without a trusted health care system leaves some participants feeling alone and without agency, especially for participants with multiple health problems or those who are acting as caregivers. Several AARPs described untoward experiences with providers, including feeling overmedicated (12), being the victim of falsified medical records (6), being misdiagnosed (20), lacking provider touch during examinations (24), being physically harmed by providers (23), and additional bad experiences that linger in the memories of AARPs (22). Moreover, a deep analysis revealed these experiences impact the AARPs in two ways: 1. Racism experiences influenced AA self-efficacy to engage with the health care system, which caused several AARPs to rethink healthcare interactions or 2. Racism experiences empowered self-advocacy, which contributed to their use of grassroots sources of healthcare (including the grass root researcher) that are outside of the health care system.

> *"As one AARP express, "There are some Black people I know that will not take the vaccine. You cannot pay them to take that vaccine because they don't trust the medical community. You got some people that won't see a physician. They will do herbs and chants and different things but will not see a physician." (28)*

It's important to note, there were three negative cases in which AARP did not report encountering negative experiences with the healthcare system. When examined further, these AARPs reported having good health insurance (11)(30)(31).

Subtheme 3:1 Mistreatment by Health Care Providers

The recurring personal encounters of the normalcy of racism in health care was exemplified by AA experiences of mistreatment at the hands of health care providers. Dimensions of abuse were found within the patient-provider relationship which included patient mistreatment, leaving with feelings of being devalued during medical visits, and experiencing delayed healthcare. One AARP, while reflecting on numerous negative health care encounters expressed,

> *"Personally, I had a good five, or maybe more negative experiences with the medical field, negative, capitalize it, underline, exclamation mark, neon lights, sky write it, I don't care how you do it, it has been terrible, it was unnecessary, it was mean spirited so I feel that me giving the way I give is just because God has blessed me and I have an understanding and a love for humanity period. But I*

> *draw the line on a lot of things just because I know what has happened in the past and what has happened to me personally in my life with the medical field." (23)*

Another AARP shared her story of delayed care when she made numerous visits to the emergency department before finding an AA physician who would diagnosis an acute health condition. The AARP explained,

> *"It took about four visits to the emergency room before anyone can really tell me what was really going on and the person that broke it down to me and told me what was going on, was indeed an African American doctor. And the other doctors were course Caucasian, but they kept telling me oh nothing's wrong, but something was wrong because I had all these symptoms. So, I really felt uneasy about this, you know I said, thank goodness, I finally got a doctor that told me what was going on and actually help me get through the infection, prescribed medications, and everything. But I found that this never sat well with me. That it took an African American doctor to really tell me what was going on and all the other doctors who were Caucasian was telling me oh nothing's wrong with you, you know it'll pass whatever, so I did not feel good about this situation. And I felt that race did have something to do with it." (7)*

Negative AA patient-provider encounters throughout this study left the AARP feeling *"underestimated"* and led to distrust. One AARP compared her story of health record misrepresentation to a well know research abuse when she expressed,

> *"Some of the symptoms that he had listed, found in my medical records were not true...It could be because I'm Black, so they underestimated. Some*

> *people say she's Black so I can do this, like that Henrietta case that they took her cells. Or maybe they never anticipated I would ask for my records, but I did." (6)*

Subtheme 3:2 Seekers of Alternative Health Information

Interestingly, a positive behavior that has risen from the normalcy of racism within health care is that the AARPs sample population sought alternative means of health improvement and management by creating close social networks that incorporated health education and advice. Seekers of alternative health information includes the grassroots organizations designed to improve AA population health through social interactions in social support groups. Health information was sought in two major ways: organized social groups and the novice researcher. The participants in this study described Black community organizations, town hall meetings, and research that provided facets of health information, research opportunities, and health activities that the AA community utilizes in close-knit social circles. Gatekeepers oversee the group's activities and operate to assist the group in attaining resources that include speakers that provide health information. These groups are connected to large numbers of AA within the community. Therefore, the information one AARP receives from the social group often impacts multiple members of the AA community that includes multigenerational family members and friends within the AARPs' close social network. For example, one AARP shared her experience from participating in this research study and via word of mouth, four additional AARPs phoned and emailed requesting to participate in this study. They advocate and provide information to their members. On AARP spoke of the rippling effect on the health of the community through attendance at town hall meetings when she shared,

> *"There was someone that a young man had been to a town hall meeting about COVID 19 vaccinations, and you know, it took, I guess, multiple people talking to him, and then, finally, this town hall meeting for him to be convinced that it was something he could do, and mother was with him. She said it was kind of a snowball sort of thing; once he said he would do it, she agreed, and then she talked to a friend, and yeah, I think that we're going to get that person to get vaccinated, so you have to keep at it. The researcher said the same thing; she was one of the doctors that helped develop the Moderna." (18)*

The second form of seeker was the grassroots researcher-- an AA community member without formal training that has identified a health need in the AA community and sought to gather and share the stories of AAs' health recovery. One AARP engaged in her own research that included videoing interviews and disseminating video findings to assist the community. This AARP verbalized seeing several people in her community succumb to a specific health condition and wanted to help the community understand that people have survived the disease. Therefore, she videotaped nine AA community members telling their survival story and how they combatted the disease. In this way, she helped others to navigate symptom management and provided encouragement to those dealing with a health condition that has the potential of causing unpredictable debilitating symptoms and death.

Subtheme: 3:3 Historic Racism is not a Deterrence to Research Participation

Despite the awareness of various accounts of research mistreatment of AARP, these participants were not deterred from participating due to historical racism—they continued to pursue and participate in health research. One AARP expressed,

> *"Well, I look at it, like the people that were involved back in those days, you know I just look at it like that old saying, two wrongs don't make a right. I'll put it that way, so I feel many of the people that did that back in the day were wrong, but today, you know, we have more people more educated and have done, like you say, research and tried to make it better, you know for the Black race, so that's how I look at it today okay."(32)*

Several AARPs in this study verbalized their understanding of the history of AA mistreatment in the US, either by calling the research study by name or describing the events around the mistreatment. Factors that contributed to their ability to move past their awareness of historic racism in research included the open acknowledgment of the history and moving forward by focusing on the greater goal of improving population health. One AARP expressed how she prioritized research over the historical stories of research mistreatment when she explained,

> *"Well, I'm always one of those people that think it's just important to know what's going on with myself, with family, friends, and whatever, and I think it's important to know what's going on in the world. I do know about some of the cases so far and about. We hear about the Tuskegee and different things. We know that was so many years ago, but it's still relevant for a lot of people. Still, I think that research is important because we need to know how our bodies work, our mind's function, how we do things as well as other people, so I think it's just important. I have participated in several different ones as far as monetary, how we conduct our business, how we do things in our family life, how we feel about the environment, all those different things and we're important people too, so why shouldn't we participate? We have to." (30)*

Therefore, this patient felt the absence of participation was the absence of AA representation. Another dimension of trust is being upfront with the acknowledgment of historical mistreatment. For the AARPs born outside of the US, they were aware of the historical mistreatment of AA in research participation and were also able to share perspectives of unethical research outside of the US. One AANS expressed,

> *"One of the major challenges that we face is the historical backdrop that influences Blacks and African Americans' decision to engage in research. And, of course, specifically talking about the Tuskegee study, among others, so there's has always been a level of mistrust between researchers and participants. And, and also the fact that perhaps initially we're doing a better job, but we're not there yet, but at least we're doing a better job now….I don't know whether you know this, but South Africa was one of the countries that was included in one of the studies for pharmaceuticals. When they started providing the vaccines it's only about a couple of weeks ago that South Africa had some of the vaccines to give to their own people. So those are the kinds of things we need to be careful. I guess that's one of the reasons why blacks hesitate to be part of studies. So, you engage them and then they are last in line to get the benefit from it." (3)*

One AARP suggested, using the "business model" (8) of being upfront with participants about historic mistreatment, then moving the conversation to the more relevant points.

3:3a Faith in God. A few of AARPs spoke to their spirituality (24)(23)(28) as the vehicle that helps them move past the untoward history and participate in research. One AARP stated,

> *"and I feel like god gives these researchers, such as yourself, they give them the knowledge to go and learn and to listen, I think that's what I look at, so any kind of way that I can help. I'm always available to help with doing this, you know, but I'm a helping type person anyway, that's the field that I come from. I just believed, and I'm a firm believer to whom much is given, much is required."(24)*

Theme 4: Importance of Being Respected and Valued by the Researcher

When the nature of the interactions with the researcher demonstrate that they are truly respected and valued, AARPs feel motivated to participate in health research. Dimensions related to feeling respected and valued include feeling increased comfort through personal connections with the researcher, autonomy over participation, passing the trust test as the tester (or the researcher) is often the one being tested, healthy skepticism and inclusion in research findings dissemination. The level of respect perceived by the AARP is fluid and dependent on the type of research design and the interaction had with the researcher. In addition, increased time spent with the AARP may contribute to AARPs feeling valued by the researcher. One AARP expressed,

> *“Everybody wants to feel they have value. A lot of your participants may not even graduated from high school. A lot of them have had, which is one experience, not just high school. I have never had where I felt I was stupid; I wasn’t as smart as someone else. Coming up, of course, we were known for our strength and endurance of bad times. Yeah, definitely has been change, but a whole lot of them are still doing mediocre jobs just to get through. You know, thankless jobs. So, they feel, why would they want to listen to me? They just want*

> *to get money for research, or they are going to get this and do what they want to. They are just using me. Let them know they are of value". (27)*

Subtheme 4:1 Increased Comfort Levels through Personal Connections

AARP described the increased comfort level with their researcher which was developed through efforts to make personal connections. Both verbal and nonverbal dimensions are associated with the AARP's feelings of increased comfort with their researcher over time. It's important to note that one AARP highlights the importance of "feeling culturally comfortable," which will be further discussed under the AARP Race Concordance theme. As one AARP stated,

> *"You have to be comfortable with the research in order to feel comfortable to share some things. You know, some things are cut and dry if you are doing these numbers, but if they are asking how you are feeling about certain things, you have to be comfortable. You can't share everything with everybody. So, I think that comfort level is important. You have to spend a little time to get to know them which of course you did before you just launched right into it. You have to do something to establish that level of comfort and to be a good listener and a good questioner." (18)*

In verbal interactions between AARPs and their researchers, the AARP is assessing the researcher's presentation and controlling the ebb of participation information given to the researcher. One AARP described how the researcher's presentation matters,

> "*Presentation makes the difference. When it comes to research, if you just want to do this, want to do that, and none of that straight up, just relax a little bit,*

> *let me hear it in your voice, let me hear it in your tone. As you can see, I'm that kind of person. I like to make a little laughter, to be happy. Because if I'm in my happy place, you can get what you want. If I'm not in my happy place. You only get what you ask for, and you may not get the fullness of it. Because you're not making me feel like you are serious, or I could trust you with this." (12)*

Increasing AARP's comfort level and connectedness also pertain to the type of research questions asked. One AARP provided suggestions on the types of personalizing questions to include in research, when she said,

> *"Put something personable into those questions, or when you meet that person, or into that visit. Not, making it all it's about the labs and the results, you know. It's how are you doing? How is the family? And, how you've been feeling? To be honest, that's the feeling that I get from the nurse practitioner that follows me. I can always call her. Whatever I need I call her. She has always been attentive. She made me feel valued and cared for beyond the science, beyond the research, and the PI too, I mean ever visit he's always, well I haven't seen him since COVID, but every visit he's always there. He always sees me after I see her." (6)*

In addition, an AARP participant's feeling comfortable with the researcher includes the nonverbal interaction in the researcher-AARP participant relations that includes the increased openness and transparency of the researcher. Several AARP expressed the importance of their researchers' body language openness and its contribution to increasing comfort between the AARP and researcher.

Subtheme 4:2 The Tester is the One Tested

The AARPs described positioning themselves in a vulnerable position that comes with participating in health research. In turn, the AARP expected the researcher or research team would see their humanity and protect them beyond the boundaries of research by maintaining their confidentiality and using their data in a way that helps others. Several AARPs engaged in testing the researcher to see if they were worthy of trust and of their participation in research. It's important to note the concept of trust is not static, can be lost, and is difficult to regain. As one AARP expressed,

> *"I really don't think she told the truth on this. She waivered twice. Then I told her, 'The trust is gone now' I don't trust you now. So first you say you can't do it. Now, you say you can do it, and then you say. I don't trust you. As I'm sorry. That element of trust is gone" (23)*

AARPs conduct informal tests to gauge the level of trust they have for the researcher. Even though AARPs are provided research consent forms that describe the research, several AARPs gauge trust by conducting informal background checks on the researcher, including internet searches, googling researchers' identity to "verify identity" (8), and examining the researchers' affiliated organization or institutions.

Subtheme: 4:3 Trust, Balanced by Healthy Skepticism

The vulnerability that comes with trust is balanced by healthy skepticism the participants used to protect themselves from undue harm. The "skepticism" increased with invasive studies as very few AARPs in this study participated in invasive research. Another participant who initially avoided invasive studies but later enrolled in an invasive research study reported that there's no turning back once you take the study material (6). When asked why she refused to participate in invasive research, one AARP responded,

> *"I will do survey activities. I will wear a watch that records my heartbeat or something I think is still rather personal, but I will share some of that kind of information, but I don't want DNA. I don't want anything connected to my head or body like, for example, EKG that type of device, you know where they have to put little probes on you. I don't want that, but if my research can help assist you and getting anything else, I'm fine. But don't ask me for any urine samples or blood, don't ask me what's for saliva, don't ask me for anything to be connected to me. I don't totally trust it because most of the research is done by Europeans. I mean. You know, as at the source of it. And so, it may benefit us, it may benefit African American women and then women and people, in general, I don't mind that. Still, I don't trust just because of the history and because of what happens today." (23)*

A few participants reported not having a history of participating in invasive research but spoke about the willingness to consider invasive research in the future (30).

Subtheme: 4:4 **Inclusion in Dissemination of Findings.** A few AARPs spoke about the importance of receiving research findings. This allowed them to see how their participation was used in research and how it would assist future generations. One participant reported,

> *"Showing how your research has helped in the future, how you plan on using the research and the future. So that way they can know that they're helping the community and also helping their sons' daughters, nephews, their family, and their friends." (8)*

Most of the AARPs expressed not having received post-research findings and encouraged the return of study findings to the community. There was one negative case where a participant reported a lack of necessity to receive findings. She felt her participation was enough to feel valued and giving back to the community was enough (28).

Theme 5: Race Concordance

Race concordance is defined as the perceived shared color of the skin between the AARP and the researcher. This study had 13 AARPs that had researchers that were Black. The interactions that AARP described with their race-matched researcher included feeling more culturally comfortable and identified cultural commonalities. When inquiring further as to why the AARP may experience greater comfort with an AA researcher, one AARP said,

> *"By having someone from your own race to do the research. I think would put a person more at ease, feel more comfortable than having somebody outside of your race. I would hope that one of your people would not put you through something that they wouldn't put their own parents through, that their own relative through. Do you know what I mean they would be more? And I'm not saying the other races won't be I mean I'm not saying that they're not that. I'm just saying to you ask me the question how would they feel more comfortable. Think just having your own people do the research makes you feel more comfortable. I think that's it because when you look at the different things that are going on, that have been going on since the 1800s, since way back you know during slavery it's just the whole nine yards."* (19)

Another AARP reported,

> *"I think it helped because I feel like they were into it, as well as I was, and I really trust that they would not lie to me or I think that they would be truthful and like what you said, A lot of Blacks do not participate. And I think that they*

feel more comfortable in asking why. Okay, and I would feel more comfortable saying why." (30)

One AARP described a negative experience with an AA researcher while participating in a research study during COVID. The AARP reported reaching out to an AA researcher who had not completed gathering the research information and received no response. The AARP questioned if the researcher concluded the research when she stated,

> *"I wondered if you are Black doing research, do you finish your research? I know we tend not to finish things we start, so my thought is, does the research get done, or does this kind of thing happening with all the other Black people who do research that they get the information, and they don't finish it?... (29).*

To add additional context to this situation, it's important to note that during the COVID 19 pandemic, research across the nation was halted and delayed due to increased risks associated with the coronavirus.   Therefore, several research studies were prohibited from conducting face to face research. This was not explained to this participant, so they surmised it was a problem with the researcher.

Subtheme 5:1 "Culturally Comfortable" Through Shared Cultural Experiences

AARPs and AA researchers experienced similar challenges of being Black in the US. Participants reported that this left them feeling culturally comfortable through these shared cultural experiences. In addition, several of the AARPs with racially concordant researchers perceived genuine intentions and increased comfort with the researcher because of the shared Black cultural experiences, which included growing up in similar Black communities, experiences with racism, and Black spirituality. One AARP stated, *"I* *can roughly say we experienced the same stuff"* (8). When I asked the participant to provide an example, the AARP explained,

> *"I guess let's say you're traveling through a small town and you're like 'I don't feel safe here because I'm African American' yeah they move out to the next town and can't wait until you get on to the interstate. Stuff like that. Has that happened to you?" (8)*

Subtheme 5:2 Interactions with the Non-Race Matched Researcher

Understanding the perceptions and interactions between AARP and their researcher is important to understanding how these relationships encourage or deter research participation of AARP in health research. The findings on the relationship encounters with racially discordant or the researcher who didn't share the same color of the skin with the researcher were mixed. Several AARP had little interaction with non-race matched researchers due to the limits of the type of research (survey) or didn't see relationship differences between the non-race concordant and the shared race researcher (11)(33). One participant that had experience with both white and Black researcher reported,

> *" I have had good luck with all of my researchers and no difference with the white researchers, I cannot recall a time where I felt uncomfortable with a researcher. They were pleasant and knowledgeable." (33)*

One, however, spoke to the sterility of the research interaction with a non-Black researcher, and another spoke of the disconnect that was felt with the White researcher's failure to deeply understand what she was saying when answering a research question. One AARP expressed,

> *"Because they are White, they always have a different standard than Black people do. So, you really have to get them to understand, I know you're asking these questions, but unless you're really hearing what I'm saying, then you don't hear the answer to my question. So, I have had to do that a couple times. 'You're hearing me say this but is it penetrating beyond you just doing the research on it, that is what is important to me." ()*

It's important to add, several AARP reported that they often do not know researcher's race before the research study and had limited relationship development in research studies that were limited to online surveys.

In summary, the findings from this study revealed that AARP's willingness to participate in health research was motivated by their desire to help future members of their AA community and improve the health of society. In addition, several of the AARP in this study are leaders, provide social support as caregivers, and are active members of organizations designed to improve their local Black communities. Being respected and valued is of utmost importance in relationship building as several AARP repeat participants and have participated over several years. The findings were mixed surrounding the relationship connections between race concordance and race discordant researchers. While several AARP reported increased relationship connections with race concordant researchers, others reported experiencing no difference between the AA researcher and the race discordant researcher.

Furthermore, the AARP in this study have a strong sense of control and self-advocacy in deciding to participate and how much information they are willing to share with the researcher. There were also several AARP that found additional health resources within their close social networks and reported receiving supplemental health benefits and health knowledge from participating in health research. More importantly, neither the awareness of the historical mistreatment of AA nor the poor encounters with health care providers deterred them from participating in research. Overall, the AARP in this study were eager to participate as several contacted the researcher to participate and referred friends from their close social circle to this study.

Chapter Five: African American Nurse Scientists Findings

Chapter five describes the motivational factors of AANS that facilitate participation in research and the dimensions of the relationships between AANS and their AA research participants. The robust data set from participants' narratives from interviews and observations provided the deep descriptive data for this study.   Therefore, in this section, I will discuss the context of AANS, and significant themes generated from the data and expound on the commonalities of AARP and AANS collective mission that facilitates both groups' participation in research. See Appendix D.

