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Our story, our song: assessing and addressing black women's healthcare experiences.

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OUR STORY, OUR SONG
ASSESSING AND ADDRESSING BLACK WOMEN'S HEALTHCARE
EXPERIENCES

By

Jason Allen Deakings
MSPH., Meharry Medical College, 2018
B.S., University of Phoenix, 2016

A Dissertation
Submitted to the Faculty of the
School of Public Health and Information Sciences
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University of Louisville
Louisville, KY

May 2023

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A Dissertation Approved on

April 28, 2023

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DEDICATION

This dissertation is dedicated to all the Black women who have been manipulated, ignored, and traumatized when seeking healthcare services. To Anarcha, Betsy, and Lucy, who were violently exploited and experimented on, without consent, to advance western medicine, I lift your voices, and the voices of countless other women who suffered in the name of medical advancement. Henrietta, I honor you. Kira, I honor you. Black Women, I honor you. I will use this study and make it my life's work to continuously be your advocate in all forms of health and wellbeing.

ACKNOWLEDGMENTS

somebody who talked like my aunties, my mom. Someone who put language to what I have been feeling for so long being raised by a single mother and raised by Black women, thank you! You empowered me, you allowed me in a space not meant for me, allowed me to be pensive in my silence and gave voice to my dissertation, thank you! Lastly, to Dr. Erves, my forever mentor. I made it, you said I would. Your lessons and mentorship have been invaluable. I came to the University of Louisville super prepared! Thank you for the conversations, thank you for your sisterly advice, and thank you for holding me accountable.

I'd like to acknowledge my research partners, and my friends, The Hope Buss: Stachelle Bussey, Nannie Croney, and Angel Todd. Additionally, my research assistant, Alyssa "Kui" Kabithe and music therapist and Sister Circle facilitator, Allison Cross. This study was also for you all. Thank you for bringing these stories to life, providing light, and your lived experiences to enrich this research! I love you, thank you. To my partners, my participants, these are your stories, your opus. I hope I've made you proud and you feel seen!

Lastly, to my loving family, Audrey, Glenn, Jr., and Ericka, my heart in human form, thank you for constantly reminding me that I am not alone. My journey has been extremely untraditional, and you've told me, "Jason, it's your journey, be proud of it." Brother, achieving together has been one of the most fulfilling experiences of my life. You make me want to be great, thank you! I love you! Sister, my loudest cheerleader, thank you for letting me know that I deserve good things. Thank you for reflecting the

best parts of myself by just being you, I love you! Mommy, this research, and my

subsequent life's work is my love song to you. I wish I could show you how much you

mean to me, thank you for being the inspiration for my life! I love you!

ABSTRACT

OUR STORY, OUR SONG

ASSESSING AND ADDRESSING BLACK WOMEN'S HEALTHCARE

EXPERIENCES

Jason A. Deakings

April 28, 2023

Despite advancements in medicine and health sciences, health disparities and declining life expectancy persists among Black women in the United States. Researchers and non-traditional healthcare providers suggest alternative healing (e.g., music and Sister Circles) and research methodologies to achieve a culturally conscious, trauma-informed, quality, and holistic care and practice. The intersecting identities and cultural responsibility of Black women highly influences the barriers and facilitators on the uptake of healthcare services.

Utilizing a community engaged research approach, this qualitative study assessed the healthcare experiences, as well as the role of music in the lived and retold experiences of Black women navigating the healthcare system in Louisville, KY. A purposive sample of 25 women living in Louisville was recruited to participate in a one-on-one interview, or a Sister Circle session. Participants (n = 15) were interviewed regarding their experiences with healthcare services, perceptions of healthcare, self-help/healing methods, and the role of music in their lives. Sister Circle participants

joined a group session (n = 10) where music therapy centered healing interventions and research procedures (e.g., drum circle and song share). These non-traditional methods were also used to capture perceptions of healthcare and the power of music in their lives.

Results of this study prove that Black women are aware of their acquiescence of quality healthcare while attempting to care for their families, while also, self-advocating for their health and wellbeing besides a perception of judgement, discrimination, and differential treatment. Six themes were developed from the data by the researcher, participants, and community partners. Participants described a perception of feeling invisible in provider's offices, barriers to healthcare utilization, expectations of quality healthcare, a communalism for themselves and the larger Black community, the need for alternative healing and therapy methods, and the influence of music within their lives in and outside of the healthcare system.

Concluding, this study provides evidence supporting the need for alternative data collection, healing, and therapy methodologies when serving marginalized populations. It also gives insight into the perceptions and lived experiences of Black women navigating the healthcare system. Thus, it postulates implications for future research and healthcare policy and practices that seek to provide a quality and holistic care experience for Black women.

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CHAPTER I

INTRODUCTION

Background

History has provided structural and historical evidence of the disparity in health

and wellbeing of Black women compared to non-Black women (Collins, 2013; Jolivette,

2015). Although Black women constitute only 7.0 percent of the United States (U.S.)

population, and approximately 13.6 percent of all U.S. women, they have a higher

prevalence of chronic conditions (Chinn, Martin & Redmond, 2021).   In recent studies

among Black women, their experiences related to navigating education, healthcare,

pregnancy, and motherhood were captured and analyzed by researchers who have no

lived experience of the phenomena under investigation (Jolivette, 2015; Nayak, 2015;

Roberts, 1997). There is a dearth of literature that captures Black women's experience

with the healthcare system, positive and negative health outcomes, and trauma resiliency

within their own voice, utilizing culturally appropriate research methods (Chinn et al.,

2021; Hardeman, 2019). Eurocentric methodology and theories have continued to fail to

explain and clarify the expanding health issues that persist among this specific

population.

Cultural appropriateness (i.e., the consideration of the impact of culture in

program/intervention development) has been missing within the context of the uptake of

healthcare services among Black people (Hardeman, 2019). Generally, the definition of

culture has been universally accepted by social scientists as a phenomenon that is learned, shared, and transmitted from one generation to the next (Kreuter, Lukwago, Bucholtz, Clark & Thompson, 2003; Hardeman, 2019). Individual, behavioral, and social characteristics are not inherently "cultural," however, factors such as familial roles, communication patterns, spirituality, and collectivism, if given special meaning, value or symbolism by a group can be directly or indirectly associated with health-related behaviors (Kreuter et al., 2003).

Moreover, emotions and affects resulting from trauma require unique methods to be released. As a mode of emotional catharsis, narrative or artistic expression can facilitate the release of debilitating emotions. Historically, Black music has held this function (Visvis, 2008; Frame, Williams & Green, 1999). Black music, like the "talking cure" developed by Sigmund Freud and Josef Breuer, is posited by many Black artisans and researchers like Toni Morrison and Judith Herman to be efficacious as narratives providing insight into perceptions of Black people and essential therapy (Visvis, 2008).

Statement of the problem

No matter their socioeconomic status, Black women continue to be ignored in the healthcare setting, leading to adverse experiences with their individual health and the general health system (Collins, 2013). It is well-known that African Americans, compared to their white counterparts, experience a disproportionate burden of health problems, and receive lesser quality health care (Kreuter et al., 2011; Smedley & Stith, 2003). Within the U.S., this has led to racial and ethnic population subgroups with significant unmet health needs, none more apparent than Black women (Kreuter et al., 2011; Smedley & Stith, 2003; Chinn et al., 2021).

With their unique position of intersectionality and oppression, Black women's social status has become nearly invisible (Hull, Bell-Scott & Smith, 2015). Yet, identifying and addressing the trauma experienced by Black women in the social, political, economic, and healthcare environment is essential in improving their overall health and wellness. Their trauma, because of their varying experiences, compounds on itself. Without culturally appropriate, non-traditional evidence-based approaches and methods to address this trauma, as well as treat it and prevent further occurrences, Black women's health and wellness will continue to decline without valid explanation (Kreuter et al., 2011; Visvis, 2008; Frame et al., 1999; Frame & Williams, 1996). Their invisibility has allowed policy makers, healthcare workers, and those in systematic power to abuse the Black woman physically, politically, and socially. Their voices have been silenced, despite their necessity in the intellectual and social environment.

Theoretical Foundation

To allow for the exploration of this population's experiences, this study is structured utilizing Black Feminist Thought as a critical social theory. Black Feminism gained traction in the 1960s, as the civil rights movement excluded women from leadership positions, and the feminist movement chiefly impacted middle-class white women (Simien, 2004). This theory emphasizes the experience and perspectives of black women socially, economically, and politically, specifically in the context of their intersectionality, a term coined by author and activist Kimberle' Crenshaw in 1989. To account for their intersection (i.e., race, class, gender), that arguably, cannot be quantified, qualitative methodologies allow the researcher to explore the study phenomenon through the lens of Black feminism.

By understanding the natural presence of racism in all systems and realizing that the voices of marginalized populations (i.e., people of color) hold unique narratives and perceptions that should be present in all discussions of liberation and wellness, Black Feminist Thought supports a research justice approach to the study. Despite the double burden of racial and gender discrimination, Black women and Black feminist scholars have developed an intellectual tradition in Black Feminist Thought that is not widely known (Collins, 2000; Guy-Sheftall, 1995). With its theoretical roots drawing from narratives, poetry, music, and oral history, Black Feminist thought summarizes the multiple consciousness within which Black women have had to exist (Collins, 2000; Guy-Sheftall, 1995). Collins et al., (2000) depict the core themes of Black Feminist Thought as:

1) Work, Family, and Black Women's Oppression;

2) Controlling Images;

3) Self-Definition;

4) Sexual Politics;

5) Motherhood; and

6) Political Activism.

With the continued oppression of Black women in the Unites States, Black Feminism and subsequent theoretical base is imperative to their liberation (Collins, 2000; Guy-Sheftall, 1995). Black Feminist Thought represents an active response to the intersecting oppressions of race, class, sexuality, gender that impact Black women's social cohesion and ultimate health outcomes (Collins, 2000; Guy-Sheftall, 1995).