African American Nursing Scientist Findings

A nationwide sample of fourteen AANSs were enrolled in this study. I met saturation at around fourteen AANS research participants after conducting semi-structured interviews and taking an iterative approach to data analysis. I attempted to contact previous AANS participants for member checking to verify the developing themes but was unsuccessful. Significant themes that motivated AANS to engage in research with African Americans and the dimensions of their relationships with AARPs that contribute to AARP participation in research include:

1. AANS extrinsic and intrinsic motivational factors
2. The culture of structural racism
3. Design of culturally sensitive research
4. Relationship depth with AA research participants
5. Humanitarian respect

Table 2:

African American Nurse Scientist (AANS) Themes

Themes	Subthemes	Categories
1: AANS contextualization	1:1 Impactful nurse-patient encounters linked to AA health inequities 1:2 The absence of Black leadership 1:3 Positive mentor engagement 1:4 Ambition 1:5 Inner strength	1:3a Black mentorship. 1:3b White ally mentorship
2: Cultural experience: The normalcy of racism in health care	2:1 Racism's transition into the present 2:2 Personal experiences with racism 2:3 Coping with a society's lack of racism awareness 2:4 Dearth of Black representation in career spaces 2:5 Research barriers	
3: Design of culturally sensitive research	3:1 Using an equity lens and practicing reflexivity subtheme 3:2 Genuine intentions	3:2a The inclusion of AA community members to understand population-based needs.
4: Relationship depth with AA research participants	4:1 Community visibility and presence 4:2 Community inclusion 4:3 Time-tested trust building (Giving Back)	
5: Humanitarian respect	5:1 Power leveling 5:2 Family like relationship	

Theme 1: Context of AANS

Sample Characteristics. Of the AANSs in this research study, thirteen had a PhD in nursing and one had a PhD in a related health field. All AANS self-identified as African American and they included those born in the US or outside the US. These AANS are nested within research-intensive universities, Historically Black Colleges, federally funded research institutions, and schools of nursing (SON) across the United States. Moreover, their PhD doctoral degrees qualify them for roles as principal investigators, co-investigators, full-time researchers, professors, publishers, fellows, mentors, community-national activists, and recipients of highly funded research studies. Several AANS conduct research exclusively with AARP, and all have conducted research studies, including AARP. AANSs conduct health-related research with specialized foci in some of the most underserved communities and with the widest racial gaps in health. They were interviewed during a time of intense racial strife, including the public spectacle of the murder of George Floyd and during a worldwide pandemic. They conduct research in communities where they grew up, communities they have adopted, and communities often impacted by low socioeconomic resources. To date, that I am aware, there are no research studies that highlight and analyze the contributions of AANS, especially those who engage in research in the AA community.

Subtheme 1:1 Impactful Nurse-Patient Encounters Linked to AA Health Inequities

Extrinsic motivations to research participation are any external events that move or motivate the AANS to action in becoming a nurse scientist. An in-depth examination of AANS data revealed the external factors that influenced their desire to become nurse scientists. Many AANS had histories of working as public servants-witnessing firsthand accounts of health inequities in underserved populations, experiencing the lack of Black leadership in health care positions, and receiving guidance from engaged doctoral mentors. Before obtaining their PhDs, many AANS encountered firsthand intimate experiences as bedside nurses working in underserved communities. Working closely and providing care to the AA patient enabled them to witness firsthand accounts of provider biases that subjugated AA health needs and delivered unequal treatment of AA patients in various health care settings. One AANS described a consensus of AA patients' perception of the physicians' lack of awareness of a specific disease process that impacts the AA population. Reflecting on a conglomeration of AA patient feelings, one AANS said,

> *"It was a collective feeling of hopelessness and feeling unrecognized, and like there was nothing that could be done, and that feeling, and being that person that wants to help and empower. I need to help them; I got to help them. Because they are just in a bad spot, and no one seems to be able to do anything for them. So, that's what they would express to me. That overall feeling, I received from every woman 'why do I have this? I've been going to providers for years, and how can you, in this one visit, tell me something that multiple providers have not been able to tell me over multiple years?" (10).*

Mistreatment of AA in healthcare settings extended to health education inequities they witnessed. One AANS observed that Black patients on her nursing unit did not receive the same health education as white patients. When she approached the nurses on the unit and inquired as to why they weren't receiving the same information, the nurses expressed they didn't think the Black patients followed the health practice and therefore they didn't feel the need to provide them with the health information. When the AANS reflected on those experiences she expressed,

> *"Looking at the biases and assumptions that you have about a certain population, you know we're not getting the same care, it's not equal, so that's the story that really drives what I do and just that we talked about the nurses, they didn't realize how It was making that impact, you know they thought that they dismiss it because you're black" (15).*

An examination of the data revealed the shared narrative of AANSs engaged as nurses working with underserved populations in the US, as well as in missionary work in various countries, and many verbalized enjoying providing care as nurses in multiple roles, including directors of nursing, triage nurses, and nurse practitioners. Furthermore, their clinical experiences are often where they witnessed firsthand the visible inequities that has inspired their desires to improve health AAs disparities through becoming an AANS.

Subtheme 1:2 The Absence of Black Leadership

Another motivator for becoming an AANS is the gap participants witnessed in the lack of Blacks in leadership positions. The awareness of the dearth of Black leadership in healthcare spaces motivated several AANS to pursue leadership roles to create positive, meaningful change in the AA community. One AANS spoke to this when he said,

> *"It's important for us to have champions who look like us, you know, so it's important to have champions, who are AA who can speak with our AAs, use themselves as examples and also be open and transparent and be honest about our experiences." (1)*

In addition, the nurse's role allowed AANS to engage with the community, many of which were communities in which they lived. During patient encounters, AANS were often inspired and moved to contemplate the importance of having Black leadership in AA communities that are impacted by marginalization and oppression. A few AANS take pride in conducting research exclusively with AARP. One researcher stated,

> *“All women don't have the same number of disparities in (a chronic health condition), when you look at Black women compared to Latinx women compared to white women and consistently, they are much higher, and so it is unapologetic, unapologetically that I focus on Black women that it is important to include them in the research because. The stats and you know what supports that, and so I’m intentional, my inclusion criteria are Black women.” (16)*

Subtheme 1:3 Positive Mentor Engagement

The parallels between the lack of AA leadership in the healthcare setting are similar to the lack of AA leadership experienced in the academic setting during the AANS’ climb up the nursing career ladder. Another significant catalyst that drives AANS to become researchers is the positive experiences of mentorship they received as doctoral students. Several AANS were motivated by mentorship from advisors inside and outside nursing schools and AANS mentorship programs. Mentorship of the AANS doctoral student was instrumental in helping the doctoral student to navigate their academic experiences and their development as researchers. There were two types of mentorships identified in the data:

1. Black mentors
2. White ally mentors

1:3a Black Mentorship. Black mentorship is the examined experiences of AANS reflecting on the guidance they received by Black leaders or Black faculty throughout their nursing, doctoral and postdoctoral studies. Interestingly, very few AANS had Black mentors, and of the AANS that did, they spoke to seeking Black mentorship outside the school of nursing due to the lack of Black representation in leadership and faculty roles within their nursing programs. Therefore, the challenges for AA nursing students that preferred Black mentorship were palpable when one AANS expressed,

> *"I did not have a single Black professor outside of the African American studies department. I minored in AA studies, had I not had that minor, I would have gone 5 years of undergraduate education, never having a Black professor; the nursing department had no Black professors. Ah, that's not true; they had two but were in the graduate program. There were none for undergraduate students. It made it very difficult for me at times to feel like I had professors that could relate to me. Being a first-generation college student, there were things I wanted to talk to my professors about or needed help in a certain area because I could not rely on my family necessarily to give me advice about their experiences. I felt like I didn't really have people that understood me holistically, so as far as my cultural upbringing things that were important to me there, my faith. They were great instructors, but I didn't feel like they got me if that makes sense. And so, I really clung to members of the chapter of the Black Nurses Association that I was in. As soon as I started nursing courses, myself, and a good friend of mine joined the local chapter and those are the nurses who we felt like we could really [emphasis]*

> *talk to, be ourselves around and they helped and guided and mentored us so much." (9)*

One AANS spoke of seeking out the Black mentors and the contribution the mentors provided to her as a doctoral student when she said,

> *"They're just able to… just been able to give me like a bit of insight into the hidden curriculum in terms of success and how to maintain balance and stay authentic in the work I want to do, and those kinds of things." (4)*

When asked about what it was like having a Black mentor, one participant said, *"it was a good fit for my desire for what I wanted to look like as a nurse scientist"* (4), and another AANS said the Black mentor *"it was by the grace of God, she understood my vision."*

Like many of the AANS, she referred to a "hidden curriculum," meaning the presence of unwritten and unspoken rules, values, and behaviors in the educational program. The AANS spoke to the AA mentors' ability to navigate hidden challenges experienced by being an AA student. AANS identified the hidden difficulties experienced by the AANS student as the "ivory tower" (9) or the "unspoken curriculum" (4) that many students of color experienced. When one AANS reflected on her experience with her Black mentors she expressed,

> *"They're just able to give me a little bit of insight into the hidden curriculum in terms of success and how to maintain balance and stay authentic in the work I want to do" (4)*

This AANS operationalizes this experience with a Black mentor by turning her attention to Black PhD students to help them navigate challenges faced by Black students. She explained,

> *"It's my personal mission to make sure that the hidden curriculum that we're not always privy to is transparent and open. So, I try to be as transparent and open about all of the ways that success can look in these institutions that are built on structural racism. So, I think figuring out navigating the system is one of the things that I think is most valuable for students to learn and be able to get support about. Because you just don't know what you don't know, and nobody feels the need to tell you. I feel like that's unjust, and so I guess that's kind of what I do. I just make sure that everyone knows I tried to make sure as much as I can, in my position, that the tools that you need in the toolbox I kind of points you to where those are. And then try to work with what they are, even though they might be, one screwdriver instead of the three that everyone else has you know, let's figure out how best to make that screwdriver work for you. Well, I think as a Black faculty member, I can fit that, and that's unique."* (4)

AANS experiences surrounding the AA mentor were that the AA mentor provided the AANS with additional mentorship that included navigating these challenges, providing other educational resources, and mentoring relationships that grew into lifelong friendships. It's important to note that one negative case differed from the overall evidence when the participant spoke about not getting along with her Black mentor (25).

1:3b White Ally Mentorship. Due to the lack of Black mentorship, the contributions and role of the White ally mentor cannot be overstated. White mentors nurtured the AA doctoral students' research goals in a setting with very few to no AA mentors. Moreover, white mentors successfully guided their AA students and were strong advocates for them. While reflecting on her doctoral student experience, one AANS spoke of the strengths of White mentorship and having received outstanding mentorship. She said,

> *"I'll speak from my perspective, that's impacted me positively, you know, because my mentor who is a Caucasian female you know, really did advocate for me which, which was helpful. I struggled, then I have some very documented challenges in my doctoral program that led to significant changes in policy and program. So yes, I mean I've experienced some of those challenges, and you know really did advocate for myself, but I also had people who advocated for me naturally, that should be discouraging, but I think I'm just the kind of person who you know after I experienced something negative my goal now is to identify ways to advocate for others, so they don't experience the same. So, I turn around and I work for the same institution." (1)*

It's important to note that a few AANS spoke to the challenges that came with having a non-race matched mentor. Negative experiences included varying research agendas, the lack of research direction, or relatability experienced by having a non-Black mentor. Many AANS expressed appreciation for having mentors that understood their goals of helping the AA community.

Subtheme 1:4 Ambition

Exploring the context of intrinsic motivation factors among the data, it was found that AANS are ambitious; this is, they have an inner strength of purpose that drives them to become AANS that are dedicated to work with AA research participants. Moreover, AANS shared a focused call to action aimed at closing the gap of AA health disparities. One AANS exclaimed, *"I enjoyed being a nurse and doing my work as a nurse it's just that I wanted to do something about the disparities I was seeing in the hospital on our ward." (3)*

The AANSs in this study are ambitious and driven to finding solutions to rid AAs of health disparities. A significant step toward reaching their goal of contributing to the AA community and research was their climb of the education ladder, which included attaining advanced degrees. Furthermore, in addition to their PhDs, they are practitioners, researchers, health educators, mentors, and community collaborators that cultivate intimate personal relationships with patients and members of the AA community. Even more impressively, several AANS have demonstrated their ambitiousness under the pressure of being the only Black in their family with a doctoral degree, the only or one of very few Black student(s) in their nursing programs, or the only Black in their academic institutions. Therefore, their ambitions are coupled with the overwhelming need to succeed in spaces where being different elicits "hypervisibility." (21) or "macroaggressions" (16) and overcoming structural resistance from research funding gatekeepers for their desire to create AA targeted research (21). Hypervisibility is where the AANS stands out because they are the only person of color in their leadership role and may be targeted differently and microaggressions are the non-exaggerated attacks that occur over time that are designed to put negative pressure on a person of color, One AANS stated,

> *"I have seen in my line of work towards me how I'm treated as well. I have to come ten times better than my white counterparts. There's no room for error when it comes to me or for me to say welp, 'I really don't know', where my White counterpart will say I don't know that, and everyone keeps moving, but with me, it's an issue that gets belabored. These are similarities that I see in Black and Brown communities that they are not regarded when thinking about various*

> *access to care issues and information and how it doesn't get to these communities that really need this information or receiving poor care. That really motivates me to do the work that I do." (5)*

Subtheme 1:5 Inner Strength

AANSs' inner strength is grounded in their purpose to ameliorate life challenges for future generations and improve AA communities that have a long history of suffering at the hands of unethical researchers and from social barriers related to research participation. Furthermore, their desires to push forward and remain committed to the greater cause of improving population health exceeds their firsthand experiences with racism. One participant stated, "*I was not going to stop. I'm a person who will not be stopped*" (10). Another participant passionately expressed,

> *"It was the bigger idea behind it, that is, the world can be different, and the future could be too.... Everybody's children deserve better, we all deserve better-- This is the existential question, right? If you are going to take up space on this planet, and you're doing nothing. You might rethink, you might want to go lay on the beach somewhere and figure out why you are here because [unrecognizable] my whole thing is, I want to leave something better than I found it. The future deserves that, but we won't get to some future we've ever been dreaming about it like someone's got to build it. So, from where I sit, what else am I supposed to be doing? Right, that's how I think about it, and you know nursing, I believe, so deeply in the power of nursing, I've never done anything else as an adult right like I keep telling people. Yeah, I had been a nurse for almost 30 years and a licensed nurse, and the service like is such a gift".* (21)

An examination of the AANS of this study revealed their inner strength of passion that drives them to be nurse scientists and positioned them to make a difference in the AA community. For many, this includes not allowing their individual experiences with racism to supersede their ultimate goal.

Theme 2: AANS Cultural Experience with Structural Racism

Racism consists of behaviors by individuals and societal structures designed by those in power to position Black people in a lower social status and in a disadvantaged societal position. Nearly all AANS spoke about their personal and professional experiences with racism. Their experiences of racism included:

- Racism's transition into the present.
- Personal experiences with racism.
- Coping with a society's lack of racism awareness.
- A dearth of Black representation in academia and career spaces.
- Structural racial research barriers.

Subtheme 2:1 Racism's Transition into the Present

Structural racism is an ever-evolving concept as Critical Race Theorist, Derrick Bell calls it the "anti-Black theme" (Bell, 2017). Through their narratives, the participants in this study expressed how alive and well racism operates in the spaces of research and is validated by their personal experiences. One AANS drawing a parallel between the current COVID vaccination crisis to the Tuskegee experimentation when he expressed,

> *"The expectation that African Americans would freely volunteer to be part of any studies would be missing the point. It means we are misinformed, and I think based on that, if we continue to create these generic research policies, not*

> *necessarily taking into account what's happened in the past, we as researchers are further negatively influencing. You know this structural racism, so using this current pandemic as an example. A lot of AA refusing to take the vaccine. If we go back to the Tuskegee experiment, it's almost the same because we're not being sensitive enough to stop and educate our minority patients to help them understand exactly what it is we're trying to do…. I believe, you know, as we're constructing a lot of our research procedures, we're not necessarily taking that into account, and I think that's adding to the structural racism." (1)*

They spoke to their awareness of the many events of unethical research on the AA enslaved laborers, AARPs of the Tuskegee Syphilis study, Ms. Henrietta Lacks, and the impact from the lack of reprimanding scientists for poor and unethical research conducted on the AA community. Segregation of researchers from the Black communities, the dearth of AANSs, the widening gap of health disparities within the AA communities, and the public spectacle of the murder of George Floyds impacted AANSs and AARPs alike.

Subtheme 2:2 Personal Experiences with Racism

AANSs' individual experiences with racism are multilayered and all-consuming. For the AANS that experienced overt or outward attacks from racially driven events, their encounters spanned from their experiences in childhood to adulthood. They referred to staggering labels of their experiences, using terms like macroaggressions, unnecessary trauma, systemic fraud, and a place of sadness. One AANS spoke of how her experiences with racism validate the experiences of AARPs,

> *"My personal interactions with racism have afforded me the opportunity to easily identify and ask the question, how is racism operating here? Because I*

> *could identify with knowing that racism it validated my experience. I use it to also determine and validate the experiences of others in research…. I made a conscious decision, I'm not always successful but to be conscious of including the person weather be structural or cultural perspective or racism in the work that I do." (13)*

There was a consistent description of what it was like growing up without adequate Black leadership in education, health care, and academic settings, with the lack of Black teachers from grade school to higher education. A few AANS spoke about the need to "resist" and "pushback" on racist encounters. One AANS was able to parallel the encounters she experienced with the racism encounters experienced by the AA community. She expressed,

> *"I've seen in my line of work, I've seen in my research activities, I have to come ten times better than my white counterparts, or even more. There is no room for error when it comes to me or for me to be able to say, well, you know, I don't really know. Whereas my white counterparts can say I don't know that I can look that up, and it's not a problem. But if it is me, it gets belabored. I see the same thing in the Black and Brown communities where they're not regarded, and when thinking about various access to care, access to knowledge, it doesn't get to these communities that really need it. That motivates me to do the work that I do. (5)*

Another AANS spoke on her observations in her environment of those who speak up and how they are labeled. She reported,

> *"African Americans who speak up. Sometimes can be labeled. It depends on how they speak up and are they aggressive with it and how they come about it.*

> *And do people say oh here's an angry black woman, here's the angry black man. That's what I'm observing in the environment that I'm in"* (25).

In contrast, other AANSs spoke of the need to relocate due to their employers' lack of appreciation or "retreating" due to the overwhelming feelings brought on by the recent racial climate (15)(14). There were very few that verbalized not experiencing overt personal experiences from racism. These nurses spoke to their ability to narrow their focus on the greater cause toward public health, which they prioritized over their personal responses to overt racist experiences.

Subtheme 2:3 Coping with a Society's Lack of Racism Awareness.