Study Overview

Due to the lack of literature focused on Black women's health, wellbeing, and trauma resiliency, specifically within the context of the healthcare system, this study will grant more information to the subject matter. The data provided can be used to improve the knowledge of researchers, healthcare workers, and healthcare providers, as well as the community that the study targets. The historic and current research and medical abuse/violence towards Black women has supported the increasing separation between this community and the quality of services and information that researchers and persons working in the healthcare system provide (Erves et al. 2017; Lang et al., 2013). Because of this population's exceptionally oppressed identities, it is imperative that their perspectives be captured to develop culturally appropriate interventions, community-based healthcare models, and ultimately shift the culture of health care to provide a more holistic and caring approach to fit their needs. Not only will this study capture Black women's experiences navigating the healthcare system, but it will also provide a unique therapy response, via music, to bring to the forefront any suppressed affect and/or emotion that resulted from their existing trauma.

Research Objectives

This research seeks to engage Black women and subsequent stakeholders on Black women's health and wellbeing utilizing Black Feminist Thought as a critical social theory, focusing on giving Black women a voice in telling their own stories, as well as their unique position under the weight of white supremacy and patriarchy. This study utilizes a non-traditional qualitative research design with two distinct questions and subsequent pertinent aims:

Research Question 1: What are the experiences of Black women navigating the healthcare system?

- Aim 1A: To examine the health and wellbeing of Black women navigating the healthcare system.

- Aim 1B: To identify unique health and wellness resources for Black women when they are navigating the healthcare system.

Research Question 2: What is the role of music in the lived and retold experiences of Black women navigating the healthcare system?

- Aim 2A: To assess the impact of music on the affect and resiliency of Black women navigating the healthcare system.

- Aim 2B: To identify alternative therapeutic resources for Black women when they are navigating the healthcare system.

Study Setting This study specifically explores the lived experiences of Black women in Louisville, Kentucky.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Despite the exuberant amount of innovation and advancements in western medicine, particularly in the United States, specific populations (e.g., Black women) have continued to experience negative health outcomes and adverse experiences within the healthcare system (Chinn et al., 2021). Well before western medicine was established, "healing the ill" was a concern for most ancient civilizations (Silvano, 2021; Gross & Sepkowitz, 2018). Hippocrates' four humors theory was pivotal in the developing origins of medicine, and was expounded upon by others, with the thought that anatomy was the foundation of all medicine (Conti, 2018; Smith, 1979). However, interpreting what it means to lose wellbeing, or to experience health and healing, in its foundational theoretical conception has varied across scientists throughout the world including Europe, the Middle East, and Western Asia (Silvano, 2021). Western medicine was established by early fourteenth century scholars to treat disease and illness that impaired physical health (Silvano, 2021; Gross & Sepkowitz, 1998; Conti, 2018), even still, from its inception, western medicine has been ambiguous in its definition and operation (Silvano, 2021; Conti, 2018). In more recent history, advancements in the areas of anatomy, physiology, pathology, surgery, and therapy have continued to present new knowledge to the healing art form (Silvano, 2021). Yet the science of medicine has consistently excluded social positioning as a factor in health outcomes. Because social constructs are

used to delineate differences among humans, western medicine and thus, positive health outcomes, have been disparate across populations of varying identities (Conti, 2011; Chinn, Martin & Redmond, 2021).

Within recent years, practitioners and researchers alike have established the patient-centered medical home (PCMH) model as best practice (American College of Physicians [ACP], 2021). In the PCMH care delivery model, patient treatment is coordinated through the primary care practitioner to ensure the necessary care is received when and where they need it, as well as delivered in a manner that they can understand (ACP, 2021). Despite the need to integrate the PCMH model into the routine policy and practices throughout the healthcare system, the United States has struggled to widely utilize this method to improve health outcomes, specifically for marginalized populations (ACP, 2021; Odell, 2016). The difficulty in its implementation is the absence of populations who 1) do not have a primary care practitioner, 2) have limited or no access to health insurance, 3) lack a social support system that encourages positive health decisions, and 4) have perceived the healthcare system to be traumatic or bothersome due to their own experiences (ACP, 2021; Odell, 2016).

With the growing disparity of negative health outcomes across populations, despite the advancements in western medicine, academic conversations surrounding trauma-informed care and alternative medicine and therapies have begun to challenge traditional western medicine practice and present a new way to structure healthcare as unique to each patient. This study will raise the voices of Black women, a group that despite social positioning continue to suffer negative health outcomes compared to their

white counterparts and allow them to tell their experiences navigating the healthcare system and the subsequent impact it has had on their health and wellbeing.

Western Medicine

The ambiguity of the origins of medicine has contributed to the disparate interpretations of how "healing the ill" applies to varying demographic populations (Silvano, 2021; Gross & Sepkowitz, 1998). Definitions on what the absence of wellbeing, "good health", and quality healing have changed drastically throughout history based on the theories of foundational practitioners and researchers, cultures, and ancient civilizations (Silvano, 2021; Conti, 2018). With the origins of medicine being developed as the art of healing, and the natural attractiveness to translate the practice to human and economic capital, "good health" was and is considered to be a precious commodity to those seeking healthcare (Silvano, 2021; Conti, 2018). From the ancient world to the present, major breakthroughs in western medicine include anatomy, physiology, pathology, microbiology, virology, and medical and surgical therapy (Silvano, 2021). Medicine has transitioned into a planetary enterprise, and as such, has and will influence the health outcomes for most all populations (Silvano, 2021; Conti, 2018; Conti, 2011).

Origins

Fundamentally, medicine has transformed and developed since the third century with philosopher Hippocrates and his four-humor theory (i.e., blood, yellow bile, black bile, and phlegm; Silvano, 2021; Conti, 2018; Karamanou et al., 2012). The Ancient Greek physician is credited to be among the first persons to construct theories on the paradigm of disease, approximately 2300 years ago (Silvano, 2021; Ashcraft, 2020). Included in the theory, Hippocrates posited that existence was represented by the four

basic elements – earth, air, fire, and water (Ashcraft, 2020; National Library of Medicine, 2013). In humans, the four elements correlated to the four basic humors (Silvano, 2021; Ashcraft, 2020). The Hippocratic theory postulated that the four humors related to a particular organ (i.e., the brain, lung, spleen, and gall bladder), and the balance of a person's humors dictated their personality type, making a person sanguine, phlegmatic, melancholic, or choleric (Silvano, 2021; Ashcraft, 2020). Furthermore, the imbalance of the four humors constituted a person being ill, and as such required the removal of a specific amount of excessive humor by various means, including bloodletting (Silvano, 2021; Ashcraft, 2020; Conti, 2018).

The Hippocratic School of philosophy became central to the Western tradition of medicine for centuries (Slivano, 2021; Conti, 2018; Smith, 1979). From pneumonia to tuberculosis, in many European hospitals, bloodletting and Hippocratic theory was considered the cornerstone of treatment (Conti, 2018; Smith, 1979). During the nearly two millennia that the Hippocratic theory dominated the landscape of medicine, many other researchers and physicians expanded on and/or hypothesized new foundations for medicine and healing (Silvano, 2021; Conti, 2018). Pedanius Dioscorides of Rome produced the *De Materia Medica*, a work illuminating the advances in herbal medicine (Silvano, 2021). Additionally, the most well-known physician in Rome, Claudius Galen, although accepting of Hippocrates' four humors theory, theorized further that the anatomy was the true foundation of all medicine (Silvano, 2021; Gross & Sepkowtiz, 1998). Galen described muscles and tendons of the human body and successfully demonstrated the kidneys' role in producing urine. The Hippocratic School of philosophy encompassed all these subsequent hypotheses, and it was not until the 16th

and 17th centuries that the theories were examined further (Silvano, 2021; Gross & Sepkowtiz, 1998).

Throughout the Renaissance period (i.e., 14th – 17th centuries), other concepts of health and medicine were proposed by various scholars (Conti, 2018; Porter, 1997). Paracelsus, a German-Swiss physician, and alchemist posited that human health relies on the harmonic correspondence between the microcosm of the human being and the macrocosm of the entire universe (Conti, 2018). He attributed the causes of diseases to specific entities—the spiritual, the ideal, the natural, the poisonous, and the planetary—in his work "Opus Paramirum" (1531). Additionally, he theorized that foundation of health and wellness could be observed and identified by the proper balance of the elements sulphur, mercury, and salt (Silvano, 2021; Conti, 2018). To remedy disease, Paracelsus suggested the implementation of the concept of similarity as a curative principle (i.e., "similia similibus"), meaning that "things should be treated with similar things" (Conti, 2018; Weeks, 2008).

On the basis of the observation of the multiple infectious diseases of the time, Italian physician and astronomer, Girolamo Fracastoro hypothesized that pathologies were determined by the transmission of "seminaria" (i.e., seeds of disease), that promulgated from sick people to healthy ones through direct contact and/or by means of personal items (Conti, 2018; Weeks, 2008). His idea of seminaria was examined through the frequent occurrence of syphilis, and as such proved to be the precursor to the foundational knowledge of modern germs and microbes (Silvano, 2021; Conti, 2018; Weeks, 2008). Medical historians cite Fracastoro's innovative work on health and

disease as the foundation of the modern epidemiologic assessment of (infectious) pathologies in large populations (Silvano, 2021; Conti, 2018; Conti, 2011; Weeks, 2008).

In the 18th century, other notable scholars and practitioners continued to expand the concept of health and disease with their foundation in both anatomy and physiology (Silvano, 2021; Conti, 2018). Italian physician and anatomist Giovanni Battista Morgagni accurately described and considered disease to be the anatomical alteration of one or more organs of human bodies (Conti, 2018; Conti, 2011). His findings came from the hundreds of dissections on the human body which he personally performed (Silvano, 2021; Conti, 2018). Conversely, the physiological theories proposed by scholars such as John Brown, creator of the "excitability" theory of medicine, and Swiss professor of medicine Albrecht von Haller, considered one of the founders of experimental physiology, created a far-reaching description of the perceptive faculty characteristics of nervous fibers (i.e., "sensibility"), as well as a description of the contractile muscular capacity prompted by irritation (i.e., "irritability;" Conti, 2018; Conti, 2013; Steinke, 2005).

Nineteenth century ideas of health and disease continued to pursue the concepts based upon physiological and anatomical research (Silvano, 2021; Conti, 2018). Pioneer of the experimentation of the life sciences, Claude Bernard, detailed the concept of the "internal environment" of organisms, leading to the revolutionary conception of human homeostasis (Conti, 2018; Porter, 1997). In addition to the theory of homeostasis, the roots, and concepts of pathology (i.e., identifying that triggering points of disease originate from altered cells) began to develop and saturate the framework of western medicine (Silvano, 2021; Conti, 2018; Porter, 1997). German researchers pioneered

numerous studies on pathological processes, as well as scientific investigations on a cellular level (Silvano, 2021; Conti, 2018; Porter, 1997).