AANSs described their need to cope with a dominant society that is not aware or chooses not to be mindful that racism exists and that it significantly impacts the AA community; many AANS spoke of the lack of awareness or conspiracy of silence around racism in society that comes in the forms of denial, privilege, and ignorance. One AANS referred to the White peoples' struggles with comprehending Black scholars' plight when comparing them to societal depictions of Black inferiority in the United States saying,

> *"I mean I don't know if you've ever met a White person who was amazed that you went to Europe or something like that, or you know, I just went to, you know such and such museum what you know they're like, you do that? They are stymied, they are in their head; they're trying to reconcile. Okay, like they're baffled, it's confusing because they can't reconcile all the stereotypes that* they've heard with *your behaviors that you're exhibiting. So, they don't know because they haven't gotten to know you, as a person, they haven't gotten to know Black people*

> *as individuals. They have bought into stuff that they've been taught and that we allowed our own kids to be taught in school." (2).*

Another participant described Whites that lack awareness as a positive catalyst when she said,

> *"Whether it's a Black issue or not, it is still grounded in that privilege, it is so grounded that people don't even recognize that it even exists. And even if you… what I have been trying to explain in conversations around diversity, equity inclusion, …even if your incivility occurs with people who look like you who are White, whenever you place that incivility on me now that I'm Black, it places a whole other layer with it. So, you can call it what whatever you want to call it, but that personal experience changed my view of research in a positive way, because what it did, is it calls me to stay the course"*

Subtheme 2:4 Dearth of Black Representation in Career Spaces

Many AANSs contended with navigating spaces that lacked Black representation in both colleagueship and leadership. The dearth of Black representation is multilayered throughout their lives as they experience its lack of Black leadership: in nurse-patient relationships, doctoral faculty-student mentoring, and the lack of Black leadership to assist in navigating the "unseen curriculum." One AANS reported, *"The lack of nurse scientists is grounded in structural racism" (16)* Interestingly, when several AANSs reflected on their doctoral experience, they spoke of the polarization or misalignment with their mentors that came from the mentor's lack of understanding of their commitment to AA research as pivotal in their growth as doctoral students.

Subtheme 2:5 Research Barriers

Structural research governance barriers are related to the barriers faced by AANS within the structure of research that overtly or covertly curtail AA researchers and AA research. Several AANSs spoke to the racism seen in the research peer review process, the "good old boys" system that repetitively funds popular White researchers, and the deterrence of research projects aimed at improving the health of the AA population. Once participant spoke of the overt racism within research when he said,

> *"At the time, well-meaning policies were put in place without necessarily thinking of a diverse group of people and systematically eliminating certain people from having full access, full understanding, full autonomy of decision making and the same processes and by way eliminating them from either benefiting or just being a part of whatever that initiative is." (1).*

Another AANS spoke of the barrier surrounding the review and funding process when she said,

> *"When you look at how the system is structured. You will find around the table of review was mostly Whites—mostly men. Mostly medical practitioners are very limited in studies in disciplines like nurses and social work they're mostly, basically scientists. Right? And our interest as minorities is mostly around social behavior… all kinds of research, so that puts you at a lower level in terms of your review of your application. The second thing is that over the years have gone to come to recognize and acknowledge that. The reviewers are looking for people who already know what they're doing. Let me rephrase that-- to not know what they're doing but have been provided funding before, have been awarded funding before. Yeah and if it is not that person, then who are those person's trainees, and*

> *they give them the funding because they are the people that they know and what tends to happen, then you have the funding being recycled and focused on only specific institutions, as well as specific individuals, and of course, it continues, then, to put minorities, I said at a disadvantage in a secular way over an extensive period of time." (3)*

However, out of the AANSs' narratives about the impacts of racism, there's a strength demonstrated towards rejecting and ameliorating the present state of racism and taking matters into their own hands to improve AA health. Their stellar scholarship demands they belong in leadership spaces.

Theme 3: Design of Culturally Sensitive Research

Subtheme 3:1 Using an Equity Lens and Practicing Reflexivity

In the design of research projects and entering into research relationships with AAs, the AANS use their lived experience as experts of the Black experience. They have a heightened awareness of the barriers to research participation related to indirect and direct structural racism and the impacts of the justifiable distrust of research experienced by people of color in the US. One AANS reported,

> *"Everything I do has an equity lens…. far too long we've had health disparities in the Black community, and at this point, we keep having the same conversations, and so I think that as a Black nurse scientist, that I have a lived experience that is as equally important as the science. And I think that we have to get to a point where we recognize our lived experience as being experts in that in that space and so, really just wanting to be a trusted partner in the community*

> *and to be able to conduct research, but not for the purposes of my own benefit, but for the benefit of the community truly". (16)*

Moreover, several AANSs were born and raised in the same communities as their AARPs and shared the impacts of the historical trauma of unethical research experimentation. In addition, their advanced studies in nursing, public health, and their roles as nurses providing care for AA patients in health care settings have awakened an undeniable awareness of the lack of resources, health information inequities, limited medical access, and the "*policies that are put in place without thinking about diverse groups of people" (01)*. This awareness of AAs' history and social positioning in the US allows them to openly acknowledge and discuss the unadulterated history of AAs' mistreatment in research. This is a shared history with AARPs and AARPs look for its acknowledgment (08). Therefore, AANS use this heightened cultural awareness or "ways of knowing" to guide their research, in addition to the regulatory conduct set forth by research regulatory authorities. Moreover, in their dual role as nurses, AANSs understand that research is vital in reducing health disparities in the AA community. As one AANS stated,

> *"Nursing needs to contribute by dismantling racism and promoting equity through research" (4).*

Many AANS speak to seeking social justice for AARPs as they, themselves plan and participate in research to gain a holistic understanding of the research process and intentionally design research that is inclusive of the AA community and their cultural norms.

Subtheme 3:2 Genuine Intentions

Genuine intentions begin with the researchers' fundamental resolutions for conducting research that includes developing authentic relationships with AARP. Many AANSs spoke to their personal experiences with racism and self-awareness of how AAs are impacted by distrust of research. Therefore, the AANS verbalize their genuine intentions towards building respectful and trusting relationships with AA research participants coming from a genuine space; one participant stated,

> *"Making connections and helping people understand who you are and your motivation behind why you're doing what you're doing. You know it's more of a giving place than a taking place. It's all about building relationships. You know, and I think it's being genuine. You know, like fully genuine like I'm literally here because I want to help, not because I'm trying to take from you. Know that's a space that you have to operate from. You know, and I would venture to say, am I saying that that's my new phrase venture to say it's true to say that. The majority of Black African American nurse scientists are genuine you know it's not about how many papers can I publish you know what can I do to get on top of. The game of being in academia me and researcher like that's not why we do what we do… is genuinely listen, this is what I see going on in our community. For my point of view, I'm asking these questions because I want to get your point of view, you know I want to understand this, because of the various difference, challenges we're facing, and how can we better, how can we strengthen and how can we do our best for our elders, for our adults, young adults, children, you know for our communities". (14)*

Conducting research with racial sensitivity includes designing research that allows AARPs to explore the impacts race has on their health. Distrust for the research community is abundant; therefore, cautioning against conducting research with a lack of awareness of cultural differences is warranted. In addition, it is important to note, several of the AANSs found it essential to engage in researcher reflexivity before proceeding with any research study involving AA participants. One AANS spoke about their recommendations for researchers,

> *"I think that you have to be really thoughtful about your presumptions, about the population you're working with and even write those down. What do you think about it? what are your processes? and procedures and then work together with your team and your group to work through what you have on this list are true. You know and what on this list maybe stuff that's not so true and do it yourself first, so you're not embarrassed, you know, and then you also have to have a trusted team that you're working with. You guys can have the sort of open and frank conversations where people can feel comfortable talking about the things that they're not comfortable with. Because otherwise, people aren't going to tell you that I'll feel comfortable going into the city after dark or my spouse doesn't feel comfortable [with me] going. Then you don't understand why you can't get anybody to go do." (17).*

This self-reflexivity ensures the researcher is not imposing implicit biases on the AARP. When working with the AARPs and non-Black scientists, self-awareness is critical, not being fragile if accidentally offending an AARPs as one AANS reported,

> *"Awareness of offending participants, being ready to apologize, and then open to learning" (10)*

An additional facet is the understanding and importance of AA verification of the research to ensure research credibility and to capture the AARPs' authentic voice. The importance of research rigor is essential and cannot be accomplished without including members of the AA community and gatekeepers to verify the research findings.

3:2a The Inclusion of AA Community Members to Understand Population-based Needs.

The inclusion of AA community members in assessing population needs is about conducting a population-based assessment. This includes building relationships to find out what the health needs of the AA community are and asking them directly for their perspectives. Several AANS spoke to the importance of cultural awareness and training. The depth of health disparities and inequities in the AA community is so vast that cultural competency training only captures a superficial understanding of health inequities in the AA community. Moreover, the need for complete awareness of the inequities experienced by the AA community comes from experts of the lived experience. Therefore, AA representation necessitates a research team inclusive of Black experts of the lived experience with an *"empathetic presence"* (4). Accurate representation includes more than recruiting and retaining AA research assistants or AA gatekeepers on your team. It includes having an AANS or AA scientist expert critique, oversee, and provide feedback on the research process, including conception, design, implementation, and findings dissemination. One researcher stated,

> *“So, in the current study, we are doing a lot of leg work to get to the point where we can begin recruiting people for the actual intervention. And again, this has been years of work. To start the study, the PI on the study, she talked to community members about their needs in the community. What their health care needs were. What types of things they would like to see that she could feasibly do in the community? She interviewed about 1100 people”. (9*)

Inclusion of experts of the Black experience on the research team and cultural awareness training is necessary for all research team members. Because AAs are not a monolith, as expounded on by several AANSs, the importance of tailoring research to the AARPs needs is crucial. This is done by conducting a needs assessment of the research population. Similar to a head-to-toe assessment conducted by the nurse, the necessity of conducting a research population assessment is critical to understanding the research population. One AANS reported the importance of initiating pre-study preparation work, including community assistance, before recruiting participants (9). Taking note of the geographical, economic, and health needs is essential to designing research that reflects the AA community's needs. Several researchers suggested population inquiry through conducting preliminary surveys that ask the community to prioritize their most pertinent health needs. One scientist stated, *"All scientists, more importantly, need to listen to the AA as they identify their own needs" (13).* Another participant stated, regardless of the shared color of the researcher's skin, *"if you are not sensitive to their needs and their issues that you know that particular group my face, then you probably will not get enough participants" (15).*

Theme 4: Relationship Depth with AA Research Participants

A major component of designing culturally sensitive research is attending to the relationship depth that the AANS seeks with AARPs. This is seen in the quality and amount of time the AANS invests in building relationships with AARPs. The overall consensus of AANSs spoke to the multilevel level dimensions of their relationships with their AARPs. Dimensions of these relationships include the development of a community research partnership utilizing community leaders and gatekeepers throughout the research process, and importantly, AANS-sustained presence and infusion into the AA community, research inclusion, and time-tested trust-building relationships often extend post the research.

Subtheme 4:1 Community Visibility and Presence

Successful design of culturally sensitive research includes the community's awareness of the researcher's consistent visibility and presence in the community. One AANS described community presence as an *"investment, investment, investment, investing in your team investing in the people" (25).* Several AANSs in this study spoke about their sustained presence within the AA community. This presence in the AA community included time-tested community engagement. This type of presence cannot be accomplished by an *"armchair research" (21)* approach, which is conducting research on the AA community without physically engaging in community activities. More importantly, maintaining AANS visibility is not limited to attending a single event; instead, the researcher is actively present on multiple occasions and meaningful events in the AA community. One gave the rationale for their sustained presence in the AA community when they said they aim, *"To recreate the relationship between researcher and community that the relationship can be a partnership versus a one-way street. (14)*

Another AANS explained how she avoids the attitude *"I need you today and gone tomorrow but establish a sustained presence." (13).* In addition, several AANS sought out opportunities and looked to build relationships within the AA community outside the boundaries of the research study and often included engaging with the community after the study concluded. A few AANSs are immersed in the AA community because they live in the research community in which they conduct research, therefore there's a "hypervisibility" (21) of the AANS's presence in the AA community demonstrated by attending church functions (2), shopping in local grocery stores (21), attending health events and support groups, and freely participating in invited AA community events. As one AANS stated, *"You want me to MC at an event? I'm gonna go. It doesn't matter if it's related to my research or not, because I'm a member of the village (21)".* AANS are demonstrating time-tested, sustained longevity in the community by participating in community activities inside and outside the constraints of the research project and this contributes to these bidirectional partnerships.

Subtheme 4:2 Community Inclusion

Relationship depth is cultivated through inclusive community partnership relationships that AANS build with the AARPs. This includes partnership relationships with AA community's gatekeepers. Several of these relationships were found among AANSs that used Community Participatory Based Research (CPBR) to guide their research studies. Several AANSs described gatekeepers as being viewed as community protectors and experts that hold access to the AA community. Interestingly, several AANSs identified members of AA gatekeepers to include hair salon workers, leaders of motorcycle clubs, church pastors, and community advisory board members. In partnering with AANS, their role as experts in their community is to protect the AA community from undue research harm by guarding the access to the AA community. Gatekeeper protectiveness exceeds the color of the researchers' skin due to the history of the Black nurse coercing participants in the Tuskegee Syphilis Study. One participant spoke this when she said,

> *"But by me being Black, I understand the questions that she asked me and understood why she asked me those questions, I was not bothered by the question she asked me. Because I will do the exact same thing. If I am opening my door to somebody because you hear the term research, your brain automatically goes there's a Black person in the Tuskegee Syphilis Study I think for a lot of people,*

> *you know and remember the nurse that was overseeing that was Black. She was deceived as well. But I think just making those collaborations and building trust in the places that you recruit, will go a long way, regardless of your skin color. Because people, Black people, African American people are going to have participants that are going to be a little leery when you say research." (15)*

Gatekeepers participate in screening and verifying researcher's credibility, assisting in research recruitment, and denying or granting access to the AA community members. The value of relationships with AA gatekeepers cannot be overstated, as sustained presence with the gatekeeper is one factor that contributes to a researcher building trust with the AA community.

In addition, AANSs are looking for ways to include the AA community in every aspect of the research, from asking the community to assist in shaping the research question, carefully crafting budgets that provide funding for the community, funding gatekeepers' contributions to research, funding that supports reimbursement and food for the participants and returning to offer data and findings updates for the community. Terms like *"my community"* were often used when the AANS was speaking of the AA community. One example of this is in a AANS story of an experience with a curious member of the AA community. The AANS shared,

> *'So, we were at this church on a Saturday because we were doing this focus group, and this older gentleman came up to me and said, 'Young lady, let me talk to you. So, how did you get here?' I don't know what you mean. I took 95, turned right. 'Come on, how did you get to this position. Do you trust in this? I just came to see what's going on in our community. I'm not down with this. I heard some things.' That's why I'm here too. I wanted to see what was going on in our community. I felt that because we came here to this area, I wasn't sure if*

> *anyone would show up, but I wanted to give my story about how important it is for us to change history. We can't change what has happened, but we can change what's going forward and how I got here was just wanting to be an advocate for my people, for you, for your family and my family, and for my community because I'm tired of us not being represented and that's why I'm here to represent. (10).*

Subtheme 4:3 Time-tested Trust Building (Giving Back)

Time-tested trust-building is the demonstration of sustained trustworthiness within the researcher-participant relationship. Trustworthiness is found in the researcher's ability to conduct high-level research that represents the AA community. A theme across AANS participants is that there has been a history of researchers conducting research in the community to collect data, analyze findings and leave the community without contributing to the community's needs. To increase trustworthiness, several AANS built in post-study transparency by returning to the AA research community with collaborative research findings. One AANS said,

> *"Just try to make sure that what I am interpreting from the data are vetted and confirmed from the stakeholders from within the community okay. And then, just trying to find creative ways to get even preliminary findings, or you know even like the main outcomes".*

It's important to note that the trust building relationship does not come without participant skepticism of the AANS. The AARP may demonstrate skepticism related to the AANS's degree attainment that differs from their own educational level, as well as what the AARP perceives the intention of the research to be. This is one area where the AANS is viewed as an outsider as skepticism supersedes the shared color of the skin of the AANS and AARP. Suspicion increases when the AARP identifies a lack of transparency surrounding the research

(1). This skepticism is also related to the AANS having a PhD AANS report participants may question their loyalty to the AA population and if the elevated degree or education impacts the AANS's sensitivity to and affiliation with the AA community. One AANS reported, *"People see me a little differently once they know, I have a PhD… 'Are you still down, are you still Black; are you still for AA?" (10)*. Another AARP was noted asking the NS, *"Are you being used to get us in?" (10)* or *"Did you assimilate?"* (10) Within this study, increased skepticism is related to a lack of knowledge surrounding the population understanding the role of the AANS and the desire of the AANS to help the community (10).

The AANS in this study understand that skepticism exists. Trust is not automatically given and is a vital factor of building relationships that reduce skepticism. The way to combat skepticism is through trust-building. Trust-building through connecting with the participant on various levels besides education (e.g., involving participants in research design, living in the same area, and clearly verbalizing the researcher's motives and intentions for conducting the research) are ways to reduce AARP skepticism (14).

Theme 5: Humanitarian Respect

Having humanitarian respect for one's research participants involves honoring them on a human level that transcends the color of one's skin. It is not race-centric, but participant-centric. Moreover, it's the idea that all people should be valued and honored. In this study, AANS demonstrated their humanity by humanizing the research participants. This included the researcher being highly empathetic to the participant's needs. More specifically, the tangible and intangible needs of the research participant are elicited, understood, and respected. For example, one research found a participant struggling to read the consent form. The researcher found ways to maintain the participant's dignity and assist the participant without embarrassing him. One

AANS stated, *"I did not want to make him embarrassed " (2)* Empathy can only begin with being attentive and having deep participant awareness. This includes a heightened vigilance by paying attention to verbal and nonverbal cues the participant gives the researcher, checking in frequently, and active listening.

Subtheme 5:1 Power Leveling

Power leveling is the AANS positioning themselves in a servant-partnership rather than in a higher power position seen in a hierarchical society. AANS reduced the power hierarchy by viewing the participants as experts and shared partners in the research-participant relations. In addition, AANS demonstrated power centering through actions that increased participant comfort and reduced participation perceptions of taking from them nor their shared community. One AANS spoke about the power shift that needs to take place when working with AARP in research. She stated,

> *"Research is not a one-way street. There's a power shift that has to take place where you have to get out of this perspective that you are the only one bringing your knowledge to the table and are coming to do something to the community. That is why you only end up with limited, non-sustainable interventions. Instead of thinking about innovative ways in which communities can continue to sustain themselves or interventions that lift up the strengths that are already present. In the community and recognizing the power and strengths that are already there. I have as much to learn from the individuals that are already there as they have to learn from me, and I think that's one of the other this that is very different, is that perspective isn't the same we don't come to the tale the same and I think that people pick up on that pretty quickly. (17)*

Several AANS operationalize the desire to help those that have not been helped in the past. One AANS, while reflecting on conversations with her participant reported,

> *"Sometimes I'm seen as not part of the community. 'I'm inside, I have a PhD, I'm highly educated, and far removed 'No I'm not removed from anything. I can't take this skin off. Wherever I go I take this skin with me. So, although I have these degrees, First, I have my Blackness with me. No one sees my degree when they see me. So, I make sure to tell them that, and they are like 'Oh, okay. 'And if you are uncomfortable at any time, with anything that is going on, please come to me because I'll give you what I know. I understand that mistrust. I'm a part of that community, I'm part of Tuskegee, I'm a part of every that has been done. That is why I'm here. I'm here to make sure you have everything that you need and if there is any discomfort, you have a voice. (10).*

In addition, several AANS approach the participants as they are experts of their experience and verbalize the importance of their joint efforts in improving the AA community. One AANS spoke about her mutual partnership with the AA participants when she said,

> *"Well, it's my understanding, or is my belief that communities are experts in their experiences and so I start from that framework. I let communities know that 'you're the experts in on this topic, though I may have some experiences and expertise in some topics, I'm coming to say I'm coming to work with you on this shared topic and the parts of it that you think is important. What parts do you think are important, and this is what I was thinking, what are your thoughts?' (17)*

Another AANS spoke about reducing the power dynamics by being attentive to the clothes she wears during researcher-AARP encounter. The AANS expressed,

> *"When I first started doing research like qualitative study, I used to dress up to meet my participants, and I can't remember what somebody said to me or where I was going along the way that I realized that I was too formal. I think one day somebody called me at the last minute on a Saturday and I went to a home, so I was like I'm not changing close. I was wearing Saturday casual, and I just went on because it was at the last-minute thing. I noticed how much more comfortable that participant was how much more open. It was a difference in the way she talked to me and what she said to me. 'I was expecting you to come in a white coat, and it was going to be something formal. You're just a normal person" (15).*

Subtheme 5:2 Family Like Relationship

AANSs described the nature of their relationships with AARPs as family-like connectedness. This family connection includes the AANS viewing AARPs as part of their extended family; attributes include nonverbal connectedness, boundaries balancing, and shared Black cultural experiences. Several AANS viewed AA research participants as an extension of their race family. Rather than looking at the participant as an outsider or an "other," they visualized features of their participants as those they see within their immediate family. One AANS while referring to her AARP as, *"They were my family," (2)* and another AANS reported the rationale for this action was,

> *"We've been underrepresented so much in clinical trials and other studies that whenever we come on board, to be able to communicate with the sister I didn't know you were here, brother I didn't know you were here" (21).*

One AANS used looking at the participant as a family member to reduce anxiety (2) in researcher-participant interactions. In addition, AANS witness this phenomenon as verbalized by their AA research participants. This is verbalized by their family-like participants when they looked at the researcher and said, *"All right, sis, we're gonna do this,"* (2) speaking on their collective mission to improve AA population health. In addition to the verbalized family connection, a nonverbal connectedness is often challenging for AANS to describe. There is a feeling of connection experienced when one Black person looks at another. One researcher describes it, *"I could give you face to face contact like you were my cousin for 15 years, and we don't have a say a word that we know exactly… we just communicate with each other" (16*), Another researcher said, *"When I see another brown person, I automatically connect with them" (25).* This connection is balanced in research with the AANS understanding personal boundaries. Personal boundaries in the research included establishing the limitations of researcher transparency and cautioning against over-engagement to not bias the research. When asked to clarify potential research bias, one AANS reported the family-like relationship is a form of recruitment *"connectiveness"* and therefore, is not seen as a bias as the participant ultimately decides whether to participate or not to participate (25). Furthermore, the family-like insider experiences are linked to the shared cultural experiences of growing up in similar environments. These similar spirituality experiences included worshiping in Black churches and growing up with similar family dynamics, such as food sharing. One AANS reported, *"Outsiders are not "privy to" the culture (3).* Theses shared commonalties are used as relationship-building strategies with their AARPs. On AANS stated, *"Now I noticed that you're from this area, you know I have family that lives there as well."*(25)

The family-like relationship dimensions, which included AANS viewing AA participants as members of their extended family contributed to increased researcher-participant connectedness. This was identified especially in research involving face-to-face interactions.