The transition of the focus of health and disease to a pathology level promoted the consideration of sub-cellular components, and "medicine" became more molecular and microscopic (Silvano, 2021; Conti, 2018). The advancement of the medical sciences from the 14th to 19th centuries was immense, with many of the achievements leading to a change of paradigms in numerous biomedical areas that significantly influenced the concepts of health and disease (Silvano, 2021; Conti, 2017). Challenging the worldview of established European scholars, scientists and physicians in the early 20th century conversely saw health and disease as components of one spectrum rather than rigidly separate entities (Silvano, 2021; Conti, 2018; Porter, 1997). The varying advancements on the idea of health and disease has led to a historic divergent conceptualization of science, bioethics, and the fundamental notions of western medicine (Conti, 2017, Conti, 2010). Western medicine has provided breakthroughs in the curing of fatal diseases, successful progressions in surgery, as well as vaccine development (Silvano, 2021; Conti, 2018). However, challenges still exist in medicine with the lack of provisions for several auto-immune disorders, syndromes, tumors, and the remaining disparate health outcomes that persist across the general population (Silvano, 2021; Conti, 2010).

Health Outcomes

Dramatic advancements in science and western medicine in the focal areas of anatomy, physiology, pathology, and surgery have positively influenced health outcomes globally (Silvano, 2021; Savel & Munro, 2015). Within the United States (U.S.), life expectancy and survival rates have improved significantly for over two centuries

(National Research Council, 2013). The expedited production of vaccines, transition to robotic surgery and transplantology, and development of cures to fatal diseases on a molecular level are just some of the ways in which western medicine has contributed to the increased quality and quantity of life for the population at large (Silvano, 2021; Cassell, 2013). The overall mortality rate (i.e., number of deaths per 100,000 people) in the United States reached an all-time low of 725 deaths per 100,000 in 2015—a 30 percent decline from 1039 deaths per 100,000 in 1990 (Ramirez, Kamal & Cox, 2019). The healthcare system (i.e., hospitals, clinics, etc.) has also contributed to a decline in mortality rates. Changes in mortality for medical conditions for which there are healthcare interventions (expected to prevent death), provide information about how effectively healthcare is being delivered (Ramirez et al., 2019). From 2000 to 2014, the mortality rate for deaths amenable to healthcare in the U.S. declined approximately 17 percent (Ramirez et al., 2019; Murphy et al., 2018).

The healthcare system has also helped to reduce premature death (i.e., the measure of years of potential life lost due to death occurring before the age of 75; Ramirez et al., 2019; Centers for Disease Control and Prevention, 1986). The rate of premature deaths in the U.S. declined by 26 percent (15,890 to 11,794 YLL per 100,000 people) between 1990 and 2014 (Ramirez et al., 2019). Disease burden has also taken a significant plummet during the same time. Measured by disability adjusted life years (DALYs), disease burden considers years of life lost due to premature death as well as years of productive life lost to poor health or disability (Ramirez et al., 2019; Centers for Disease Control and Prevention, 1986). Widespread infectious disease among children (i.e., ages 12 months to 17 years) has been reduced through the advancements in

immunology and vaccinations (Ramirez et al., 2019). Western medicine innovation has

also garnered a decline in the mortality rates for respiratory diseases and among infant

health (Ramirez et al., 2019; Murphy et al., 2018). Preventive screening tests (e.g.,

mammography, colonoscopy, etc.) have ensured timely and accurate diagnoses of cancer

and cellular irregularities and halted the spread of the disease to other parts of the human

body (Ramirez et al., Centers for Disease Control and Prevention, 1986). Subsequently,

the mortality for all cancers and tumors (neoplasms) has fallen in the U.S. over the past

30 years. The age-adjusted cancer rate has dropped from 220 deaths per 100,000 people

in 1990 to approximately 157 per 100,000 in 2018, a roughly 28 percent decrease

(Ramirez et al., 2019; Murphy et al., 2018; Centers for Disease Control and Prevention,

1986).

Opportunities for Improvement

Yet, despite the advancements in science and medicine and the subsequent

increased life expectancy and survival rates, over the past century, Americans are living

shorter lives and are experiencing more injuries and illnesses than people in comparable

high-income countries (Ramirez et al., 2019; Murphy et al., 2018; National Research

Council, 2013). Several analyses have shown a difference in health outcomes in the

United States comparable to 16 "peer" countries: Australia, Austria, Canada, Denmark,

Finland, France, Germany, Italy, Japan, Norway, Portugal, Spain, Sweden, Switzerland,

the Netherlands, and the United Kingdom (Ramirez et al., 2019; Murphy et al., 2018;

National Research Council, 2013). Trends spanning over recent decades (i.e., 1990-

2018) have uncovered a pattern of higher mortality and inferior health in the United

States, beginning at birth (Ramirez et al., 2019; National Research Council, 2013). The

rates of premature death, disease burden, obesity, and mortality from nutritional and

metabolic diseases have continued to increase in the U.S. for nearly a decade (Ramirez et

al., 2019; National Research Council, 2013). Consistently, Americans have shorter life

expectancy compared to other "peer" countries, and, in fact, the difference in life

expectancy across the globe has grown exponentially, especially among women (National

Research Council, 2013). The pervasive health disadvantage among Americans affects

all age groups up to age 75 and is a result of a myriad of diseases, biological and

behavioral risk facts, and injuries (Ramirez et al., 2019; Murphy et al., 2018; National

Research Council, 2013).

     When comparing the U.S. with other "high-income" countries, the health

disparities existing are comprised of nine specific health domains (Ramirez et al., 2019;

National Research Council, 2013):

1) Adverse birth outcomes: The United States has experienced the highest infant

    mortality rates and poor birth outcomes.

2) Injuries and homicides: These two areas consist of deaths from violence, motor

    vehicle crashes, and non-transportation-related injuries. Since the 1950s, U.S.

    adolescents have died at higher rates of traffic accidents and violence than their

    counterparts.

3) Adolescent pregnancy and sexually transmitted infections: U.S. adolescents have had

    the highest rates of pregnancies and are more likely to acquire sexually transmitted

    infections since the 1990s.

4) HIV and AIDS: The United States has the second highest prevalence of HIV

    infection among the 17 peer countries.

5) Drug-related mortality: Americans lose more life years to alcohol and drugs than any other country.

6) Obesity and diabetes: The obesity and prevalence rate of diabetes have remained among the highest across high-income countries.

7) Heart Disease: Adults over the age of 50 in the United States are more likely to develop and die from cardiovascular disease than are older adults in other high-income countries.

8) Chronic lung disease: lung disease is more prevalent and associated with higher mortality in the United States than in the United Kingdom and other European countries.

9) Disability: Arthritis and activity limitations are reported at a higher rate in the United States compared to its counterparts.

This list of health domains depicts the general health outcomes of Americans aged 18 years and older (National Research Council, 2013). Deaths resulting from these conditions constitute approximately two-thirds of the difference in life-expectancy between males under the age of 50 compared to peer countries, and almost one-third of the difference among females (Ramirez et al., 2019; Murphy et al., 2018; National Research Council, 2013). The quality standards of these health domains have consistently plummeted in the United States over time (Murphy et al., 2018; National Research Council, 2013). Since the 1980s, the United States has had the first or second lowest probability of surviving to age 50 among the 17 peer countries (Murphy et al., 2018; National Research Council, 2013). However, Americans who did reach the age of 50 typically arrive at this age in poorer health, and higher rates of morbidity and

mortality resulting from chronic diseases that arise from risk factors (e.g., smoking, obesity, diabetes) that are often developed earlier in life (Ramirez et al., 2019; Murphy et al., 2018; National Research Council, 2013).

Table 2.1 displays the leading causes and numbers of death in the United States comparative of 1980 and 2018. These numbers are provided and listed by all persons, which include persons of differing sex, race, and Hispanic origin. The National Vital Statistics System (2018) provided these data, extracted from calculations from death certificated (Murphy et al., 2018).

Table 2.1

Leading causes of death and numbers of death, by sex, race, and Hispanic origin: United States. 1980 and 2018 (Murphy et al., 2018).

! "#$%&' (")*(+"+',-'$%"' . /0/'	1980		2018	
	Cause of death	Deaths	Cause of death	Deaths
All persons				
Rank	All causes...............1,989,841		All causes...............2,839,205	
1	Diseases of heart.........761,085		Diseases of heart.........655,381	
2	Malignant neoplasms....416,509		Malignant neoplasms....599,274	
3	Cerebrovascular dx......170,225		Unintentional injuries....167,127	
4	Unintentional injuries...105,718		Chronic lower resp dx....159,486	
5	Chronic obst pulm dx…..56,050		Cerebrovascular dx…....147,810	
6	Pneumonia and Flu.......54,619		Alzheimer's dx………...122,019	
7	Diabetes mellitus……...34,851		Diabetes mellitus………..84,946	
8	Chronic liver dx………..30,583		Pneumonia and Flu…......59,120	
9	Atherosclerosis………...29,449		Nephritis and nephrosis…51,386	
10	Suicide………………….26,869		Suicide…………………..48,344	

Contrary to the wealth and assets of the United States, as well as the astronomical level of per capita spending on health care, a persistent health disadvantage and poorer health outcomes and wellbeing continue to grow (Murphy et al., 2018; National Research Council, 2013). Throughout the years, the National Research Council has studied health outcomes across populations, and it has been difficult to pinpoint the potential explanations for the differences in health outcomes (National Research Council, 2013). The quality of healthcare and the prevalence of negative health-related behaviors are the two most highly cited explanations (Murphy et al., 2018; National Research Council, 2013). Unlike in peer countries, the U.S. health system is highly disjointed, with limited public health and primary care resources and a large uninsured population. As a result, Americans are more likely to report healthcare as being inaccessible or unaffordable, and ultimately find the quality and safety of healthcare outside of hospitals to be less than adequate (Ramirez et al., 2019; Murphy et al., 2018; National Research Council, 2013).