This familiar connectedness promoted researcher-participant relationship-building that may ultimately impact the AA community-research community relationship**.**

The findings in this study have demonstrated the AANS contribution to research. Their contributions cannot be overstated as they are motivated by their nursing journeys and intimate experiences with racism and health inequities. In addition, the study findings point to an ambitious nature to help the AA community in which they take ownership. Their inner strengths are built on the challenges experienced from navigating through structural barriers that often go unnoticed and being the only Black in multiple leadership roles. The AANS in this study engaged in research starting from a place of genuine intention and designed research through an equity lens that was inclusive of the ideas and perceptions of the AA community. More importantly, they treated their AA research participants with respect, reduced power barriers as many of their participants looked like members of their own families.

Collectivist Commitment to Improve AA Population Health

African American commitment to improving their population's health is an overarching salient theme that is seen across both research populations. AANS and AARP research participants were highly committed to the importance of improving the health of African Americans. This theme underscores their collective embrace of a greater purpose that exceeds their shared experience of historical mistreatment of AA in research. Dimensions of this phenomenon include:

1. Supporting the AA community towards the greater purpose of improving health through health research
2. Responsibility sharing - leveling power dynamics
3. Shared cultural awareness

This collective effort for health improvement was seen as each individual felt the importance of acting as a proactive cohesive team to move the pendulum forward of improving AA population health.

Theme 1: Supporting the AA Community Towards the Greater Purpose of Improving Community Health Through Participating in Health Research

It is clear that both AARPs and AANSs share a collective commitment to the greater purpose of improving AA community health. The AANSs prioritize community visibility in their shared AA communities to support health initiatives and research recruitment efforts. They spoke about the increased visibility and time they spent in the AA community. AANSs talked about their *"authentic community engagement"* (21) as evidenced by their increased visibility at AA community events that included "*community requested speaking engagements*" (17). A few AANSs act as resource connectors, connecting AA community members with resources such as additional food (5)(9)17), education through dissemination of findings (13)(14)(16)(25), community improvement resources (14)(17), and appropriate incentives (17) like blood pressure cuffs.

Similar commitment to the greater purpose of improving health through research participation is also seen in the AARP community with their assistance in collective research efforts. Many reported their involvement in community efforts that support AA research participation. One AARP talked about assisting in recruiting those from her close social circle when she stated.

> *"Usually, when I talk to people, I explain how this will help us. Because so often you hear all the time 'well that's just for those people, or you know for them'. But how do you know when you don't participate. You're not even open to*

> *listening to what they're trying to do. You just have automatically assume that. And how can you be in the count if you don't participate". (24)*

Further, several AARPs are caregivers (12)(22)(20), members of participant pools, and research registries with the choice to participate in various types of invasive and non-invasive research. Several AARPs are members of social organizations that include health and research information (12)(26)(24). Therefore, their commitment to improving community health includes sharing research information with other AA members of their family and group.

Subtheme 1:1 A Cohesive Team with Family-Like Attributes

An exhaustive examination of the data revealed that both participant groups considered their participation together as a cohesive team that works together. A strong component of this team cohesiveness includes AANS and AARP feeling like they are members of an extended family. AARP and AANS perceived each other as members of the extended Black family with family-like attributes or used terms that signified belonging to the same group. They described their interactions and feelings as related to this family connection. While not blood related, the strong sense of connectedness was identified by one AANS when speaking about the family-like connections she had with her AA participants,

> *"They were my brother, my uncle, my father, my husband. It wasn't like I do anything extra. If anything, I had to remember this is Uncle Robert (changed name to protect confidentiality), your brother, your cousin. So, that I could relax to be like 'I'm the researcher'. If I had acted anything other than myself, it would have been a front and I don't think I could build relationship in the short time that I was there." (2)*

When asked about how the AANS maintains the family-like relationship within the boundaries of research, one AANS explained,

> *"Ultimately it's up to the participant if they want to participate in the study. I think it's a connection that we have. Whenever I see another brown person, I automatically connect with them and maybe even know them, but it's something because, to me, you're in a situation that's right for you. Usually, a situation where you're sick or ill. I think it's a way of connecting and communicating, and I think that's part of recruitment. A person can decide if they want to do this or not because one of the first things, I will tell you is you can withdraw from the study at any time."* (25)

This familiar type of relationship is apparent in both the researcher and participant populations and is often described by the AANS as "*effortless," (2)* "*authentic," (15)* and "*genuine*," (14) and "*readily accepted*" (1) by the AARP. This family-like nature of the AANS-AARP relationship was also verbalized by the research participant. One AARP reported "*Think just having your own people do the research makes you feel more comfortable"* (19). When asked to describe this connection with the researcher, the AARP expressed, "*It has helped, they are my people and because they're trying to do something for the African American group."* (12)

The AARP used fewer family-like terms when talking about their black researcher but instead used words like possessive determiners which signified belonging or being on the same team. One AARP stated,

> *"I'm connected with a whole bunch of people…there's a lot of African American things I try to get involved in to help our people. that's why I said, I don't mind giving to our culture. I'll give to anybody, don't get me wrong. But,*

> *right off the top you don't have any problems with me when you say African American or Black, whatever you want to call us, it's our people. I'm going to do what I can. You can have everything out of me. There are no secrets" (12)*

Subtheme 1:2 Unsolicited Generative Mentoring

With the perceptions related to being a cohesive team comes unsolicited generative mentoring that is reciprocal between the AARP and AANS which included advice, helpful suggestions, and words of wisdom that contribute to professional and personal growth of the AANS and AARP. This mentoring includes thoughts and valuable ideas that come from experiential and generational wisdom. In addition, AANS demonstrated a willingness to take on the double roles of conducting research, as well as serving as an AARP in order to contribute to the improvement of health research. One AANS spoke of her experience as an AA research participant,

> *"because of my knowledge of the lack of AA that participate in research studies, I try my best, I don't try to overwhelm myself, I try to participate in as much as I can, so I see something comes across my desk, I'll fill out that survey, or if there's something of interest to me, I'll call to participate in the study, and I think that's important. Because I realize as a researcher how hard it is to get participants, especially in our community. I try to lend my hand where I can." (9)*

In this study, I experienced mentorship by the AANSs who were then in the role of the research participant. For example, while looking at the consent form, one AANS said, *"I don't know if I would word this section of your consent like this."* (2) The same nurturing mentoring strategies displayed by the AANSs are also seen in the AARP population. One AARP offered several research questions he would like to see addressed in the AA community when he said,

> *"I would love you people to do research on economic empowerment, you know for Black Americans. Why is it that we stay lagging behind other ethnic groups? Is there a relationship between economic confidence and how long African Americans or people of color live? If satisfied, with their economic position, do they live longer, or it dissatisfy do they die sooner? (26)"*

Another AARP felt it necessary to question and mentor the researcher on the use of the term African American. I allowed the time and space to understand why he felt the term African American was not a term that promotes growth within the Black community. The AARP said, "*Why do you call yourself African American? You are not African American, you are Black."* (26)

Theme 2: Responsibility Sharing That Includes Leveling Power Dynamics

Both participant groups understood that research participation required their presence and cooperation to create meaningful change in improving the health of the AA community. AANS reduced the power dynamics within their researcher-participant encounters so that each research participant felt valued, and AARPs assumed the role of the expert informant by providing valuable information to the researcher. In addition, the AARPs viewed the importance of the AA researcher as an expert researcher with intentions toward towards moving the research forward with the hopes that it would improve the AA community. An in-depth examination of this synergistic relationship between AANS and AARP revealed a shared responsibility towards improving the health of the AA community through research participation. Therefore, many nurse scientists in this study assumed a role that included leveling power dynamics, also reported as *"coming from a place of service"* (14) by one AANS and *"centering the margins"* (21) by another AANS.

AANS demonstrate power-sharing throughout the research process and therefore benefit from increased AA participation, robust data collection, and long-term relationships inclusive of the AA community. One AANS reported approaching research intending to *"empower the powerless"* (10) and verbalizing the message of collaboration with the participants, expressing *"…it will take a shared effort to improve "our" community."* One AANS said while speaking with her AA participant, she stresses, "*I can't do it by myself, "This research is for us," "The information you have can make a change if you allow us to enter into your space."* (10)

Another example of leveling the power dynamics is viewing the AA participants as experts in the research study. One AANS (21) stated, *"because the people we serve actually have the solutions that we are looking for."* This was demonstrated as many of the AANSs considered participants as the experts in the research study by openly acknowledging *"the community is the expert"* (13), including AARP in speaking engagements (21), and compensating AARPs as research consultants for their service in the study. AANS sought ways to compensate gatekeepers and members of the research advisory boards for their time and assistance in research rather than viewing their assistance as free services.

Theme 3: Shared Cultural Awareness

There was a consensus that both AANS and AARP understand the historical barriers to research participation in health research. While several mentioned the Tuskegee Syphilis Study there were additional cases discussed. One AARP acknowledges,

> *"To be frank, like what happened in the 60s. I believe they gave the babies radiation, the pregnant women radiation through their food, and said it would benefit the baby. I'm not sure if you know about that….In the 1930s, they were trying to research radiation, so they gathered up different African Americans and*

> *gave them baby formula and said this would help their babies. In reality, they were basically using them to see how different babies would react to different radiation, so there are even adults alive today that are suffering because of that. Yeah so, different stuff like that harms the trust between government research and African Americans." (8)*

On AANS highlighted the past and present factors that contribute to health disparities when she observed,

> *"Even with the death of George Floyd and Brianna Taylor. I thought I understood it until I had to actually visually see it. So, the structures, even with Nikole Hannah Jones' situation. The structures are put into place to impede, block, oppose, and elevation of underrepresented people like ourselves. And that's the structures that are in place, the people that are in place that block successes that block opportunities it, it has been detrimental. And so, I would say. How has it impeded African American participation? They're nervous and scared, Still thinking about the Tuskegee Syphilis, you know, think about the vaccinations people still talking about they're not vaccinated because I think it's this the fear of what's going to happen, the fear of the unknown. And I don't want to be a number. I'm not willing to try it out. I'm not willing to trust the system. I don't trust the people. It has led to poor care, quality of care, and huge health disparities that we see continue to widen." (25)*

Despite the historical implications, several AARP reported the history not having an impact on their decision to participate in health research (7)(11)(18)(12)(27). Instead, they discussed deciding to participate in spite of the history, intentionally prioritizing the greater good of positive gains for their community. This shared cultural awareness allows both AANS and AARP the openness to speak about the impact historical and racial barriers have on research participation. One AANS spoke about taking an anti-racist approach to research. She said,

> *"That self-reflection allows researchers to look to see how bias is informing the results or interpretations and really call out what are some of the structural, cultural, or interpersonal factors that the participants are identifying and try as much as possible to take the bias out so that you're not imposing views on the participants but allowing participants to speak their truth and getting the data from what they are experiencing. Without the anti-racist approach, you may not even allow participants to fully explore the implications of racism on their health outcomes. This may be something that you ignore." (13)*

With a shared cultural awareness comes the ability to openly acknowledge the past (10) and this acknowledgement was requested by a few AARPs. One AARP stated. *"Acknowledge it happens yeah and like I said. Give them time"* (27). Another AARP advised on how to acknowledge the history of research mistreatment suggesting that researchers use a business model to improve the relationships: *"Get the bad stuff out of the way first so the conversation can be focused on the best aspects" (*8). In addition, there were perceptions of amelioration toward taking something that is negative and changing it for the good of improving the AARP population evidenced in both groups. Several AANSs spoke on the false perception of racism in research as solely a historic event when it continues to be experienced today (16). AANS reported, how there are *"Policies put in place without necessarily thinking of diverse groups of people"* (1) and how *"nursing needs to contribute by dismantling racism and promoting equity through research"* (4).

The overarching shared theme between the AANS and AARP cannot be overstated as they work as a cohesive team and share the common goal of improving AA population health. They support the AA community by actively integrating as leaders in various roles, including caregivers, Black organizational leaders, local Black support groups, health speakers, and nurse scientists. Several AARP and AANS engaged in decreasing power dynamics through mutual respect and view each other as family and a collective group. Finally, as AANS and AARP, share the impacts of the historical trauma of unethical research, they also provide the space for reflexivity, open discussions, and examining how the past and present experiences with racism impact the health of the AA community. Their greater pursuit to improving the AA population supersedes their fears, and therefore, they go forth and participate with the hope that their efforts are not in vain and will change the narrative of AA through improved health.

Chapter Six: Study Summation, Contributions to Science, & Implications for Nursing Research

Chapter six aims to provide a comprehensive examination of the study findings, including a review of the findings, positioning them within the state of science, identifying study limitations, and implications for nursing and future research.

The strength of this research study is that it advances nursing knowledge and extends our understanding of AARP motivations to participate in research by identifying and describing the nature and dimensions of the relationships that influenced AARP research participation in the US. To the best of my knowledge, there are no research studies that analyze and illuminate the contributions of AANSs in health research and explore the AANS and AARP collective mission to improve the health of AAs in the US, therefore making this study a seminal contribution to nursing science.

This study contributes to the advancement of knowledge by understanding participants' perceptions through qualitative narratives that revealed targeted themes, which will provide the foundation for interventions towards improving AARPs' recruitment and retention strategies. Overall, this study will contribute to the ever-increasing demands for diverse populations' participation in research to reduce health disparities, improve national health, and justifies the need for successful recruitment and retention strategies of AARP who are disproportionately underrepresented in research (Al Hadidi, 2020; Simon et al., 2014).

Furthermore, the study also challenges the dominant ideology that low accrual rates are solely a result of AAs being hard to recruit, not interested in participating because of the Tuskegee Syphilis Study, or biases associated with the perception that they are less likely to participate in health research. On the contrary, given the appropriate level of access, transparency, and most importantly, respect, AAs are eager to participate in research with potential benefit to the AA community.

Research Questions

Two primary research questions guided this research and findings will be discussed according to those most salient to AARPs, AANSs, and those which overlap both groups.

1. What are the shared motivational factors of AA nurse scientists and AAs that facilitate participation in research studies?

2. What are the nature and dimensions of the relationships and shared motivational factors, behaviors, and interactions of AA nurse scientists and AA participants that impact participation?

Discussion of AARP Findings

Motivational Factors That Influence Research Participation

In this study, salient motivational factors that influenced AARP to participate in health research included altruism towards improving society's health and improving the health of one's AA community. The importance of this theme cannot be overstated, as it has been identified as the overarching theme that allows the AAPR to prioritize participation over their fears of participation related to the justifiable distrust from centuries of mistreatment of AARP by the research community.

Altruistic motivational behaviors to participate are consistent with previous studies as the motivation to research was either identified as altruism or AARPs' desires to help future generations. A recent study by Ewing (2019), which included 200 AARPs, examined the motivations of AA towards providing biospecimens in cancer research. They concluded there was an increased desire to offer research specimens in those with high determination to help future generations. In addition, Owens' (2013) study that examined the perspectives of AA in oncology clinical trials found helping "family or society" as motivators to research participation. Further, one AARP in the McDonald's (2021) study that examined AA research participants "knowledge and attitudes about medical research" revealed her reason for participation was to improve her race; overall, the study suggested a more global form of altruism as a motivation factor to research participation. Drake (2017) suggested an increased willingness to participate if they were aware their participation would help a family member.

AARPs are also motivated by receiving health benefits and improving their health awareness from participating in health research. Additional health benefits reported by participants in the study included medical diagnostic scans, and dental and medical knowledge that several participants reported using after participating in the research. Owens (2013) suggested several AA participants were without health insurance and receiving medical benefits within the research as a participation motivator.

Finally, this study identified several AARPs that highly regarded their personal agency and choice in various aspects of the research process. This included their ability to choose to participate and their choice of how much information they were willing to share with their researcher. The AA population has an extensive history of oppression, lack of agency, and choice. Understanding how AA self-agency operates in the space is essential to understanding what motivates them to participate in research. Moreover, to my knowledge, there were no previous studies that addressed participant agency to participate in health research, therefore these findings amplify what is known about motivation to participate.

The Cultural Experience: Normalcy of Racism in Health Care

The perceived impact of racism on the AARP in the patient-provider relationship necessitates acknowledgment and discussion. AARPs use of the terms research and medical interchangeably occurred several times during the interview—experiences within healthcare and research were not differentiated when examined further, one AARP explained, "in the black community, we have a lot of trust issues when it comes to this medical stuff that you are doing this research stuff, we think it's medical, ok and because of the lack of medical attention or needs that we've gotten throughout the years and not getting the right information or the full information, there's a lot of mistrust." (12) This required the researcher to clarify the meaning of stories surrounding their experiences and perceptions of racism and to consider the impact of general health care experiences on motivation to participate.

In addition, understanding the interactions AARPs in the patient-physician relationship is vital as several AARP seek their provider's input in decision-making for participating in invasive research. Critical Race Theory (CRT) requires an examination of the normalcy of racism, therefore in this study, the normality of racism, especially within the patient-provider relationship was examined several participants spoke of encounters of abuse and neglect and questioning their relationships with providers the normalcy of racism in healthcare was illustrated in the disparate treatment of AARPSs in the role of patients in the health care setting. it is essential to note that the one participant that reported having good patient-physician encounters linked them to having good health insurance and the agency to find a new provider if they did not receive adequate care

Prior studies have emphasized providers' lack of awareness of research, bias-related perceived assumption of AA unwillingness to participate in research, and deterrence of research opportunities the Niranjan et al. study (2020) that examined both clinicians and researchers found restrictions of research opportunities for AARP. For example, Al Hadidi (2021) suggested low AA participation rates were due to physician biases and not providing research opportunities to AA research participants. while several research studies suggested the need to address provider bias and acknowledge the lack of research participation due to the physicians' lack of awareness of research, several questions regarding aa perceptions and the impact of mistreatment in research participation remain to be addressed these study findings underscore that despite the AARP encounters of mistreatment at the hand of their health providers, they continue to pursue research if given the opportunity.