Furthermore, despite its robust and powerful economy, the United States has higher rates of poverty and income disparity than most other high-income countries (National Research Council, 2013). Socioeconomic positioning in America influences nearly every aspect of a person's life, including education, employment opportunities, environmental quality, financial stability, insurance security, and individual behaviors, in addition to access to healthcare, and ultimately, health outcomes (Silvano, 2021; Conti, 2018; National Research Council, 2013). Hostile social and economic conditions contribute greatly to poor health in the U.S. and affect a large segment of its population (Silvano, 2021; Conti, 2018). The U.S. health disadvantage depicts the experience of Americans who are unable to afford quality healthcare coverage and acquire financial

stability. It also greatly impacts, on a greater scale, those who are socially disadvantaged by the arms of American political governance structures that impede the potential for social mobility (National Research Council, 2013; Williams & Sternthal, 2010). The most adversely affected/socially disadvantaged populations in the United States are those that identify and/or are designated as poor, as well as racial and ethnic minorities (National Research Council, 2013; Williams & Sternthal, 2010; Anderson & Massey, 2001).

Social Determinants of Health

The Office of Disease Prevention and Health Promotion (2022) define the social determinants of health (SDOH) as the "conditions in the environment where people are born, live, learn, work, play, worship, and age that impact a wide range of health, functioning, and quality of life outcomes and risks" (p. 1). SDOH can typically be split into five major categories: (1) economic stability, (2) education access and quality, (3) healthcare access and quality, neighborhood and built environment, and (5) social and community context (ODPHP, 2022; Davidson, 2019). Within these five categories are a number of social factors and contexts that either positively or negatively impact people's health and quality of life (ODPHP, 2022). Some examples of SDOH include:

- Income and social status

- Social support networks

- Education and literacy

- Employment and working conditions

- Physical environments

- Access to nutritious foods and physical activity opportunities

- Health services

- Gender and culture

- Racism, discrimination, and violence

In particular, *income, social status, social support, race, gender, employment, and neighborhood and housing have been signaled as the most significant when it comes to influence on health outcomes* (Davidson, 2019). Across populations that are marginalized and disadvantaged in their experiences of these factors (e.g., Latinx, Indigenous people, and African Americans) there are aligning differences in life expectancy, disease patterns, and disability rates compared to white populations (Davidson, 2019; Murphy et al., 2018). The World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) list these determinants as the underlying contributors to health disparities that are most experienced by racial minorities, and are often dismissed by healthcare professionals (ODPHP, 2022; Davidson, 2019). These consistent statistics suggest that the context in which populations live highly influence their health, wellbeing and life-expectancy (Davidson, 2019; Murphy et al., 2018).

Disparities in Black Health

Generally, the health of Americans has improved and life expectancy has been steadily increasing over the last century (Braithwaite et al., 2009). However, at the same time, Black people have consistently faced significant health challenges and disparities relative to other ethnic groups, and especially when compared to their Caucasian counterparts (Braithwaite, Taylor & Treadwell, 2009). A thorough review of peer-reviewed research led the Institute of Medicine to confirm evidence of consistent

disparities in health care across a range of disease types and health care racial and ethnic

groups, most prominent among African Americans (Braithwaite et al., 2009; Smedley,

Stith & Nelson, 2003). Even controlling for several socioeconomic factors (e.g.,

education level, income, age, and marital status) that could potentially influence the

disparate health outcomes that researchers and physicians have continued to observe in

Black communities, race continued to be a significant factor in multiple studies

examining the phenomenon (Braithwaite et al., 2009; Williams & Sternthal, 2010;

Smedley et al., 2003). Studies have also pointed to limited access to healthcare and

inequities in health outcomes because of the social and economic inequities that are

innate in the U.S. infrastructure, and that play a central role to an individual's ability to

thrive (Braithwaite et al., 2009; Williams & Sternthal, 2010). The excessive incidence of

chronic diseases (i.e., diabetes, stroke, heart disease, and cancer) not only contributes to

the general U.S. morbidity and mortality rates, but also threatens the health and survival

of Black families (see Table 2.2; Braithwaite et al., 2009; Williams & Sternthal, 2010;

Smedley et al., 2003).

Table 2.2

Leading Causes of Death for Non-Hispanic Black American Females: United States.

1980 and 2018. (Murphy et al., 2018).

	1980		2018	
	Cause of death	Deaths	Cause of death	Deaths
Non-Hispanic Black Females				
Rank	All causes.......................102,997		All causes.......................165,588	
1	Diseases of heart…………35,079		Diseases of heart………..38,165	
2	Malignant neoplasms……19,176		Malignant neoplasms…...35,019	
3	Cerebrovascular dx………10,941		Cerebrovascular dx….…..10,705	
4	Unintentional injuries…….3,779		Diabetes mellitus………...7,530	
5	Diabetes mellitus………....3,534		Alzheimer's dx….............6,434	
6	Certain conditions in Prenatal period…….……...3,092		Unintentional injuries……6,199	
7	Pneumonia and Flu……….2,262		Chronic low resp dx……...5,897	
8	Homicide…………………1,898		Nephritis…......................4,964	
9	Chronic liver dx….……....1,770		Septicemia………….…...3,611	
10	Nephritis………………….1,722		Hypertension……….……3,317	

Historical context

The inequities and historical racial health gap can be attributed to the silenced

medical history that recounts in detail the gradual development of a lack of trust in health

care among the African American population (Erves et al., 2016; Lang et al., 2013). A

common thread in African Americans' decision-making process to utilize care and

available resources—or not—is substantiated fear of the health care system and medical

research (Erves et al., 2016; Lang et al., 2013), arising from the experimental exploitation

of enslaved and freed African Americans in the foundation and innovation of western

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medicine (Washington, 2006; Farmer, 2007; Shavers, Lynch & Burmeister, 2002). This medical aversion has frequently been referred to as "baseless," with no reference to the atrocities that have taken place to advance medicine to its present state (Washington, 2006). Omitted events from history of medicine courses, curated medical museums, and missing literature have led to a general unawareness of the tragic abuses of African Americans in western medicine and medical research (Washington, 2006; Shavers, Lynch & Burmeister, 2001).

Several researchers have tried to investigate the role of medical ethics and medical policy in the longstanding aversion to medicine and subsequent research (Erves et al., 2016; Lang et al., 2013; Shavers, 2002; Shavers, 2001). Although cited as the major cause of the racial health gap, the Tuskegee Syphilis Study is not the only instance of problematic medical experimentation (Erves et al., 2016; Washington, 2006; Shavers, 2001). From the observation of vaccination efficacy to the involuntary discovery of anatomy and physiology innovations, corrupt research and experimentation in the name of science advancement has been evasive in the U.S. throughout its history (Skloot, 2018; Washington, 2006; Leary, 2005). Contemporary studies have continued to illustrate the connection between the negative historical medical procedures and the lack of positive health-seeking behavior among Black Americans (Erves et al., 2016; Lang et al., 2013). Scholar Harriet A. Washington (2006) and others have emphasized the need to understand how negative experiences throughout medical care history have plagued Black Americans. Washington goes on to say, "…because trying to ameliorate African American health without understanding the pertinent history of medical care is like trying

to treat a patient without eliciting a thorough medical history: a hazardous, and probably futile approach" (p. 21).

Enslavement and Medicine

The creation and evolution of western medicine and medical science contributed to the persistence of slavery in the U.S. (Washington, 2006). Western medicine, particularly in the southern U.S. during the seventeenth, eighteenth, and early nineteenth centuries was harsh, ineffective, and experimental by nature (Washington, 2006; Fett, 2002). Despite the advancements in Europe around public health measures, vaccinations, education, and hospitalization, American progress in medicine lagged, particularly in southern states (Washington, 2006). In the early nineteenth century, southern states were unhealthier compared to other regions of America (Washington, 2006; Fett, 2002). Western medicine, particularly in southern states, was dangerously misinformed utilizing therapies such as caustic medicines containing chemical poisons, induced vomiting, bloodletting, blistering, and diarrhea induction (Washington, 2006). The use of harsh materials (i.e., Arsenic and Mercury) contributed to a wide range of health issues, including injury and damage to the nervous system, heart and kidney disease, lung injury, and respiratory distress (1998).

The South was also home to 90 percent of the American Blacks, the majority of whom were enslaved until 1865 (Washington, 2006; Savitt, 2002). Enslaved Black Americans suffered life-threatening infections with speed due to the unawareness of the connection between bacteria and infection, immunological unfamiliarity to microbes, and surgical procedures taking place in poorly constructed "slave hospitals" (i.e., slave shacks; Washington, 2006). Despite slave owners and physicians sharing a vested

interested in preserving slave's health, the enslaved individual medical preferences were vehemently ignored, and the antagonism between African Americans and western medicine began (Washington, 2006; Fett, 2002; Savitt, 2002).

Physicians were active participants in the exploitation of African American bodies. Physicians during that time were dependent upon slavery for both the economic security and the enslaved "clinical material" that nurtured the American medical research and training that promoted physicians' professional advancement (Washington, 2006; Fett, 2002; Savitt, 2002). Numerous physicians' memoirs, medical journals, and planter records have revealed that enslaved Black Americans stood the worst abuses of the crude practices, which countenanced a hazardous degree of experimentation in medications and surgical experiments in the daily practice among slaves (Washington, 2006; Fett, 2002; Savitt, 2002).

Owners often restricted access to medical care by accusing Blacks of malingering. Slave narratives and planter records corroborate this belief, often citing that a sick slave would be accused of feigning illness (Washington, 2006; Fett, 2002). Additionally, owners relied on physicians to pinpoint potential malingering and ultimately get Blacks, healthy or not, back into the fields (Washington, 2006). With most physicians at that time sharing economic and political interests with slave owners and planters, a conspiracy began to subjugate the enslaved to frequent and invasive wellness checks to benefit the greater economy (Washington, 2006; Browne, 2000).

Faultfinding beliefs about the minds and bodies of people of African descent are a core tenant of scientific racism (Washington, 2006; Browne, 2000). Both slaves and freedman were medically neglected and abused because they were powerless and legally

invisible; the federal court system was completely apathetic in the safety and health rights of African Americans (Washington, 2006; Savitt, 2002). The beliefs were further encouraged by research findings and scientific theories, and promulgated by whites, across disciplines, who were sympathetic to and/or were actively profiting from the institution of enslavement (Washington, 2006; Browne, 2000; Leary, 2000). Despite their claim to hold authority over the analyzation of Blacks due to their proximity, southern scientists and physicians developed their deductions on substandard research that was based in the unmerited mythology about the biology of nature of Blacks (Washington, 2006; Saenz & Morales, 2005).