Race Concordance

In this study, AARPs described and contrasted their relationships with AA researchers and researchers that were not of their race. In the AARP-AA researcher relationships, the AARP reported experiencing increased comfort, clear communication, relatability, and perceptions of genuine intentions from the AA researchers due to the shared historical backgrounds and cultural familiarity. These feelings of connectedness led to participants' willingness to share more research information with the researchers. Several AARPs reported using their control over the information they were willing to share or not share. AARPs verbalized an unsaid expectation of the of the AA researcher: They expected the AA researcher to protect them from research harm and they entrusted the AA researcher to use their research data to improve the AA community. It is important to note that race concordance does not eliminate elements of skepticism related to educational attainment. In addition, several AARPs reported experiencing differences between the AA researcher and the AARP as they felt the same relationship with both concordant and non-concordant researchers. One participant (27) highlighted the lack of Black researchers conducting research and awareness of resource inequities of Black researchers related to structural racism.

A number of authors have recognized that race concordance improves research participation (Ewing, 2017; Frierson, 2017). A review (2014) reported that race-matched African American research participants and researchers improved research participation because of enhanced communication and relatability, a theme verified in this study. This study, however, adds a more nuanced understanding of the relationship dimensions of race concordance that contribute to research participation. This study also highlights the commonalities found in AARPs' perceived genuine intentions and expectations for their same race researchers to move the science forward in proving the health of their shared AA community.

Importance of Being Respected and Valued by the Researcher

The finding that there is the strong need for AARPs to feel respected and valued by their researcher was of paramount importance. Many of the participants controlled their level of engagement with the researcher through relationship dimensions that include comfort levels with the researcher and interactions surrounding the AARP autonomy over research choice. In addition, the AARPs were very active in engaging in informal testing of the researcher during participant-researcher interactions to determine if the researcher was trustworthy, had genuine intentions, and was worthy of their time and effort to participate.

Several AARPs spoke about the need to be valued over the research and not seen as an object in research. This involved the researcher making the AARP feel comfortable throughout with the researchers' introductory research presentations and open body language (for example, eye-to-eye contact) during face-to-face encounters. Feeling respected was demonstrated by the researcher being open and honest with the research participant and allowing the AARP to speak their truths even if their perceptions were in conflict with the researchers, as they are the experts of their lived experiences. In addition, the AARP feeling valued includes the researcher conducting the appropriate research safety checks and using the research data in ways that do not harm the AARP or the AA community. Researchers' transparency-- being upfront during the consenting process and throughout the entire research process is an essential component of the AARP feeling valued. This allows the AARP to make an informed choice to participate in health research and is critical for encouraging the return of AARPs to research participation as several AARPs have participated in numerous research studies that span over several years and decades.

All AARPs except two were born in the United States and most shared the historical implications of living in the US where AAs were oppressed, lacked agency of choice, and felt devalued and disrespected. Therefore, today, AARPs are eager to share their opinions, seek spaces for their truths to be told, and search to be listened to by attentive researchers. While they are committing to participate in research, there is an awareness of past wrongs coupled with the hope that the present researcher will protect them during the vulnerabilities of being a research participant. Therefore, healthy skepticism guides their decision-making process to participate.

An examination of the literature revealed studies that briefly touched on the respectability of the research towards the participant and alignment of research with the AARP values (Kenerson, 2020, Suarez, 2020). On the contrary, to my knowledge, the strong need and expectation of AARPs to feel valued and respected in the setting of health research has not been previously identified.

Discussion of AANS Findings

This is the first study to date that specifically examined how AANSs have approached research and their relationships with their AA participants. This study brings to light the intentionality that AANSs bring to their unique and authentic approach to research and how they build their relationships with their AARPs. In addition, while not the specific focus of this research, a key finding in this participant group is what nurses had to say about their education experience (expected motivation). They went deep into descriptions of their educational journey in order to provide context for their motivation to conduct research to benefit AAs. More importantly, it is essential to understand their resilience in the process of becoming AANSs who are sensitive to AARPs in research participation.

AANS Unique Approach to Research

Culturally Sensitive Research

AANSs in this study designed their research through an equity lens. As AA nurses and experts of their lived Black experience, they understand the depth of the impacts of both the historical mistreatment of AA in research and health disparities on AA health outcomes. In addition, they are aware of the social structure and policies that are in place that make it challenging for AAs in research. They also understand that their first researcher-participant encounter may be the AARP's first time engaging with an AANS. Therefore, they begin research with genuine and transparent intentions to help the AA community, design and implement research ensuring AARP inclusivity and advocate for health improvement in the AA community. In addition, several engage in community participatory practices that included assessing community needs, asking AA community members about their research interests, and working with AA gatekeepers and Black organizations. AANSs also contribute to the health of their families and communities as they are seen as leaders and health educators within society. For example, several spoke on being approached to discuss the science surrounding the COVID vaccine. These interrelated efforts support relationship-building between the research and the AA community.

ANNS Relationship Dimensions with AARP

Humanitarian Respect

An examination of the finding of the AANS relationships with AARP found AANS priority of honoring AARPs on a humanitarian level. This was exhibited by AANSs' verbalizing their strong commitment to participant-centered engagement and conducting research that was sensitive to their basic needs. The AANSs reinforced AARP dignity by validating the importance of the AARPs' contributions to research participation. Even if a participant chose not to participate, AANSs sought ways to improve their research by respectfully inquiring to understand and reevaluate their research processes to be more acceptable to potential participants. In addition, the AANSs would show they cared about the participant by being empathetic to diverse SES and educational levels and adjust their presentation accordingly to ensure the participant felt of value in the research.

Furthermore, AANS were hypervigilant to scrutinize the fair value of research incentives and advocated for appropriate remuneration for AARPs, AA gatekeepers, and the AA communities. Including participants and gatekeepers in identifying what type of incentives were appropriate helped show their genuine research intent and prevent perceptions of research exploitation. Further, the AANSs in this study made a conscious effort to change the narrative surrounding researchers taking from the AA community by honoring their commitments to dissemination and maintaining sustained relationships. This is essential for the AA community to see their participation and contributions were valued and how their participation is linked to research dissemination. Honoring the participant was also seen in the AANS engagement with AARP communities, discussed further under the theme of relationship depth. Overall, the AANSs demonstrated humanitarian effort in line with The International Covenant on Civil and Political Rights (1976), Article 10, which states, "All person deprived of their liberty shall be treated with humanity and respect for the inherent dignity of the human person." This research practice is also consistent with the principles of CRT.

Relationship Depth

AANSs reported that building relationships with depth were a key dimension to build trust. Understanding relationship building takes time, AANS sought out and developed community partnerships that shared their goal of improving AA health. In addition, they viewed their sustained community presence as investing in their community which included researcher visibility at community activities such as going to funerals, church, and town hall meetings. The AANSs also demonstrated the willingness to participate in events at the request of the AA community. Their visibility is not limited to attending an event one time but multiple times and being perceived as a part of the community.

Several AANS verbalized the importance of not taking from the AA community. From the data, there is the sense that researchers are conducting research to collect data, obtain findings, and leave the community without contributing to addressing the community's needs. AANSs are actively combating the 'here today, gone tomorrow' research impression by looking for ways to include the community in every aspect of the research. This includes asking the community to assist in shaping the research question, carefully crafting budgets that provide funding for the AA community, fair and equitable funding to gatekeepers, providing funding that supports monetary and food for the participants, and returning to disseminate understandable findings for the community. These community investments contributed to a sustained presence in the AA community and were designed to increased researcher credibility and limited thoughts of the ‘here today, gone tomorrow,’ exploitive mentality. They also understand that their positionality as researcher comes with participant skepticism related to different educational levels; the position that comes with being a doctoral-prepared nurse scientist supersedes the shared color of their skin. AANSs persistently work to combat participant skepticism by engaging in research transparency, verbalizing research intentions, and leveling power differentials.

AANS Educational Experiences

Motivations

An in-depth examination of what motivates AANS to participate in health research reveals motivational factors that often begin with their firsthand clinical experience as nurses, working with underserved populations, and the contributions of doctoral student mentorship. Nursing students are required to complete clinical rotations in diverse health care settings. These clinical experiences as nursing students provided initial firsthand experiences caring for patients with disparate health conditions. These foundational experiences in nursing education followed them into the clinical arena where, as bedside and community nurses, they often witnessed unfair treatment, delayed care, including health education inequities, the lack of Black health providers, and the unequal treatment of AA patients. Therefore, most AANSs were inspired and made it their mission to serve and improve the health of the AA community impacted by health inequities. These experiences also made them contemplate the importance of having Black leadership in health care in these communities.

Additional motivation included the contribution of the mentorship AANSs received as doctoral students. All AANS spoke on their experiences with mentors while becoming nurse scientists. There was a theme of Black mentorship scarcity among those who sought specifically to have Black mentorship. When reflecting on their doctoral journey, serval reported wanting Black mentorship from someone who shared their research desires and goals towards conducting AA health research and who could guide them through the cultural differences and racial barriers commonly experienced by students of color. Mentors' relationships with their AANS were significant as these relationships often did not end with the student graduating but became life-long mentorship and friendships. AANSs described their AA mentors as available to students' off-hours, providing food, scholarship resources, and assisted first-generation AA doctoral students with challenges their families could not solve. They also aligned the AANS student with additional opportunities through networking and scholarship attainment. The shortage of Black mentors led many AANS doctoral students to seek AA mentorship from different disciplines outside nursing schools, including AA physicians and AA nursing organizations. For example, a few reported having no Black faculty or Black mentors, therefore pushing them to seek mentorship from other disciplines outside the school of nursing.

Barring the availability of Black mentorship, some AANSs spoke about the importance of mentoring from a white or other non-Black ally. Several underscored strong and critically important relationships with their white mentors, however, having a mentor who has had similar race-related barriers to overcome as a doctoral student was particularly supportive and beneficial to navigating the predominantly white contexts of academia and research.

Cultural Experiences with Structural Racism

AANS experiences with racism is a theme they share with AARP. The unspoken struggles of the AANS are vast and multifaceted. These struggles are not directed at a specific time point in their career but are all-encompassing. There is a “hypervisibility” (21) that exists among AANSs in that they are most often the only Black (or one of a very few) in several leadership spaces. One AANS stated Black people must be twice as good to compete with their white counterparts and "there is no room for error "(5). Several AANSs spoke of the challenges compounded by mentorship deserts, micro- and macroaggressions, funding discrimination, and organizational lack of trust in their skills, intelligence, and desires to serve the AA communities. These prolonged battles with structural racism have left scientists feeling traumatized and interfered with timely progression in their career paths. While the scars remain with them, their ambition and inner strength have turned these barriers into positive catalysts aimed at improving AA health through conducting research that is inclusive of the AA community.

Collectivist Commitment to Improve AA Population Health Through Participation in Research

One of the most important and overarching findings in this study was the uncovering of a shared strong commitment of AANSs and AARPs that includes their selfless desire to mutually support the AA community towards “the greater purpose” of improving the health of the AA community, now and for future generations. This collective commitment theme was shared across both participant groups and stems from the sustained witnessing of poor health outcomes in AA patients’ health, their battles with chronic disease, and the multigenerational impacts of poor health outcomes. In addition, each of these participant groups stressed the experiences they have had with structural racism in health care, academia and research and this shared experience contributes to the collective mission to work together to promote AA population health.

As a cohesive team, AANS and AARP experienced heightened connections with one another with family-like attributes, as many spoke of research relationships that were similar to being part of an extended family. Several AANS see their family members in their AARP, and AARP expect the AANS to treat them as if they were like their own family. There is also a leveling of power dynamics where AANS authentically demonstrate respect toward the AARP and treat them as experts in their own experiences with shared common interests in helping the AA community. While the AARP is eager to share their lived experiences with the researcher, the researcher-participant role is enhanced with the participant providing the researcher with tips and words of wisdom to guide the researcher. It is noteworthy that this was my experience as many of the AARP wanted to mentor the me in the conduct of this study and research in the AA population in general. See Appendix C.

There is a collective sense of responsibility towards the AA community as each participant group takes ownership and roles within the AA community by calling it "our community." AARP take the role of the expert of their experiences in research and several AARP participate in multiple research studies, considering this a personal commitment or mission. In addition, many AARP are leaders of formal and informal Black organizations that provide resources to their close social circles and caregivers of family members with chronic health conditions. Many personally provide extended care for multiple generations. Interestingly, several AARP spoke of the importance of helping the Black researcher further their educational goals with the hope that the researcher will use the information to further the joint goal of assisting the AA community. The AANS share in this joint responsibility towards the AA community in their roles as nurse scientists and leaders in the AA community, mentors for up-and-coming doctoral students, health providers, and educators in the AA community, and advocates for change at a local and national level.

The salient and novel theme of collective commitment to AA research and AA population health is an important contribution to our understanding of AA research participation.

Research Limitations and Strengths

This study contributes to a deep understanding of the nature and dimensions of the relationships and shared motivational factors, behaviors, and interactions of AANS and AARP and explores the impact of their shared cultural experiences. An extensive review identified both limitations and strengths in the study. Despite extensive recruitment efforts, this study includes [4] AA males out of [32] research participants and may not fully capture the full extent of the challenges that may come with the intersectionality of race and gender. Second, most of the AARP were identified from a specific national AA research participant pool and are already motivated to participate in research; therefore, they may not include the experiences of participants that are not active members of such a research organization. This study does contain a small but reasonable sample size for qualitative research; however, the sample is representative of the national population of AANS and AARP who have agreed to participate in additional research and who are part of a national registry. It will be essential to recruit more participants who are not a part of a designated research pool in future research. Despite these limitations, the findings of this study provide current evidence (in the setting of a worldwide pandemic) as to AA motivators to participate in health research and is the first study to illuminate the contributions of AANS, as well as the collective mission of AANS and AARP to improve AA health.

Implications for Practice

Evidence generated from study findings will provide the framework for developing interventions directed towards increasing AA participation in research, designing mentorship programs to increase the numbers and support of AA nurse scientists, and provide the foundation for research policy development (Graham, Brown-Jeffy, Aronson, & Stephens, 2011).

Implications for the Collectivist Commitment to Improve AA Population Health

The shared commitment of AANS and AARP includes their selfless desire to reduce the health gap and improve the health of the AA community now and for future generations. Shared connections, cultural experiences, and collective commitment to improve AA population health between AANS and AARP cannot be overstated. Dimensions of the shared behaviors that motivate AARP include a partnering as a cohesive team, responsibility-sharing that includes leveling power dynamics, shared cultural awareness of the history and policies encompassing AA research, and the ultimate goal of supporting the African American community towards “The greater purpose” of improving community health. The synergist factors that motivate AAs to participate in research, as both participants and investigators are essential in shaping how research is conducted in the AA community. This collective mission is evident by the consensus of interaction, behaviors, and motivation factors to participate in research despite historical awareness and justifiable generational distrust associated with AA participation in research. The shared comfort and respect that equates to increased trust, as evidenced by the shared cultural experiences with racism and desires to help improve the AA community, cannot be understated as AANSs are actively engaged in research directed towards the AA community.

Therefore, these shared connections of AANS and AARP need to be developed and fostered in research settings. These relationships need to be valued as they lend themselves to a higher quality of research data collections as evident by the AARP verbalizing the willingness to provide more information to the Black researcher. AANSs need to have their numbers counted and included in leadership roles in studies that include AARP. In addition, the lack of AANS in the spaces of research has resulted in scholarly research conducted by race discordant NSs and researchers. This is due to a consensus that there are very few AANS in research institutions. At the same time, it is important to note that this study does not suggest the promotion of segregated research but supports non-race matched research if conducted with every team member demonstrating cultural humility and awareness. This may be accomplished by including AANS in leadership roles through nurse scientist (NS) collaborations in studies and is vital as the AANS provides extensive knowledge because of their shared cultural and historical experiences that cannot be ignored or discounted. Therefore, the inclusion of race concordant research leaders will provide oversite and direction that comes with an equity awareness from the Black experience. AANS are experts of the lived Black experience and are necessary to develop the intimate connections between researchers and participants described in this study. Close connections experienced and developed through shared family-like relationships, lived experiences, spiritual upbringing, and non-verbal communication that many participants reported were present but could not put into words is the key to obtaining robust data to produce higher level evidence-based nursing research that is representative of and useful to the Black community.

In addition, being proactive in seeking collaboration with AANS in research is vital to producing research representative of the population, as AAs make up 13.4 % of the US population (US Census Bureau, 2019) Researchers making the assumption that the Tuskegee trial is the primary and sole rationale for low participation accrual rates in health research is unethical, especially when there are scientists that are able to consistently enroll AA research participants. Furthermore, it is vital to note that seeking inclusive collaborations involves more than seeking AAs for researcher assistants and data collectors but prioritizing locating AANS with culturally appropriate research skills and experience who are eager to help the AA community and have shown time-tested longevity in the AA community.

Implications for Research Practice and Policy

A prevalent theme across AANS participants is the structural barriers, including reviewer biases in research that eliminate populations from research and adversely impact AA research. There is a suggestion that power structures, such as research funding institutions, research advertising, and research review boards, lack cultural understanding, historical awareness, and cultural sensitivity towards AA researchers and AA targeted research. Research deterrence, popularity (repetitive) funding, and budget restrictions can only confound health inequities and negatively impact the health of the AA community. Therefore, there should be an examination of how research money is dispersed for federally funded research and how much of that goes back into the AA community. In addition, there should be a reexamination of research structures that were once built on positivist principles and white male dominant society that lacks diversity. There is a heightened need to improve research processes that is equitable, inclusive and will improve the quality of research that reflects the diverse US population.

The findings from this study demonstrated the necessity of prolonged researcher engagement with the AA community to develop meaningful relationships built on the researchers' increased visibility in the AA community. Therefore, policies and institutional review boards (IRB) should mandate research transparency by providing research proposals that include research project timelines that accurately reflect how much time was spent in the community. Time accountability will encourage institutions to appropriate adequate time to the researchers' schedules and prevent workload inequities. In addition, mandates requiring post-study findings returned to the AA community and recommendations for a fixed rate of the grant funding be allocated to the participating community. Based on the studies' conclusions, returning study findings and resources to the AA community demonstrates the research community respects and value the participants. Finally, an itemized cost analysis of the research funding should show how much money is returned to the research community. This will allow for the identification of gaps in research funding distributions. Mandated respectful engagement, dissemination of findings, and funding transparency may decrease the AARP perceptions that researchers are taking from their communities.

Implications for African American Research Participation

The AARP in this study were very open and eager to discuss motivations, challenges, and rationale for research participation as they are experts of their experiences. An overarching theme within this participant group was the importance of feeling comfortable with their researchers. It is important to acknowledge that several AARP did not develop extensive relationships with their researchers due to the type of research. For example, there was no extensive relationship building in research involving health surveys or single visit research. On the contrary, several AARP engaged in multiple encounters with researchers, especially in research designed with multiple in-person visits or studies that were held over a longer amount of time. AA participants reported the ability to quickly assess the researcher, pick up on the researcher’s “vibe,” and control how much they were willing to contribute to the research study

(12). Improving these interactions is critical to receiving robust data and improving future encounters with AARP. Participants were willing to share intimate details that, for some, were the first time they talked about. For example, in starting her story about an adverse event she experienced in research, one participant stated, “I've never shared with anybody.” One participant reported the key to developing the relationship is noticing a person's cue, body language, and efforts to increase the participant’s comfort. Researchers who have not invested time in relationship building or do not know how due to limited contact with AA people are at a disadvantage and may not receive optimal research data.