The foundational framework that was utilized to create "scientific" and medical theories about Blacks was influenced heavily by the historical writings, racial descriptions from antiquity, natural scientists' fictional catalogs of "racial" traits, and biblical interpretations (Washington, 2006; Browne, 2000; Leary, 2000). Scientific medical thought regarding race centered on historic European physicians that provided justification for biological differences, from sex organs to comparably smaller brain size (Washington, 2006; Waters, 2002). No experimental data, control groups, or fact-based theories supported these race-based assumptions (Washington, 2006). Without tests for confounding factors or removal of ethnocentric bias, science and western medicine served a vital role in the political environment, for it provided a biological and ethical rationale for enslavement and racist practices (Washington, 2006; Browne, 2000).

In the eighteenth century the slave trade grew with the biological distinctiveness of humans being imperative to America's economic success (Washington, 2006; Waters, 2000). Ethnologists who studied different groups of men and served as forefathers for

anthropology, applied the classification methods of natural sciences (i.e., taxonomy), made famous by Carolus Linnaeus, to the study of man (Washington, 2006; Waters, 2002; Leary, 2000). Linnaeus categorized Africans, and indirectly U.S. Blacks, as *Homo afer*, conjecturing that Black men had different evolutionary descents and had evolved along an evolutionary track separate from white men. Despite the efforts of Black and white abolitionists to shift the world and domestic opinion against enslavement, ethnologists and scientists persisted the physiological differences of African Americans (Washington, 2006). Polygenists and ethnologists emphasized the physical inferiority of Blacks. Additionally, they were liars, malingerers, hypersexual, and indolent (Washington, 2006; Fett, 2002). Moreover, the eighteenth century brought constant comparison of Blacks to beasts, and later to European children who lacked adult judgement, which rendered Blacks unable to care for themselves and thus provided yet another justification for slavery (Washington, 2006; Fett, 2002, Waters, 2002).

Physicians like Samuel A. Cartwright, prominent in the eighteenth century, gained renown by publishing a plethora of articles and communications on Negro medicine, particularly in southern medical journals (Washington, 2006). Cartwright and French scientist Louis-Pierre Gratiolet suggested that the cranium of Blacks were approximately 10 percent smaller than that of whites, and that unlike a temple to protect their brain, their cranium serves as more of a helmet for resisting heavy blows (Washington, 2006; Wingate, 1929). Postulating that this lack of brain development caused a stunting of Black intellect, both scholars theorized the impossibility for them to survive without white supervision and care (Washington, 2006; Wingate, 1929).

With its many justifications for enslavement, western medicine and its subsequent

profit relied heavily on the medical treatment of slaves (Washington, 2006; Fett, 2002,

Waters, 2002). Physicians were contracted by potential buyers and slave auction leaders

to determine slave value (Washington, 2006; Waters, 2002). From the kidnapped

Africans thrown overboard the slave ships who were deemed by physicians "not fit" to

complete the journey, to the fitness guarantees provided for the enslaved who were to be

bought and sold, western medicine and its physicians were highly influenced by the

economy and the lucrativeness of providing services to ensure quality slave labor

(Washington, 2006; Savitt, 2002; Graves, 2001). The priority for both slave-owners and

physicians was an enslaved individual's fitness for work, rather than their welfare. In

other words, it was more financially beneficial for slave buyers/owners, physicians, and

the greater national economy to create a system that deemed enslaved individuals as

ready to work, regardless of health standards or individual wellbeing (Washington, 2006;

Savitt, 2002; Graves, 2001). Physical stature (i.e., muscle mass and tone), attractiveness,

and reproductive ability were all attributes deemed valuable by potential buyers of those

that were enslaved.

Enslaved Women and Medicine

Though men were recruited based on their physical prowess, enslaved women

were most sought after and traumatized, physically, due to their perceived profitability

for the general economy (Washington, 2006; Savitt, 2002; Graves, 2001). Ultimately, the

sustenance of slavery was directly influenced by Black procreation (Washington, 2006;

Leary, 2005; Roberts, 2000). Because the childbearing of enslaved women replenished

the slave labor force, slave masters observed an economic incentive to govern Black

women's reproductive lives (Washington, 2006; Roberts, 2000). In one of many of Thomas Jefferson's formal writings, he says, "I consider a slave woman who breeds once every two years as a profitable as the best worker on the farm" (Washington, 2006, p. 44; Eppes, 1953). Sailors on slave ships, as well as slave masters, reduced Black women to animal-like treatment and sexual objection (Roberts, 2000; Gates, 1987). Enslaved women were raped, bred and were accused of not being able to control their "powerful sex drives," again compared to that of animals, which led to the enticement of white men and their inappropriate sexual relations (Washington, 2006; Roberts, 2000; Gates, 1987).

Considered and indeed legal personal property of the master, Black women had no protection from negative social or criminal activity thrust upon them (Washington, 2006; Roberts, 2000). They could legally be physically or sexually assaulted (i.e., raped), and when pregnant and deemed "healthy" by physicians, were forced to continue hard labor until their fifth month (Washington, 2006; Roberts, 2000). Further, if found to be insubordinate, pregnant enslaved women were forced to lie in trenches that accommodated their bellies so that they could be beaten without harm to the unborn child (Washington, 2006).

In fact, any wellness considerations given to pregnant slave women were based solely on potential economic gain (Washington, 2006; Leary, 2005; Roberts, 2000); the level of medical care of any slave was dependent on the desires of the master, the judgement of the physician, and the value placed on the enslaved per the physician's assessment (Washington, 2006; Fett, 2002). Physicians in the era of enslavement did not receive financial security and professional status compared to physicians in the present. Rather, most of their income depended on the caring of the enslaved, and they therefore

relied heavily on the profitability of the slave system (Washington, 2006, Fett, 2002; Waters, 2002, Roberts, 2000). With physicians having a direct stake in the economy of slavery, as well as being slaveholders themselves, their potential profit was based in the usual ways – fieldwork, housework, rented labor, concubines, and breeders. Physicians thus determined value of Black women and men on the auction block, in plantations, and during house calls deemed necessary by masters to assess slave utility (Washington, 2006; Fett, 2002). Additionally, racial medical theories and diagnoses supported the slave system. Enslavement created a partnership between physicians and planters that completely obscured the patient-physician relationship that traditional Western healing and medicine practices espoused (Washington, 2006, Fett, 2002). Planters had full power of consent on the regulations of medical procedures (e.g., sterilization), amputation, and autopsy (Washington, 2006). The enslaved were not consulted, not informed, and had no agency over the satisfaction of their treatment or lack thereof from their physicians (Fett, 2002; Waters, 2002).

Medical Experimentation

Black iatrophobia (i.e., the fear of medical care and/or doctors) has a long history in America, one that begins at enslavement and remains in the present era of western medicine and healthcare treatment (Washington, 2006). Additionally, during the eighteenth and nineteenth centuries, physicians bought and hired the enslaved on whom they would conduct medical experiments deemed too painful, risky, and/or objectionable to perform on whites (Washington, 2006; Leary, 2005; Roberts, 2000). Informed consent (i.e., permission to proceed in a process to a provider with the patient having full knowledge of all the benefits and risks) was not part of ethical protocol and was not

required by law (Washington, 2006; Leary, 2005; Savitt, 2002). Involuntary medical experimentation forced the enslaved into medical service, not to cure, but for economic gain (Washington, 2006; Savitt, 2002). Medical experimentation then benefited whites, as care would not be provided until the medical process had been perfected (Washington, 2006; Savitt, 2002).

Historic archives of institutional records, medical journals, and physicians' "recollections" profile a pattern of abusing African Americans over time, which was supported by custom and oftentimes by law (Williams, 2011; Washington, 2006). Narratives and/or accounts in these documents were extremely frank, as they were only for the eyes of white male physicians in their own socioeconomic class (Washington, 2006). Without legal protection, African Americans were unable to halt physicians' unethical activities. Additionally, those who were enslaved were not the only subjects of medical experimentation (Williams, 2011; Washington, 2006; Savitt, 2002). Justifications for the unethical experimentation centered around scientists' and physicians' proposed medical fiction that depicted Blacks as having low intellectual capacities and being sexually promiscuous, as well as untrustworthy to take medicine and/or maintain basic hygiene without white supervision (Williams, 2011; Washington, 2006; Fett, 2002). Moreover, physicians in the eighteenth and nineteenth century believed that Blacks naturally harbored disease which threatened the health of whites (Dain, 2012; Washington, 2006). One of the most persistent beliefs was that Blacks did not feel pain or anxiety, which satisfied and/or pardoned the abusive medical experimentation and surgical explorations that many scientists and physicians performed (Dain, 2012; Williams, 2011; Washington, 2006; Fett, 2002).

Medical experimentation on Black people for the advancement of healthcare (i.e., western medicine) mirrored the more structural abuses (e.g., economic and social) that the larger society of the eighteenth and nineteenth centuries perpetuated against people of color, particularly African Americans (Dain, 2012; Washington, 2006; Fett, 2002). The unethical practices of western medicine not only impacted those that were enslaved, but African Americans far beyond the passing of the Emancipation Proclamation of 1863, continuing to be an overt issue at the time of the Civil Rights Act of 1964 (Dain, 2012; Williams, 2011; Washington, 2006). Physicians were supported by medical advancement, theory of racial dominance, and in some states, law, as well as by an unofficial organization of resurrectionists named by African Americans as "night doctors" (Fry, 2001). During and after the period of enslavement in the United States, slaveowners, overseers, physicians, and other whites sought to control the Black population by way of murder, kidnapping, and grave robbing in the name of science and economics (Skloot, 2018; Haleprin, 2007; Washington, 2006; Fry, 2001). Night doctors, often characterized as Black folklore, have been proven to exist via historical journal accounts of physicians, the enslaved, and freedmen in which medical schools, physicians, and former slave owners offered money for the exchange of African Americans to test drugs and practice surgical operations and dissection (Skloot, 2018; Haleprin, 2007; Washington, 2006; Fry, 2001).

The accounts of medical experimentation on Blacks and subsequent healthcare innovation are substantial and pervasive in the United States (Skloot, 2018; Dain, 2012; Washington, 2006; Leary, 2005). In the United States in the eighteenth and nineteenth centuries, Blacks disproportionately constituted approximately 80 percent of

experimental subjects in medical advancements (Skloot, 2018; Washington, 2006). Examples abound: Dr. James Dugas developed a new eye surgery where four of his five test subjects were Black (Washington, 2006; Savitt, 2002). Physicians and surgeons such as Drs. Charles White and Francois M. Prevost performed several amputations and operations on both enslaved and freed African Americans without anesthesia and consent (Washington, 2006; Savitt, 2002; Fett, 2002). Thomas Jefferson used his political positioning to deflect potential criticism resulting from his vaccination experimentation when he sought to advance the work of Edward Jenner's vaccination technique (i.e., inoculation) by injecting his slaves with cowpox to produce immunity to smallpox (Washington, 2006; Savitt, 2002; Fett, 2002). He continued work on the vaccine until the enslaved escaped illness. Once immunity was established, he would then inject his own family (Washington, 2006). In 1832, Dr. Robert G. Jennings attempted to combat the typhoid fever epidemic that was raging in Virginia by administering the smallpox vaccine to thirty Blacks, enslaved and free (Washington, 2006; Savitt, 2002; Fett, 2002). Withholding vaccine from a portion of the subjects, Jennings recorded the "successful" experiment on the population, despite the fact smallpox vaccine is not efficacious against typhoid (Washington, 2006; Savitt, 2002; Fett, 2002). In his nineteenth century records, Dr. Walter F. Jones revealed that he poured boiling water on naked Black pneumonia patients at four-hour intervals (Washington, 2006; Savitt, 2002; Fett, 2002). Around the same time, John M.B. Harden, M.D. of Georgia described in an article in the Southern Medical and Surgical Journal how he stripped blood vessels from the limbs of "a Negro" (Washington, 2006; Savitt, 2002; Fett, 2002). Furthering anatomical knowledge, Harden determined the areas of the trunks and branches of arteries (Washington, 2006).

The most cited and widely known unethical treatment of African Americans is the

U.S. Public Health Service (USPHS) Syphilis Study at Tuskegee (Erves et al., 2017;

Erves et al., 2016). The immoral conduct that occurred during this study has frequently

been used as a reason why Blacks are less likely to participate in medical research and

healthcare compared to whites (Erves et al., 2016; Davis, Green & Katz, 2012). The

infamous, 40-yearlong study (1932 to 1972) was one in which the USPHS recruited

approximately 399 Black sharecroppers from Macon County, Alabama, and injected

them with syphilis to study its effects (Davis et al., 2012; Katz et al., 2008).

Accompanied with the other medical atrocities, the Syphilis Study at Tuskegee remains

in the African American consciousness (Erves et al., 2017; Erves et al., 2016; Davis et

al., 2012). The resulting iatrophobia and conspiracy theories concerning negative health

outcomes and disparities among African Americans can be attributed to the population's

knowledge of this medical history (Davis et al., 2012; Zekeri & Habtemariam, 2006). The

combination of scientific racism (i.e., polygenism), abusive medical attentions, and

iatrophobia has exacerbated and perpetuated the mistrust and loathing of the American

medical establishment (i.e., modern western medicine) (Washington, 2006).

Black Women Experiences with Medicine and Healthcare

It is imperative to note that Black women are not a monolithic group; instead,

they comprise multiple cultures and ethnicity (Chinn et al., 2021; Agyemang, Bhopal &

Bruijnzeels, 2005). This review will refer to "Black women" in their collective identities,

which include diverse ethnicities, shared oppression, and experiences (Chinn et al.,

2021). Black women endured the same unethical treatment and oppression as Black men

throughout history (Washington, 2006; Leary, 2005). However, due to their

intersectionality (i.e., race and gender), their experiences with western medicine and healthcare have been unique (Braithwaite et al., 2009; Washington, 2006; Leary, 2005). Health inequity among Black women is rooted in slavery and continues into contemporary times (Chinn et al., 2021; Hardeman, 2019). Enslavers viewed enslaved Black women as a commodity needed for economic gain (Chinn et al., 2021). Black women's bodies were disregarded and abused for their reproductive health and medical advancement (Chinn et al., 2021; Office of Disease Prevention and Health Promotion, 2020; Leary, 2005; Roberts, 2000). During enslavement, Black women were forced to procreate with no self-agency and limited and monitored access to medical care (Chinn et al., 2021; Roberts, 2000). Children of the enslaved women were taken and sold to slaveholders offering the most capital and mothers often never saw their babies again (Roberts, 2000). Enslaved women were held responsible for their infant deaths (Washington, 2006).

Despite considerable health improvements in the last century, Black women continue to experience excess mortality (e.g., shorter life expectancies and higher rates of maternal mortality) compared to other U.S. women (Chinn et al., 2021; Centers for Disease Control and Prevention, 2020; National Center for Health Statistics, 2019). Women of color, and Black women in particular, are disproportionately impacted by chronic conditions, such as cardiovascular disease, diabetes, and obesity (Chinn et al., 2021; Braithwaite, 2009). Researchers and physicians agree that health outcomes do not occur independently from the social conditions in which they exist (Chinn et al., 2021). The higher burden of these chronic conditions, and the increased mortality rate, illustrate the systemic inequities within and outside the health system that Black women

experience throughout their life course (Chinn et al., 2021). To discuss health equity among Black women without the consideration of forms of racism at both the institutional and individual levels would be an incomplete depiction of the purveying problems (Chinn et al., 2021; Washington, 2006; Leary, 2005). Additionally, it is imperative to review and comprehend Black women's intersection of gender and race and the historical contexts that have influenced Black women's health in the United States (Chinn et al., 2021; Williams, 2010).

Black women's experiences with healthcare (i.e., access and perceptions) and treatment by the medical science system, particularly in gynecology, has contributed to their present-day health inequities (Chinn et al., 2021; Office of Disease Prevention and Health Promotion, 2020). Physician James Marion Sims ascribed infant deaths to the mothers' moral and intellectual failures (Washington, 2006; Leary, 2005, Roberts, 2000). Sims, proclaimed the "father of gynecology," aided in the development of gynecology as a medical specialty and ushered in a period of severe danger for Black women by conducting years of painful and degrading experiments, without anesthesia or consent on enslaved women (Chinn et al., 2021; Washington, 2006). The procedure to fix vesicovaginal fistulas was his most renowned innovation (Washington, 2006; Leary, 2005). The enslaved women who were subject to over four years of experimentation were forced to undress completely, kneel on their hands and knees, be invaded with a special speculum in their vaginas, and restrained by other doctors and nurses (Sillman, Gerber, Ross & Gutierrez, 2016; Washington, 2006; Leary, 2005). Sims refused to utilize anesthesia, despite self-recorded notes on the trauma and pain the procedures brought the enslaved women (Sillman et al., 2016; Washington, 2006).

Sims was not alone in the exploitation and abuse of Black women (Chinn et al.,

Skloot, 2018). Henrietta Lacks, a Black woman who received treatment from Drs.

Howard Jones and George Gey and the John Hopkins Hospital in 1951, unwittingly had

her unique cells taken (i.e., HeLa cells) and were/are used to study the effects of toxins,

drugs, hormones, and the human genome (Skloot, 2018; Sillman et al., 2016). Her cells

played a crucial role in the development of the polio and COVID-19 vaccines (Skloot,

2018; Sillman et al., 2016). The Eugenics movement, birthed in the nineteenth century,

sought to control nationwide reproduction in order to improve society (Roberts, 2000).

This movement was fueled by the belief that intelligence and other "superior" personality

traits were inherited (Savitt, 2002; Fett, 2002; Roberts, 2000). Eugenicists targeted the

poor and Black community pronouncing them to be "undesirable," unintelligent, and

incapable of raising children (Roberts, 2000). As recently as the early 1970s, Black

women were subject to involuntary sterilizations by doctors paid by the government to

provide healthcare in the form of social programs (Chinn et al., 2021; Leary, 2005;

Roberts, 2000). Teaching hospitals in the U.S. performed unnecessary hysterectomies on

Black women as practice for their medical residents (Chinn et al., 2021; Roberts, 2000).

This history has resulted in the accumulation of disadvantages across generations

(Chinn et al., 2021), and inequities persist because of the social, economic, and/or

environmental conditions that create the space for them to exist (Chinn et al., 2021;

Office of Disease Prevention and Health Promotion, 2020). No matter the socioeconomic

positioning, Black women's health is an emerging public health emergency (Chinn et al.,

2021; Braithwaite, 2009; Washington, 2006). Black women currently constitute

approximately 7.0% of the U.S. population and 13.6% of all U.S. women (Chinn et al.,

2021; National Center for Health Statistics, 2019). Despite the fact that Black women are

younger on average (36.1 years) than U.S. women overall (39.6 years), they have a

higher prevalence of several health conditions, including stroke, heart disease, diabetes,

obesity, heart disease, cancers, and stress (Chinn et al., 2021; National Center for Health

Statistics, 2019). Life expectancy at birth is three years longer for non-Hispanic white

females than for non-Hispanic Black females. Infant mortality rates for children born to

non-Hispanic Black women are twice as high as those for children born to non-Hispanic

white women (Chinn et al., 2021; National Center for Health Statistics, 2019). Presently,

the maternal mortality rates for Black women are three to four times those of Non-

Hispanic White women (see Table 2.3) (Chinn et al., 2021; Centers for Disease Control

and Prevention, 2020).

Table 2.3

Descriptive Health Statistics for Women (Chinn et al., 2021)

	Non-Hispanic Black women	Non-Hispanic White women	All women
Life expectancy at birth (years)	77.9	81.0	81.0
Infant mortality	10.9	4.7	5.8
Maternal mortality	37.1	14.7	17.4
Pregnancy-related mortality	42.4	13.0	16.9
Physical health (prevalence %)			
Heart disease	9.9	10.8	10.1
Hypertension	39.9	25.6	27.7
Obesity	34.7	21.6	23.5
Mental health (prevalence %)			
Serious psychological distress	4.7	4.8	4.8
Suicide (per 100,000 population)	2.8	7.9	6.1

The harm executed against African Americans in the name of medicine and healthcare is extensive and spans time from enslavement to the present (Chinn et al., 2021; Sillman et al., 2016). The knowledge of the experiments and atrocities performed by Sims, Cartwright, and Jefferson, and the U.S. government has fed the African American aversion to the healthcare system (Washington, 2006; Leary, 2005). Accompanied with the social, economic, and political conditions that exacerbate the structural racism that influences health conditions for African Americans, the perception of medicine and clinical research among this population has subsequently soured (Erves et al., 2016; Davis et al., 2012; Washington, 2006). With its foundation in unethical treatment, manipulation, and experimentation, Blacks in the U.S. have consistently been wary of western medicine (Washington, 2006; Fett, 2002).