Therefore, one suggestion is to design research using principles of community-based participatory research (CPBR) approach, which includes developing partnerships with members of the AA community that provides for ‘key informants’ and integrating them into every aspect of the research (Brush et al., 2020). This can assist the researcher in making the necessary changes to their research before engaging in more extensive studies. It is important to essential that the AARP in this study came from diverse educational backgrounds including, teachers, leaders of health organizations, universities affiliates, research registries, and participant pools. Therefore, they were aware of the health concerns of their community and could quickly pick up on the “vibe” (20) of the researcher, which significantly impacted their decision to participate in research. Researcher posturing or nonverbal body language are just as important as the delivery of the research presentation. The participant can pick up on the researcher’s intentions for research or the “vibe” and immediately determine if they are interested in participating in the research study. This is another example that supports the necessity of including AANS as essential to increase research participation in the AARP population.

Implications for Nursing Education

The absence of AA in leadership positions in the school of nursing left minority doctoral students who preferred AA mentorship feeling lost, unable to navigate a predominantly white institution, and seeking AA mentorship outside of their local academic context. In addition, while reflecting on their doctoral experience, several AANS spoke to being the only Black doctoral student or first-generation college student seeking mentorship and guidance outside of their family or close social network. Therefore, it is crucial to improve the pipeline of AANS students, AA tenured faculty, and educate doctoral faculty on how to assist AANS doctoral students with their research goals, especially goals geared toward improving AA health and closing the gap in AA health inequities. There was also the identification of hidden barriers faced by many AA doctoral students, as one participant called it "the hidden curriculum." This "hidden curriculum" posed additional racial barriers on AA students that left them at a disadvantage of completing their graduation goals by leaving them unaware of the rules of engagement. Therefore, institutions should put in place protective mechanisms and safe havens for AANS doctoral students that support and nourish their academic achievement and foster their ability to meet their goals in an equitable manner.

Implications for AANS

Many of the AANSs take on the additional roles to their faculty responsibilities of education, research, and community service. The dearth of AA faculty equates to the compounded request from AA doctoral students seeking Black mentorship, which requires additional attention from the few AANS on staff as well as the additional time and effort spent developing community relationships. This minority tax can be insurmountable for AANS who are the only Black or one of only a few Black faculty in their departments or institutions. The structural system of Black mentorship needs a careful reevaluation and must be designed to support and build the number of tenured AANS and implement mentorship programs that support minority students. The limited pipeline of AA nursing students entering doctoral studies, the dearth and barriers surrounding tenured AANS, and the low accrual and retention of AARP in research all exaggerate the widening gap in AA health disparities. The structural pipeline to educate AANS necessitates a reexamination for it to align with the National Institutes of Nursing Research 2022-2026 development goals to promote the mentorship of nurse scientists (NINR, 2021).

Future Research

As a result of the study findings, several new directions for research were identified and needed further examination. For AARP, additional research is needed to examine their mistreatment more deeply by health providers and its impact on AA health behaviors. The overwhelming discussion by AARP of their experiences with delayed healthcare, misdiagnosis, and harm during health research warrants further examination. Distrust of health care providers has caused several AARP to seek health care outside of the standard health care system and use alternative treatment including chants, herbal medicine, diet changes, and generational cookbooks, therefore, opening another avenue for research in describing these alternative forms of health to provide a fundamental understanding of their impact of AA health behaviors.

The scarcity of data surrounding AANS deems it necessary to better understand the gaps in AANS tenured faculty and the availability of AA mentorship in academic settings. During the study, several AARP talked about the technology challenges in the Black elderly population due to the pandemic and those researchers are missing valuable information from that population.

Therefore, research examining the technology barrier in the elderly population is necessary for population inclusiveness in AA research participation.

To extend the findings of the collective missions of AANS and AARP, an ethnographic study to observe and examine AA research dyads to learn more about how they build relationships and partnerships in research in real-time would significantly contribute to nursing knowledge.

Conclusion

This study described the nature and dimensions of the relationships and shared motivational factors, behaviors, and interactions of AANS and AARP that impact participation. Moreover, this study captured the counterstories and the unique voices of the AARP and a careful historical examination to gain in-depth awareness of AA justifiable mistrust of research participation and the shared cultural experiences with racism. This study challenges the dominant ideology that AA are not eager to participate in research and offers solutions to promote research inclusive of the AARP view and perceptions.

Seminal contributions have been made by highlighting the many contributions of AANS that facilitate AA participation in research and the collectivist commitment to improving AA population health through participation in research. The literature that examines AA research participation is sparse and has decreased while the health inequities and the gap in health disparities are increasing. Therefore, research in AA research participation strategies needs to proceed urgently, including translational research so the AA community can see how research is impacting and helping future generations. More importantly, it is essential that AA who elect to participate despite historical and contemporary mistreatment based on race are valued and respected as experts as they hold the link to improving AA research participation.

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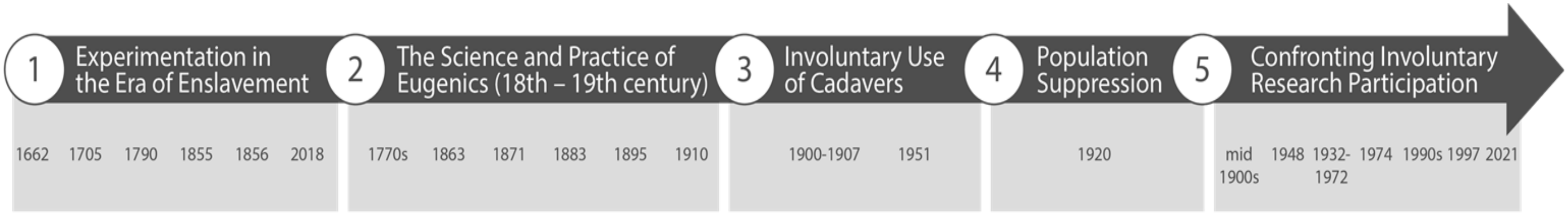
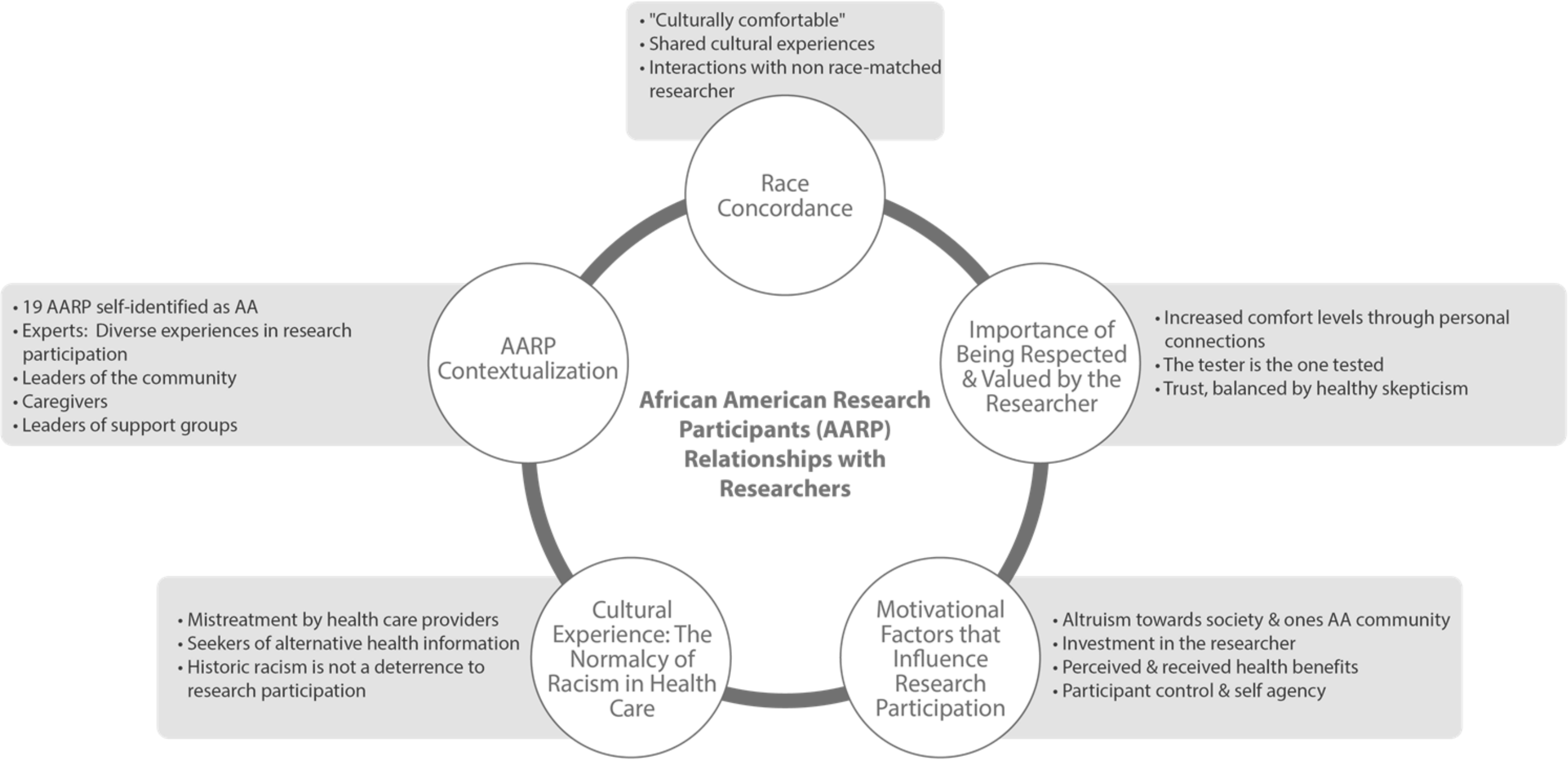
Appendices

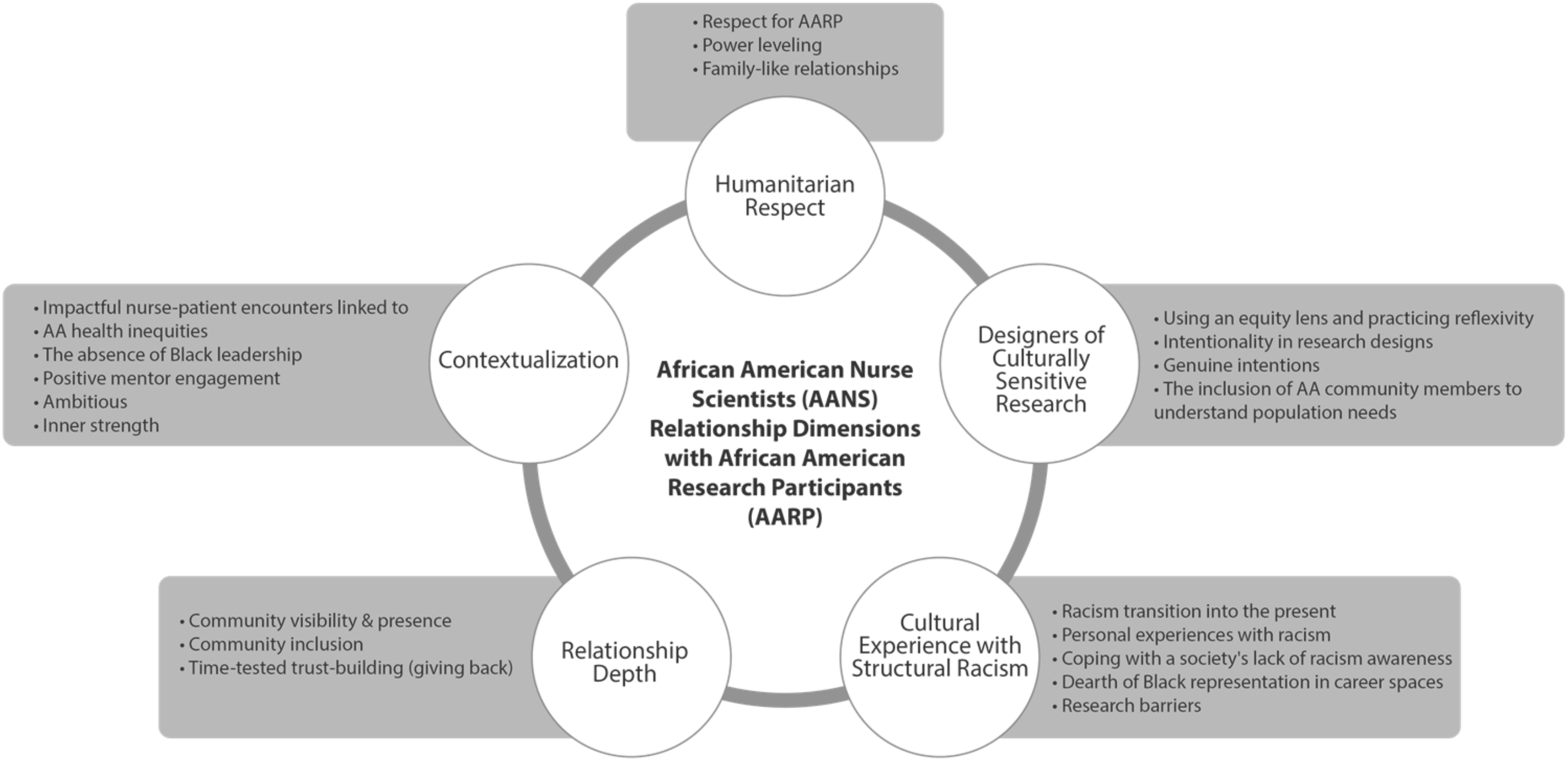
Appendix A: Historical Context Timeline



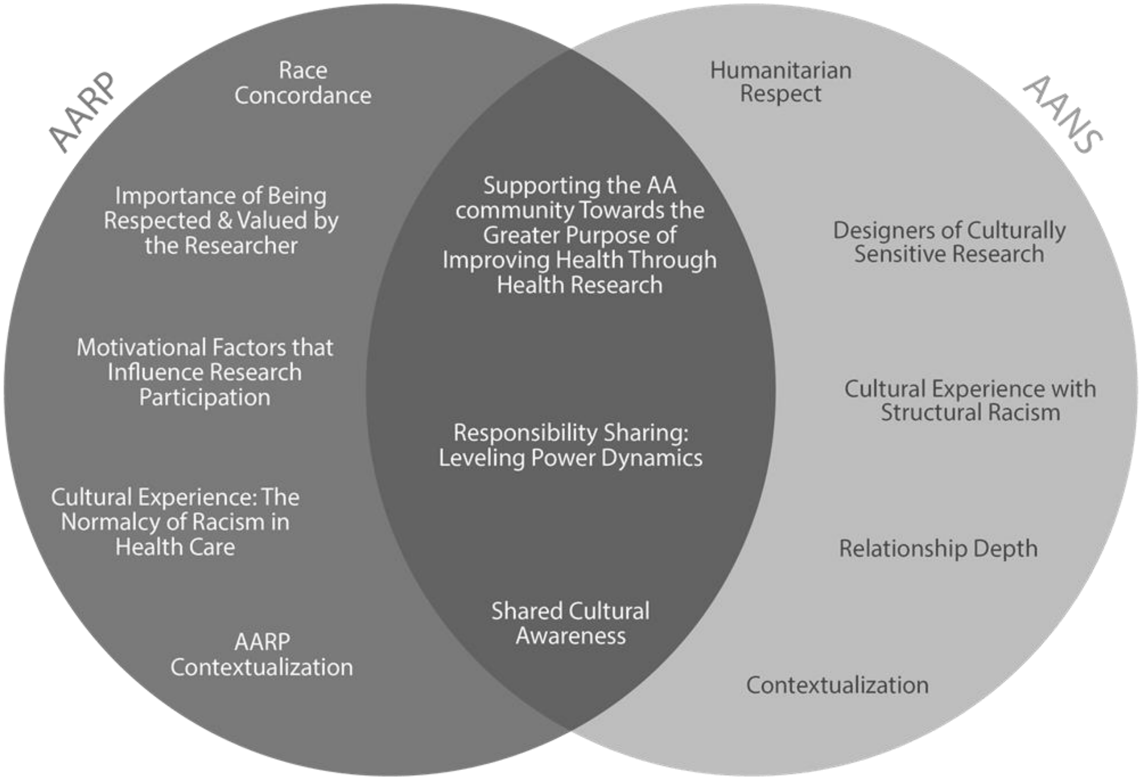
Appendix B African American Research Participants (AARP) Relationships with Researchers Diagram



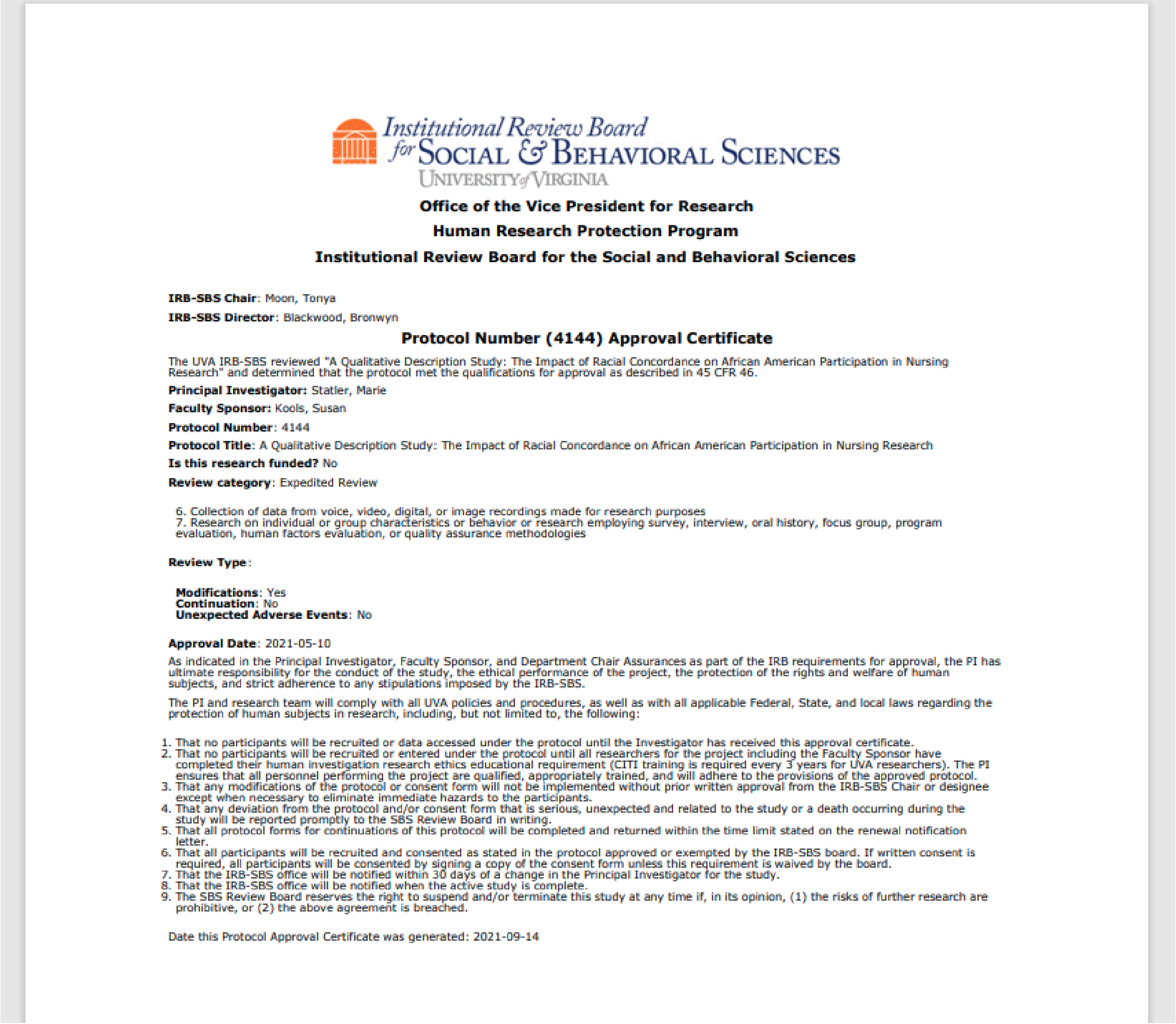
Appendix C African American Nurse Scientist Relationship Dimensions with African American Research Participants



Appendix **D: Collectivist Commitment to Improve AA Population Health Through Participation in Research Diagram**



Appendix E: Institutional Review Board IRB Approval



Institutional Review Board
for Social & Behavioral Sciences
University of Virginia

Office of the Vice President for Research
Human Research Protection Program
Institutional Review Board for the Social and Behavioral Sciences

IRB-SBS Chair: Moon, Tonya

IRB-SBS Director: Blackwood, Bronwyn

Protocol Number (4144) Approval Certificate

The UVA IRB-SBS reviewed "A Qualitative Description Study: The Impact of Racial Concordance on African American Participation in Nursing Research" and determined that the protocol met the qualifications for approval as described in 45 CFR 46.