The distrust of the healthcare system and western medicine among Black people has in some instances been compounded due to generational trauma and the lack of validation from providers and the perceptions of invisibility while in the provider setting (Zaragovia, 2021; Chinn et al., 2021). In recent years, the increased morbidity and mortality among Black people has been attributed to many factors, including the social determinants of health, systemic oppression, patient/provider interactions, and the overall quality of healthcare (Zaragovia, 2021; Bridges, 2017). A 2015 report released by the National Academy of Medicine (NAM) revealed that racial minorities, specifically Black people, receive lower quality healthcare compared to white people (Bridges, 2017). Despite controlling for income, age, insurance status, and severity of condition, Black people were still less likely than their white counterparts to receive appropriate cardiac care, kidney dialysis or transplants, and cancer, stroke, or AIDS treatment (Zaragovia,

2021; Chinn et al., 2021; Bridges, 2017). Furthering NAM's findings, one study of 400

hospitals in the U.S. showed that Black patients, even after controlling for class, health

insurance, health behaviors, and comorbidities, are less likely to receive effective

treatments from providers (Bridges, 2017). Additionally, Black patients are discharged

earlier from the hospital than their white counterparts – when discharge may be

inappropriate (Bridges, 2017). Disparities are numerous and include the disproportionate

rate of Black patient amputations, low rate of radiation therapy, and the more frequent

treatment of antipsychotic medications which have long-term negative effects and lack

empirical evidence of sufficient benefits (Chinn et al., 2021; Bridges, 2017).

Court cases and studies alike have revealed Black patients reporting their medical

complaints and symptoms being dismissed, pain untreated, and minimal referrals to

specialty care (Zaragovia, 2021; Chinn et al., 2021; Leary, 2005). Meanwhile, not much

has been systematically done to repair the trust that was lost through the historical

medical failures and abuses that western medicine and the healthcare system committed

against Black people (Zaragovia, 2021; Chinn et al., 2021; Leary, 2005). Current studies

have reported the consistent perception from Black patients that clinicians they have

encountered have been dismissive, condescending, or impatient (Zaragovia, 2021), terms

used in describing micro-aggressions aligned with systemic racism and impacting health

outcomes (Washington, 2006; Leary, 2005). For Black women specifically, the impact of

implicit bias and systemic racism in the healthcare system shows up starkly in

reproductive health (Zaragovia, 2021; Suliman, 2021). Black women are three to four

times more likely to die from pregnancy-related issues than white women (Zaragovia,

2021; King, 2019). In 2019, the CDC reported considerable racial disparities in

pregnancy-related mortality (King, 2019). Further, the Brookings Institute conducted a

study showing the most prevalent racial disparities within the U.S. and determined that

Black mothers with advanced professional degrees (i.e., master's degree or higher) have a

higher chance of maternal and infant mortality compared to white women whose highest

education level is the eighth grade (King, 2019; Reeves & Matthew, 2016).

The disparity in pregnancy-related deaths and other health outcomes impacting

Black women are rooted in systems of oppression and injustice (Suliman, 2021).

Underscoring this statistic, Shalon Irving, an epidemiologist employed by the CDC, lost

her life due to pregnancy complications after providers continued to dismiss her reported

symptoms as "normal" (Suliman, 2021; King, 2019). Leading up to her death, Irving

exhibited several red flags (e.g., leg swelling, headaches, and spikes in blood pressure

(Suliman, 2021; King, 2019). Despite her attempts to seek care, Shalon was ignored and

ultimately collapsed in her home (Suliman, 2021). In a separate case, Kira Johnson and

her husband Charles were expecting their second child and went to Cedar Sinai hospital

for their scheduled C-section surgery (King, 2019). After Charles saw his wife's catheter

fill with blood, he alerted the on-staff nurses. A CT scan was ordered; however, no

progress or procedure was performed. Despite ultrasounds depicting her enlarged

hematoma, no procedures were carried out. Approximately ten hours after reporting

blood in the catheter, Kira was taken to a procedure room (King, 2019). Kira suffered

heavy internal bleeding, had flatlined, and was in critical condition after being moved to

the room. Residents informed Charles that they found nearly 3.5 liters of blood in Kira's

abdomen. Fifteen minutes later, a physician Charles had never met came to tell him his

wife had died (King, 2019).

The maternal mortality crisis in the U.S. highlights that racism within the healthcare system is killing American Black women, as well as the general Black population (Suliman, 2021; King, 2019; Erves et al., 2019; Reeves & Matthew, 2016). The environment created by the impact of unequal treatment and systematic oppression permits the health disparities to exist and persist (Chinn et al., 2021). Yet the distinct causal pathways of the gaps in health outcomes for Black women remain unclear (Suliman, 2021; King, 2019; Leary, 2005). U.S. society continues to be white-dominated both culturally and socioeconomically (Chinn et al., 2021; Bonilla, 2003), and Black women continue to be disadvantaged compares to whites – even when they have higher incomes and level of education (Suliman, 2021; Reeves & Matthew, 2016).

The National Academies of Sciences Engineering and Medicine (NASEM) deducted that the gaps could be due to the way healthcare systems are organized and operated (King, 2019; Reeves & Matthew, 2016). Access to healthcare has long plagued those belonging to marginalized communities (Chinn et al., 2021; Office of Disease Prevention and Health Promotion, 2020). High insurance premiums, income inequity, low health literacy, lack of culturally competent healthcare providers, and a dearth of reasonably located quality healthcare facilities and providers' offices have historically and presently impeded Black women's access to healthcare (Chinn et al., 2021; Erves et al., 2019; Hardeman, 2019).

The pervasiveness of unconscious bias, prejudices, and uncertainty in the medical system and its actors (i.e., providers) are also contributing factors to the present health crisis (Suliman, 2021; King, 2019; Reeves & Matthew, 2016). Recent studies have shown that despite the level of access to healthcare (e.g., education, income level, self or

employer health coverage), Black women continue to experience medical abuses, mistreatment, and disparate health outcomes compared to white women (Chinn et al., 2021; Silliman, Gerber, Ross & Guiterrez, 2016).

Additionally, the NASEM and other studies claim that patients' attitudes and behaviors play a role in disparity (Erves, Deakings, Mayo-Gamble, Kelly-Taylor & Miller, 2019). Given the historical context of western medicine, Black patients generally do not trust healthcare professionals (Erves et al., 2019; King, 2019). A number of more recent studies have shown that if a Black patient has a Back physician, they are more likely to experience positive health outcomes (Suliman, 2021; Erves et al., 2019), evidence of the importance of representation and cultural competency in combatting disparities in healthcare.

Black Women's Intersectionality and Multiple Consciousness

Black women experience marginalization at various identity markers including race, gender, sexuality, class, and nationality (Chinn et al., 2021; Patterson et al., 2016). Black womanhood exists in the context of the interactive oppressions (i.e., sex and race) that circumscribe the lives of Black women (Anderson & Collins, 2004; Collins, 2000; Guy-Sheftall, 1995). In the United States, Black women have been cognizant of the commonalities that they share with all women, as well as the bonds that connect them to the men of their race (Leary, 2005; Collins, 2000; Guy-Sheftall, 1995). Anna Julia Cooper (1995), a formerly enslaved educator, wrote of the double enslavement of their being, "confronted by both a woman question and a race problem" (p. 294). In 1904, Mary Church Terrell expounded on the "multiple jeopardy" faced by Black women, writing, "Not only are colored women handicapped on account of their sex, but they are

almost everywhere baffled and mocked because of their race. Not only because they are women, but because they are colored women" (Guy-Sheftall, 1995, p. 294).

Yet, Black women in their sustained consciousness have resisted these oppressions from the beginning (Collins, 2000). Throughout history in the Unites States, Black women have participated in and led organized political actions, remained resilient in their day-to-say survival, and have demonstrated the ultimate tenacity for their struggle against erasure and subordination (Leary, 2005; Collins, 2000; Guy-Sheftall, 1995). Black feminist intellectuals have long researched the space of Black women's consciousness, the ideology that allows Black women to surpass the constraints of their intersection's oppressions (Collins, 2000). In the mid-nineteenth century, Sojourner Truth pronounced the unmitigated strength and perseverance of Black women (Collins, 2000; Guy-Sheftall, 1995). As an anti-slavery activist and women's right advocate, Truth's theme of strength versus objectification resonated with Black feminist intellectuals throughout America's history (Collins, 2000). Voices of the resistance like Audre Lorde, Ella Surrey, Maria Stewart, Fannie Barrier Williams, and Marita Bonner sustained Truth's foundational question, "Ain't I a woman?", and through their ideas and actions, confirmed that a self-defined Black women's standpoint exists and its presence is essential to their survival (Leary, 2005; Collins, 2000; Guy-Sheftall, 1995).

Black women's experiences across phenomena have assumed to be synonymous with that of Black males or white females (Guy-Sheftall, 1995; La Rue, 1976). With this false equivalency, Black women have mistakenly been granted that there is no difference in their lived experiences in being Black and female from being generically Black (i.e., male) or generically female (i.e., white). For example, genocide for Native Americans,

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military conquests of Mexican Americans and Puerto Ricans, and slavery and lynching of Blacks, is not comparable to the discrimination and denigration of women (Anderson & Collins, 2004; Guy-Sheftall, 1995). While Black feminist intellectuals are not arguing that some forms of racial and social oppressions are greater or more unjust than others, they are positing that the assumption of parallelism across oppression masks the differences that exist between them, specifically, in the case of Black women (Collins, 2000; Guy-Sheftall, 1995; Smith & Stewart, 1983). Similarly, bell hooks (1995) wrote, "no other group in America has so had their identity socialized out of existence as have black women. We are rarely recognized as a group separate and distinct from Black men; and when women are talked about the focus tends to be on white women" (p. 296). The comprehension of Black womanhood relies on the acknowledgement of the differences between Black men and Black women, and Black women and white women (Collins, 2000; Guy-Sheftall, 1995; Smith & Stewart, 1983). Fannie Lou Hamer, civil rights activist, when addressing the National Association for the Advancement of Colored People (NAACP) in 1971, commented on the burden and role of Black women for over 350 years: "You know I work for the liberation of all people because when I liberate myself, I'm liberating other people…her [the white woman's] freedom is shackled in chains to mine, and she realizes for the first time that she is not free until I am free" (Collins, 2000, p. 25; Guy-Sheftall, 1995). Hamer and others purposefully expounded the importance of addressing and uplifting the multiple identities and consciousness of Black women, an essential trademark of Black feminist thought (Collins, 2000; Guy-Sheftall, 1995).