Principal Investigator: Statler, Marie

Faculty Sponsor: Kools, Susan

Protocol Number: 4144

Protocol Title: A Qualitative Description Study: The Impact of Racial Concordance on African American Participation in Nursing Research

Is this research funded? No

Review category: Expedited Review

6. Collection of data from voice, video, digital, or image recordings made for research purposes
7. Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

Review Type:

Modifications: Yes
Continuation: No
Unexpected Adverse Events: No

Approval Date: 2021-05-10

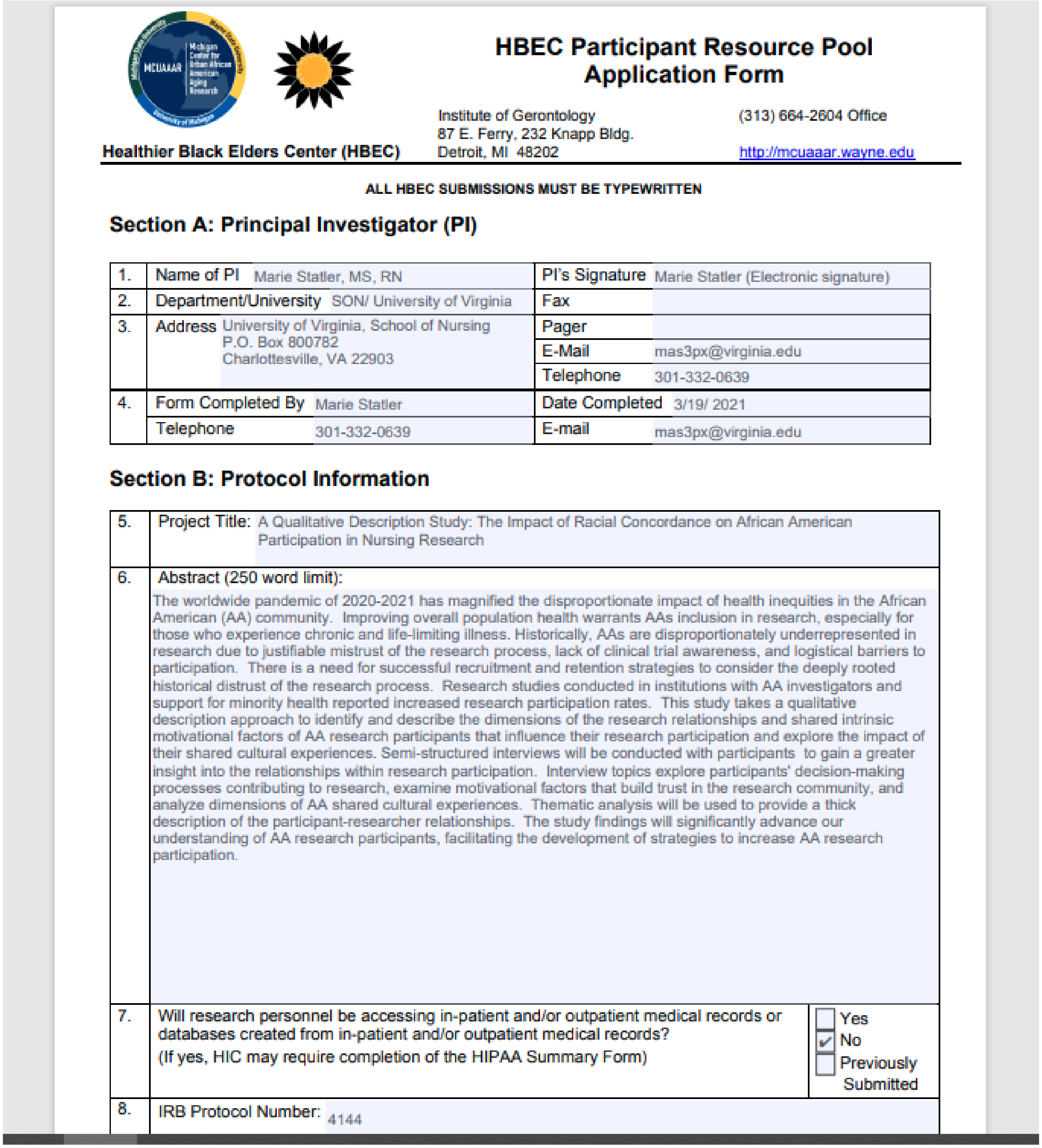
As indicated in the Principal Investigator, Faculty Sponsor, and Department Chair Assurances as part of the IRB requirements for approval, the PI has ultimate responsibility for the conduct of the study, the ethical performance of the project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the IRB-SBS.

The PI and research team will comply with all UVA policies and procedures, as well as with all applicable Federal, State, and local laws regarding the protection of human subjects in research, including, but not limited to, the following:

1. That no participants will be recruited or data accessed under the protocol until the Investigator has received this approval certificate.
2. That no participants will be recruited or entered under the protocol until all researchers for the project including the Faculty Sponsor have completed their human investigation research ethics educational requirement (CITI training is required every 3 years for UVA researchers). The PI ensures that all personnel performing the project are qualified, appropriately trained, and will adhere to the provisions of the approved protocol.
3. That any modifications of the protocol or consent form will not be implemented without prior written approval from the IRB-SBS Chair or designee except when necessary to eliminate immediate hazards to the participants.
4. That any deviation from the protocol and/or consent form that is serious, unexpected and related to the study or a death occurring during the study will be reported promptly to the SBS Review Board in writing.
5. That all protocol forms for continuations of this protocol will be completed and returned within the time limit stated on the renewal notification letter.
6. That all participants will be recruited and consented as stated in the protocol approved or exempted by the IRB-SBS board. If written consent is required, all participants will be consented by signing a copy of the consent form unless this requirement is waived by the board.
7. That the IRB-SBS office will be notified within 30 days of a change in the Principal Investigator for the study.
8. That the IRB-SBS office will be notified when the active study is complete.
9. The SBS Review Board reserves the right to suspend and/or terminate this study at any time if, in its opinion, (1) the risks of further research are prohibitive, or (2) the above agreement is breached.

Date this Protocol Approval Certificate was generated: 2021-09-14

Appendix F: HBEC Participant Resource Pool Application Form



Healthier Black Elders Center (HBEC)

HBEC Participant Resource Pool Application Form

Institute of Gerontology
87 E. Ferry, 232 Knapp Bldg.
Detroit, MI 48202

(313) 664-2604 Office
http://mcuaaar.wayne.edu

ALL HBEC SUBMISSIONS MUST BE TYPEWRITTEN

Section A: Principal Investigator (PI)

1.	Name of PI	Marie Statler, MS, RN	PI's Signature	Marie Statler (Electronic signature)
2.	Department/University	SON/ University of Virginia	Fax	
3.	Address	University of Virginia, School of Nursing P.O. Box 800782 Charlottesville, VA 22903	Pager	
			E-Mail	mas3px@virginia.edu
			Telephone	301-332-0639
4.	Form Completed By	Marie Statler	Date Completed	3/19/ 2021
	Telephone	301-332-0639	E-mail	mas3px@virginia.edu

Section B: Protocol Information

5. Project Title: A Qualitative Description Study: The Impact of Racial Concordance on African American Participation in Nursing Research

6. Abstract (250 word limit):

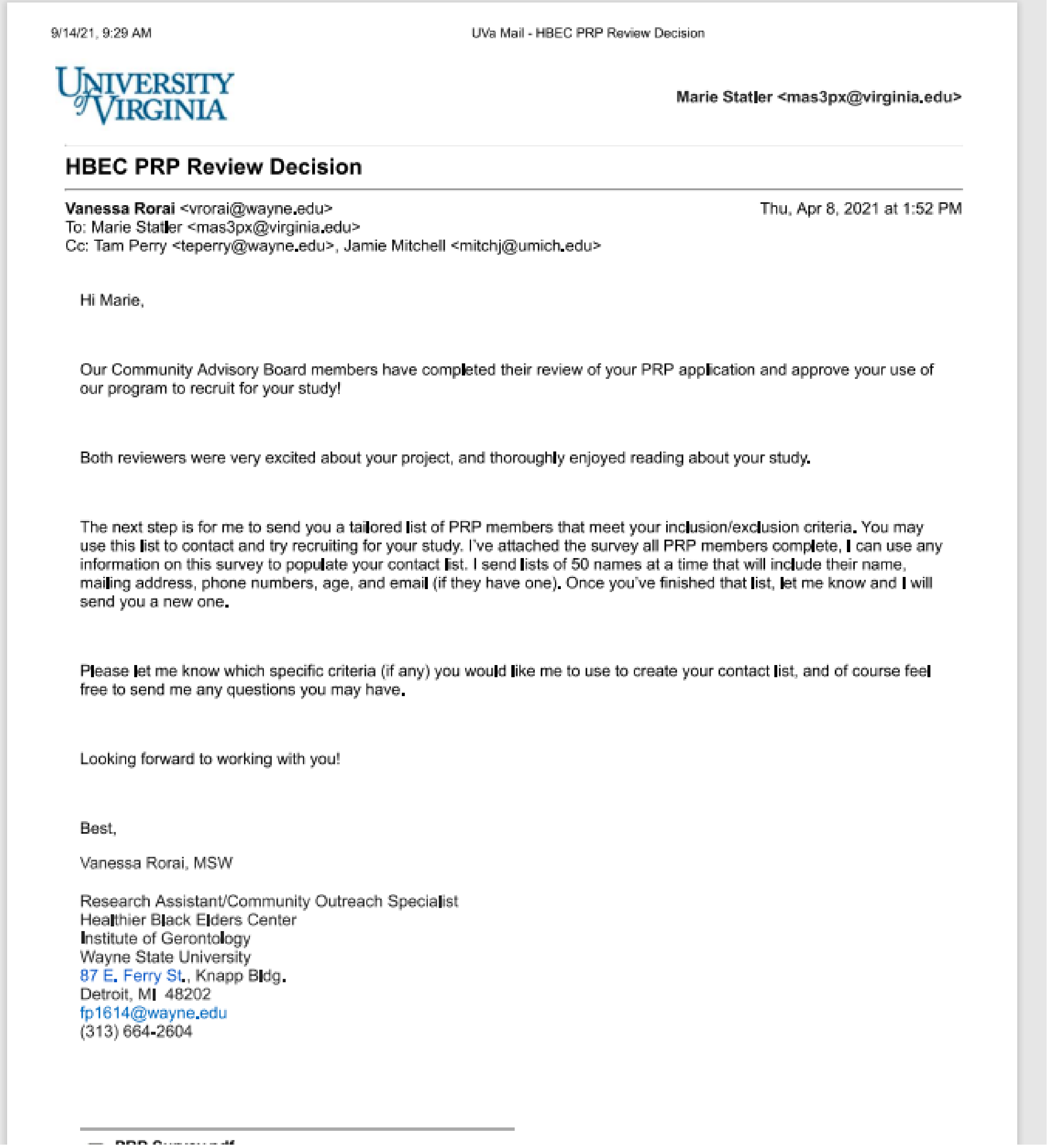
The worldwide pandemic of 2020-2021 has magnified the disproportionate impact of health inequities in the African American (AA) community. Improving overall population health warrants AAs inclusion in research, especially for those who experience chronic and life-limiting illness. Historically, AAs are disproportionately underrepresented in research due to justifiable mistrust of the research process, lack of clinical trial awareness, and logistical barriers to participation. There is a need for successful recruitment and retention strategies to consider the deeply rooted historical distrust of the research process. Research studies conducted in institutions with AA investigators and support for minority health reported increased research participation rates. This study takes a qualitative description approach to identify and describe the dimensions of the research relationships and shared intrinsic motivational factors of AA research participants that influence their research participation and explore the impact of their shared cultural experiences. Semi-structured interviews will be conducted with participants to gain a greater insight into the relationships within research participation. Interview topics explore participants' decision-making processes contributing to research, examine motivational factors that build trust in the research community, and analyze dimensions of AA shared cultural experiences. Thematic analysis will be used to provide a thick description of the participant-researcher relationships. The study findings will significantly advance our understanding of AA research participants, facilitating the development of strategies to increase AA research participation.

7. Will research personnel be accessing in-patient and/or outpatient medical records or databases created from in-patient and/or outpatient medical records?
(If yes, HIC may require completion of the HIPAA Summary Form)

☐ Yes
☑ No
☐ Previously Submitted

8. IRB Protocol Number: 4144

Appendix G: HBEC PRP Review Decision



9/14/21, 9:29 AM UVa Mail - HBEC PRP Review Decision

Marie Statler <mas3px@virginia.edu>

HBEC PRP Review Decision

Vanessa Rorai <vrorai@wayne.edu> Thu, Apr 8, 2021 at 1:52 PM
To: Marie Statler <mas3px@virginia.edu>
Cc: Tam Perry <teperry@wayne.edu>, Jamie Mitchell <mitchj@umich.edu>

Hi Marie,

Our Community Advisory Board members have completed their review of your PRP application and approve your use of our program to recruit for your study!

Both reviewers were very excited about your project, and thoroughly enjoyed reading about your study.

The next step is for me to send you a tailored list of PRP members that meet your inclusion/exclusion criteria. You may use this list to contact and try recruiting for your study. I've attached the survey all PRP members complete, I can use any information on this survey to populate your contact list. I send lists of 50 names at a time that will include their name, mailing address, phone numbers, age, and email (if they have one). Once you've finished that list, let me know and I will send you a new one.

Please let me know which specific criteria (if any) you would like me to use to create your contact list, and of course feel free to send me any questions you may have.

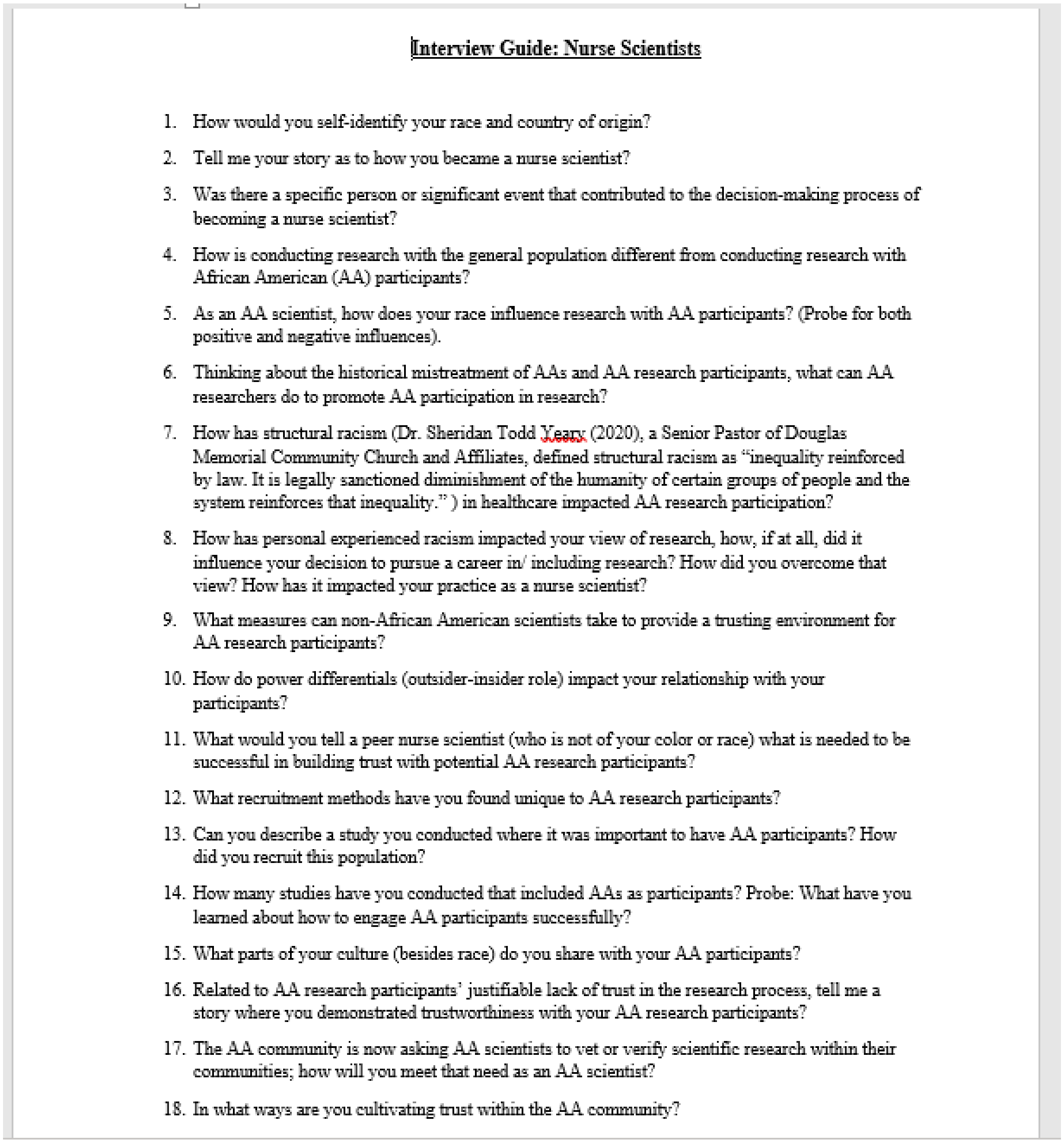
Looking forward to working with you!

Best,

Vanessa Rorai, MSW

Research Assistant/Community Outreach Specialist
Healthier Black Elders Center
Institute of Gerontology
Wayne State University
87 E. Ferry St., Knapp Bldg.
Detroit, MI 48202
fp1614@wayne.edu
(313) 664-2604

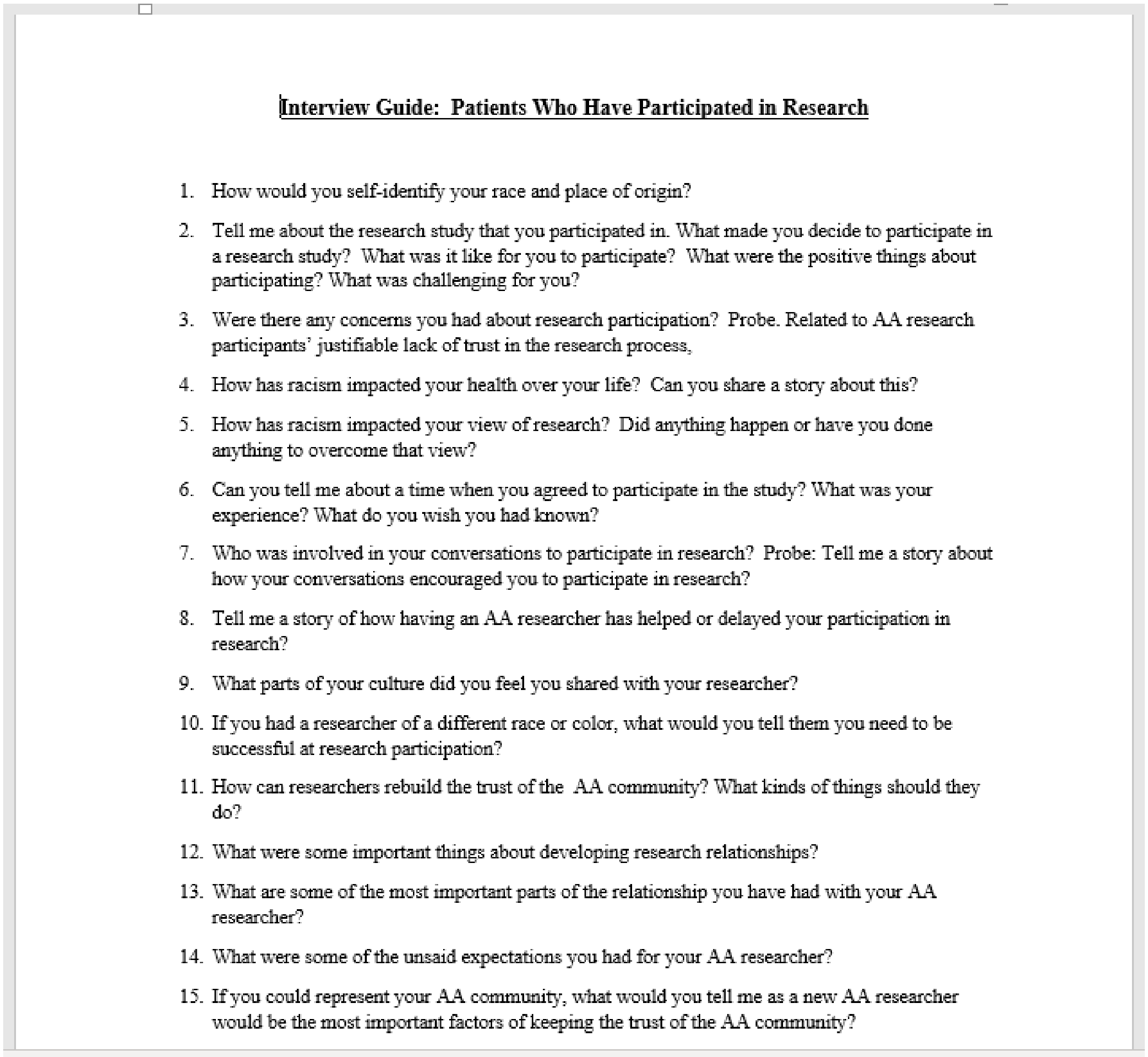
Appendix H: Interview Guide: Nurse Scientists



Interview Guide: Nurse Scientists

1. How would you self-identify your race and country of origin?
2. Tell me your story as to how you became a nurse scientist?
3. Was there a specific person or significant event that contributed to the decision-making process of becoming a nurse scientist?
4. How is conducting research with the general population different from conducting research with African American (AA) participants?
5. As an AA scientist, how does your race influence research with AA participants? (Probe for both positive and negative influences).
6. Thinking about the historical mistreatment of AAs and AA research participants, what can AA researchers do to promote AA participation in research?
7. How has structural racism (Dr. Sheridan Todd Yeary (2020), a Senior Pastor of Douglas Memorial Community Church and Affiliates, defined structural racism as "inequality reinforced by law. It is legally sanctioned diminishment of the humanity of certain groups of people and the system reinforces that inequality.") in healthcare impacted AA research participation?
8. How has personal experienced racism impacted your view of research, how, if at all, did it influence your decision to pursue a career in/ including research? How did you overcome that view? How has it impacted your practice as a nurse scientist?
9. What measures can non-African American scientists take to provide a trusting environment for AA research participants?
10. How do power differentials (outsider-insider role) impact your relationship with your participants?
11. What would you tell a peer nurse scientist (who is not of your color or race) what is needed to be successful in building trust with potential AA research participants?
12. What recruitment methods have you found unique to AA research participants?
13. Can you describe a study you conducted where it was important to have AA participants? How did you recruit this population?
14. How many studies have you conducted that included AAs as participants? Probe: What have you learned about how to engage AA participants successfully?
15. What parts of your culture (besides race) do you share with your AA participants?
16. Related to AA research participants' justifiable lack of trust in the research process, tell me a story where you demonstrated trustworthiness with your AA research participants?
17. The AA community is now asking AA scientists to vet or verify scientific research within their communities; how will you meet that need as an AA scientist?
18. In what ways are you cultivating trust within the AA community?

Appendix I: Interview Guide Patients Who Have Participated in Research



Interview Guide: Patients Who Have Participated in Research

1. How would you self-identify your race and place of origin?
2. Tell me about the research study that you participated in. What made you decide to participate in a research study? What was it like for you to participate? What were the positive things about participating? What was challenging for you?
3. Were there any concerns you had about research participation? Probe. Related to AA research participants' justifiable lack of trust in the research process,
4. How has racism impacted your health over your life? Can you share a story about this?
5. How has racism impacted your view of research? Did anything happen or have you done anything to overcome that view?
6. Can you tell me about a time when you agreed to participate in the study? What was your experience? What do you wish you had known?
7. Who was involved in your conversations to participate in research? Probe: Tell me a story about how your conversations encouraged you to participate in research?
8. Tell me a story of how having an AA researcher has helped or delayed your participation in research?
9. What parts of your culture did you feel you shared with your researcher?
10. If you had a researcher of a different race or color, what would you tell them you need to be successful at research participation?
11. How can researchers rebuild the trust of the AA community? What kinds of things should they do?
12. What were some important things about developing research relationships?
13. What are some of the most important parts of the relationship you have had with your AA researcher?
14. What were some of the unsaid expectations you had for your AA researcher?
15. If you could represent your AA community, what would you tell me as a new AA researcher would be the most important factors of keeping the trust of the AA community?

Appendix J Informed Written Consent for AARP

Informed Written Consent Agreement: Patients Who Have Participated in Research

Study Title: A Qualitative Description Study: The Impact of Racial Concordance on African American Participation in Nursing Research

Please read this consent agreement carefully before you decide to participate in the study.

Purpose of the research study: The purpose of the study is to give you, as an African American patient who has participated in research, a chance to have your voice heard. We want to hear about your stories as an African American research participant, relationships with researchers, and why you chose to participate in research.

What you will do in the study: You will be asked to provide a Zoom or phone interview. Your interview information and stories will provide very important information about the importance of research participation in the African American community. During the interview, you will be asked several questions about your relationship with African American researchers and research participation. Some of the questions are about the sensitive topic of race and how it has affected your choice to be a research participant. You can skip questions, delay the interview, and or stop the interview if at any time you feel uncomfortable.

Time required: The study will require about 60-90 minutes of your time. If you become fatigued or are interested in interviewing longer than the allotted time, the researcher will schedule the remainder of the interview at a time that works for your schedule.

Risks: The potential risks include the possibility of feeling stressed when talking about difficult experiences that happened in your past. The researcher will also provide additional counseling resources if needed. There is a very small chance your data can get out. To protect your privacy, the researcher will make every effort to keep the information safe by removing your name and important information from the recorded data.

Benefits: There are no direct benefits to you for participating in this research study. The study may help us understand African American relationships, thoughts, and feeling about research participation in the United States.

Confidentiality: The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be kept in a locked file. When the study is completed, and the data have been analyzed, this list will be destroyed. Your name will not be used in any report. All recordings and written data will be erased after five years. The study results will be used to create new ways to help African Americans with research participation and develop mentorship programs for African American nurse scientists.

Confidentiality cannot be guaranteed: Because of the nature of the data, I cannot guarantee your data will be confidential, and it may be possible that others will know what you have reported, however; there will be no attempt to do so, and your data will be reported in a way that will not identify you. The researcher will remove any identifying information (such as your name, contact information, etc.) connected to the information you provide.

Voluntary participation: Your participation in the study is completely voluntary.

Right to withdraw from the study: You have the right to withdraw from the study at any time without penalty. If you choose to withdraw from the study, all audio and video recordings will be destroyed and not used for the research study.

How to withdraw from the study: If you would like to withdraw after your materials have been submitted, please contact lead researcher Marie Campbell-Statler at 301-332-0639 to withdraw from the study. Withdrawal from the study can occur at any time during the interview or research. If you want to withdraw from the study, email or call the lead researcher and let her know you want to withdraw from the study. There is no penalty for withdrawing from the study, and you will still receive the Amazon electronic gift card of $25.00 for the study.

Payment: You will receive a $25.00 Amazon electronic gift card for participation. After the interview, the electronic gift card will be emailed to the email address you provide. Should a second interview be required, you will be paid an additional $25.00 gift card.

Using data beyond this study: The researcher will maintain access to your data and not share your data with researchers outside this study. The data you provide in this study will be retained in a secure manner by the researcher for five years and then destroyed.

If you have questions about the study, contact:
Marie Campbell-Statler
University of Virginia, School of Nursing
P.O. Box 800782
Charlottesville, VA 22903
Telephone: (301) 332-0639
Email address: mas3px@virginia.edu

Susan Kools, PhD, RN, FAAN
Faculty Sponsor
University of Virginia, School of Nursing
P.O. Box 800782
Charlottesville, VA 22903-0782
Telephone: (434) 243-3974
Email address: smk96@virginia.edu

To obtain more information about the study, ask questions about the research procedures, express concerns about your participation, or report illness, injury or other problems, please contact:
Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences
One Morton Dr Suite 500
University of Virginia, P.O. Box 800392
Charlottesville, VA 22908-0392
Telephone: (434) 924-5999
Email: irbsbshelp@virginia.edu
Website: https://research.virginia.edu/irb-sbs
Website for Research Participants: https://research.virginia.edu/research-participants

UVA IRB-SBS # 4144

Agreement:
If you agree to participate in the above study, the researcher will obtain a verbal consent and document your agreement immediately before the interview.

If you need a copy of this consent form, you may print a copy of this page for your records.

Appendix K Informed Written Consents for AANS

Informed Written Consent Agreement: Nurse Scientists

Study Title: A Qualitative Description Study: The Impact of Racial Concordance on African American Participation in Nursing Research

Please read this consent agreement carefully before you decide to participate in the study.

Purpose of the research study: The purpose of the study is to give you, as an African American Nurse Scientist, a chance to have your voices heard. We want to hear about your stories and relationships between African American research participants and African American nurse scientists, and why you chose to participate in research.

What you will do in the study: You will be asked to provide a Zoom or phone interview. Your interview information and stories will provide very important information about the importance of research participation in the African American community. During the interview, you will be asked several questions about your relationship with African American researchers and research participation. Some of the questions are about the sensitive topic of race and how it has affected your choice to be a nurse scientist. You can skip questions, delay the interview, and or stop the interview if at any time you feel uncomfortable.

Time required: The study will require about 60-90 minutes of your time. If you become fatigued or are interested in interviewing longer than the allotted time, the researcher will schedule the remainder of the interview at a time that works for your schedule.

Risks: The potential risks include the possibility of feeling stressed when talking about difficult experiences that happened in your past. The researcher will also provide additional counseling resources if needed. There is a very small chance your data can get out. To protect your privacy, the researcher will make every effort to keep the information safe by removing your name and important information from the recorded data.

Benefits: There are no direct benefits to you for participating in this research study. The study may help us understand African American relationships, thoughts, and feeling about research participation in the United States.

Confidentiality: The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be kept in a locked file. When the study is completed, and the data have been analyzed, this list will be destroyed. Your name will not be used in any report. All recordings and written data will be erased after five years. The study results will be used to create new ways to help African Americans with research participation and develop mentorship programs for African American nurse scientists.

Confidentiality cannot be guaranteed: Because of the nature of the data, I cannot guarantee your data will be confidential, and it may be possible that others will know what you have reported, however;

there will be no attempt to do so, and your data will be reported in a way that will not identify you. The researcher will remove any identifying information (such as your name, contact information, etc.) connected to the information you provide.

Voluntary participation: Your participation in the study is completely voluntary.

Right to withdraw from the study: You have the right to withdraw from the study at any time without penalty. If you choose to withdraw from the study, all audio and video recordings will be destroyed and not used for the research study.

How to withdraw from the study: If you would like to withdraw after your materials have been submitted, please contact lead researcher Marie Campbell-Statler at 301-332-0639 to withdraw from the study. Withdrawal from the study can occur at any time during the interview or research. If you want to withdraw from the study, email or call the lead researcher and let her know you want to withdraw from the study. There is no penalty for withdrawing from the study, and you will still receive the Amazon electronic gift card of $25.00 for the study.

Payment: You will receive a $25.00 Amazon electronic gift card for participation. After the interview, the electronic gift card will be emailed to the email address you provide. Should a second interview be required, you will be paid an additional $25.00 gift card.

Using data beyond this study: The researcher will maintain access to your data and not share your data with researchers outside this study. The data you provide in this study will be retained in a secure manner by the researcher for five years and then destroyed.

If you have questions about the study, contact:
Marie Campbell-Statler
University of Virginia, School of Nursing
P.O. Box 800782
Charlottesville, VA 22903
Telephone: (301) 332-0639
Email address: mas3px@virginia.edu

Susan Kools, PhD, RN, FAAN
Faculty Sponsor
University of Virginia, School of Nursing
P.O. Box 800782
Charlottesville, VA 22903-0782
Telephone: (434) 243-3974
Email address: smk96@virginia.edu

To obtain more information about the study, ask questions about the research procedures, express concerns about your participation, or report illness, injury or other problems, please contact:
Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences

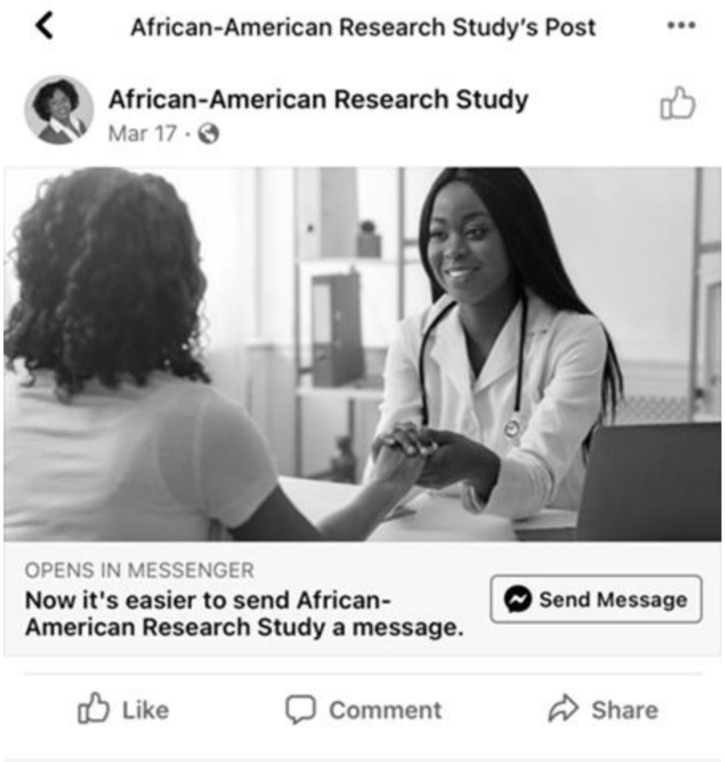
One Morton Dr Suite 500
University of Virginia, P.O. Box 800392
Charlottesville, VA 22908-0392
Telephone: (434) 924-5999
Email: irbsbshelp@virginia.edu
Website: https://research.virginia.edu/irb-sbs
Website for Research Participants: https://research.virginia.edu/research-participants

UVA IRB-SBS # 4144

Agreement:
If you agree to participate in the above study, the researcher will obtain a verbal consent and document your agreement immediately before the interview.

If you need a copy of this consent form, you may print a copy of this page for your records.

Appendix L Facebook Advertisements



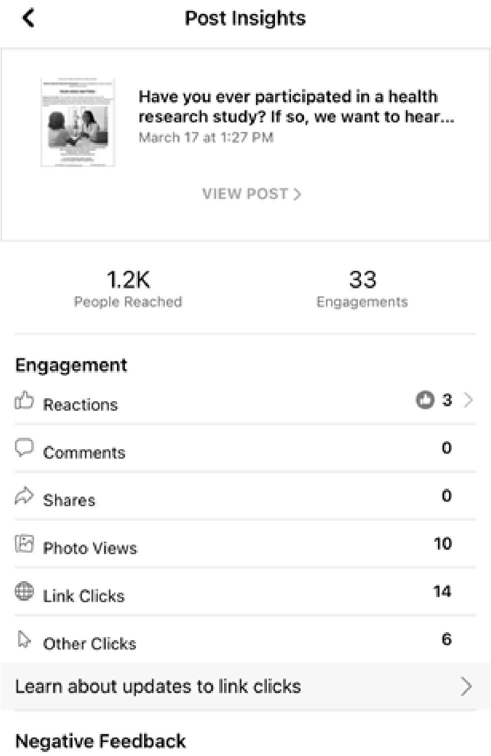
African-American Research Study's Post

African-American Research Study

Mar 17 ·

OPENS IN MESSENGER

Now it's easier to send African-American Research Study a message.



Post Insights

Have you ever participated in a health research study? If so, we want to hear...

March 17 at 1:27 PM

1.2K People Reached

33 Engagements

Engagement

Reactions	3
Comments	0
Shares	0
Photo Views	10
Link Clicks	14
Other Clicks	6

Learn about updates to link clicks

Negative Feedback

Table 1:

African American Research Participant (AARP) Themes

Themes	Subthemes	Categories
1: AARP contextualization		
2: Motivational factors that influence research participation	2:1 Altruism towards society 2:2 Altruism toward one's African American community 2:3 Investment in the researcher 2:4 Perceived and received health benefits 2:5 Participant control and self-agency	2:4a Medical and screening diagnostics. 2:4b Health education learning opportunities beyond research.
3: Cultural experience: The normalcy of racism in health care	3:1 Mistreatment by health care providers 3:2 Seekers of alternative health information 3:3 Historic racism is not a deterrence to research participation	3:3a Faith in God.
4: Importance of being respected and valued by the researcher	4:1 Increased comfort levels through personal connections 4:2 The tester is the one tested 4:3 Trust, balanced by healthy skepticism 4:4 Inclusion in dissemination of findings.	
5: Race concordance	5:1 "Culturally comfortable" Through shared cultural experiences 5:2 Interactions with the Non-race matched researcher	

Table 2:

African American Nurse Scientist (AANS) Themes

Themes	Subthemes	Categories
1: AANS contextualization	1:1 Impactful nurse-patient encounters linked to AA health inequities 1:2 The absence of Black leadership 1:3 Positive mentor engagement 1:4 Ambition 1:5 Inner strength	1:3a Black mentorship. 1:3b White ally mentorship
2: Cultural experience: The normalcy of racism in health care	2:1 Racism's transition into the present 2:2 Personal experiences with racism 2:3 Coping with a society's lack of racism awareness 2:4 Dearth of Black representation in career spaces 2:5 Research barriers	
3: Design of culturally sensitive research	3:1 Using an equity lens and practicing reflexivity subtheme 3:2 Genuine intentions	3:2a The inclusion of AA community members to understand population-based needs.
4: Relationship depth with AA research participants	4:1 Community visibility and presence 4:2 Community inclusion 4:3 Time-tested trust building (Giving Back)	
5: Humanitarian respect	5:1 Power leveling 5:2 Family like relationship	