Cultural Appropriateness and Black Women

As a group, Black women experience a disproportionate burden of health problems and a significantly lower quality of health care (Kreuter et al., 2011). It is necessary that culturally appropriate, community engaged models and treatment plans are implemented to ensure that their health needs are met and addressed adequately (Kreuter et al., 2011; Smedley & Stith, 2003). Matthew Kreuter (2002) and many authors before have developed and described strategies to make healthcare services, health promotion programs and materials more culturally appropriate. There are five main categories of these strategies and are primarily used for organizational clarity in process and procedure and are not necessarily mutually exclusive (Kreuter et al., 2011). Additionally, when used, practitioners often use strategies from more than one category to cater to specific populations (Kreuter et al, 2011; Kreuter et al., 2002). The five styles of strategies include:

1) Peripheral strategies: seeks to give programs or materials the appearance of cultural appropriateness by packaging them in ways likely to appeal to a specific group.

2) Evidential strategies: seeks to enhance the perceived relevance of a health issue for a given group by presenting evidence of its impact on that group.

3) Linguistic strategies: seeks to make health education programs and materials more accessible by providing them in dominant or native language of the target group.

4) Constituent-involving strategies: those that draw directly on the experience of the target group.

5) Sociocultural strategies: discuss health-related issues in the context of broader

   social and/or cultural values and characteristics of the intended audience.

When "culturally tailoring" (i.e., combining information or change strategies with the

intention to reach a specific group), it is imperative to operate the mechanism based on

characteristics that are unique to the person or group (Kreuter et al., 2011). Few health

promotion/education programs have historically made explicit attempts at developing

culturally appropriate strategies to meets the needs of specific populations (Kreuter et al.,

2002; Bechtel & Davidhizar, 2000). However, growing attention and recognition, has

been placed on the importance of culturally appropriate and alternative methods to,

specifically in health promotion/education programs and materials and research (Kreuter

et al., 2002; Bechtel & Davidhizar, 2000; Renicow, Baranowski, Ahluwalia &

Braithwaite, 2000; Brach & Fraser, 2000).

Alternative Medicine and Healing

Western medicine's mechanical approach to healing and the body is

philosophically contrary to the holistic African customs of healing as practiced by Black

healers (Washington, 2006; Fett, 2002; Savitt, 2002). The definition of healing has

become muddled in modern western medicine (Dobkin, 2016). The historical foundation

of western medicine, centered in art and science, has transitioned into a factory, big

business, where the absence of disease and physical injury is the goal (Dobkin, 2016;

Braithwaite, 2009). From the provider perspective, Bordreau et al. (2007) state,

"Physicianship, as we understand it, is based on the following premise: the primary goal

of medicine is healing. Healing encompasses the entire range of doctor-patient

interactions, social and environmental conditions, and treatments aimed at complete

pathophysiologic mechanisms" (p. 197). The present-day version of western medicine is not sufficient across demographic populations in the U.S. (Chinn et al., 2021; Office of Disease Prevention and Health Promotion, 2020; Dobkin, 2016).

Drs. Mount and Cassell, innovators in whole person care, promote that healing occurs in the present tense and thus a person is never healed (i.e., for good; Dobkin, 2016; Cassell, 2013; Mount, 2006). It is rather an iterative dynamic process, based on the meaning of healing for each individual patient (Dobkin, 2016; Cassell, 2013; Mount, 2006). Mount (2006) further articulates, "Healing is a shift in our quality of life away from anguish and suffering towards an experience of integrity, wholeness, and inner peace" (p. 50). Research has consistently illustrated the continued impacts of systemic oppression, bias, unequal treatment, and health disparity, specifically for Black people in the U.S., and provides evidence that there is a need for alternative healing methodology and approaches to achieve a culturally conscious, trauma-informed – whole person care that is required to achieve a sufficient quality of life (Dobkin, 2016; Cassell, 2013; Levin, 2009; Mount, 2006).

Spiritual Traditions and Healing

African Americans share cultural characteristics that ascend from unique historical experiences (e.g., African heritage, enslavement, and systematic discrimination, oppression, and victimization; Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). The African American experience is dynamic and shapes personal experience (Frame et al., 1999a; Frame & Williams, 1996). Essential to the African American worldview is the intense sense of communalism, a collective identity that manifests in strong kinship ties that reach beyond one's biological family and extend

to other networks and shared community (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). Thus, this perspective/worldview rests in a relational context where the community and individual remain on a dynamic interplay (Frame, Williams & Green, 1999a; Frame & Williams, 1996). Integral to African American communalism is the deep sense of spirituality rooted from African culture and legacy (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). During enslavement, Jim Crow, and the civil rights movement, this spirituality served as a means of connecting with the community to survive (Frame, Williams & Green, 1999a; Frame & Williams, 1996). It is a mainstay as one of the core components of African American identity (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). Spirituality in African American culture is historically grounded in the search for liberation from injustice, and the traditional African concepts that reflect the idea that spirituality manifests in every aspect of life (Frame, Williams & Green, 1999a; Frame & Williams, 1996). Instead of adhering to African holistic and spirit-centered healing systems, western physicians have relegated the traditions to the realms of superstition, "voodoo," and folklore (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). However, because African American traditions highlight experiences via stories, proverbs, and music, researchers have suggested that these cultural traditions should be integrated in research, therapy, and medical processes in practice (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996).

Black Music

Prominent and widespread features of African American spirituality are music and dance (Carr et al., 2012; Frame, Williams & Green, 1999a; Frame & Williams,

1996). Black spirituality encompasses the emotions, the senses, and the entire physical body – limbs (Frame, Williams & Green, 1999a; Frame & Williams, 1996). Musical expression for African Americans has long been forged with spirituality and can be seen as early as in enslavement and as current as the present day (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996). African American cultural patterns like improvisation, call and response sequences, and the use of metaphor, imagery, and symbolism appear in music associated with Black culture: gospel, jazz, rhythm and blues, rap, and hip-hop (Carr et al., 2012; Frame, Williams & Green, 1999a; Frame & Williams, 1996). All these genres can be viewed as spiritual expressions of resistance to exploitation, themes of liberation and racial solidarity (Chinn et al., 2021; Frame, Williams & Green, 1999a; Frame & Williams, 1996).

The social conditions that create the environment for marginalization to exist have a direct influence on the level of stress and physiological distress on health outcomes (Chinn et al., 2021; Patterson et al., 2016). Music therapy, like the "talking cure" developed by Freud, engages patients in a talking therapy, and is viewed as distressing and intuitive (Carr et al., 2012). Marginalization is followed by trauma, and music therapy offers traumatized people a chance to raise their voice and relate their experiences in a trauma-informed manner (Carr et al., 2012; Frame, Williams & Green, 1999a; Frame & Williams, 1996).

However, music therapists have historically trended to be ethnocentric in their selections of music and therapeutic methods (Campinha-Bacote & Allbright, 1992). Like in other U.S. professions, a majority of music therapists are white, and therefore tend to represent a Western-orientated style of therapy that may not be understood or appreciated

by ethnic groups, specifically African Americans (Nicholson, Berthelsen, Abad, Williams & Bradley, 2008; Campinha-Bacote & Allbright, 1992). Yet being able to identify with your provider has consistently remained important to African Americans across a myriad of research studies (Erves et al., 2019; Erves et al., 2017).

Therefore, providing effective therapy to African Americans requires the therapist/moderator to take a native view of the individual as expressed in an Afrocentric worldview (Camphina-Bacote, 1993). One major component of that worldview is the affective epistemology, the process and belief of a people discovering knowledge and truth through emotion (Nicholson et al., 2008; Camphina-Bacote, 1993). For Black people, women in particular, the gap in music therapy is displayed in its utilization in healing physical ailments and promoting educational interventions (e.g., cancer and positive parenting; Nicholson et al., 2008; Camphina-Bacote & Allbright, 1992). Capturing perspectives on cultural phenomena has never been collected in collaboration with music and/or music therapy, even though it is imperative that non-traditional, culturally specific interventions (i.e., Black music) incorporate the diverse populations' worldview and spiritual perspectives to promote physical and mental wellbeing (Nicholson et al., 2008; Camphina-Bacote, 1993). Ultimately, addressing Black health disparities and trauma resulting from the interactions with structural mechanisms requires non-traditional methods and strategies that center cultural experiences and systematic oppression that hinder equity across all social determinants of health and wellness (Chinn et al., 2021; Patterson et al., 2016; Dobkin, 2016).

Sister Circles

Another non-traditional method of healing and insight is that of "sister circles" (Gatson, Porter & Thomas, 2007). A recurrent theme across many studies is the importance for Black women to have the support from other Black women (Neal-Barnett et al., 2011). Sister Circles are intended to provide and build upon friendships, social networks, and the sense of identity and community that is commonly found among Black women (Neal-Barnett et al., 2011; Gatson et al., 2007). Centered within the Black club movement, sister circles have been an essential part of Black women's lives for over 150 years (Neal-Barnett et al., 2011; Giddings, 1984). Foundationally, sister circles provide support, help, encouragement and knowledge to Black women who share a common, yet not monolithic, lived experiences (Giddings, 1984). The unique position and meaning of sister circles have matched the community they were created to serve (Neal-Barnett et al., 2011).

Over time, however, the term has come to mean different things. For some, a sister circle is a group of women within an organization (e.g., workplace, club), who come together for a common goal or theme, such as a book club or a fitness club (Neal-Barnett et al., 2011). Sister circles have also been cited as a group of women experiencing similar health concerns (e.g., diabetes, stroke, and breast cancer) who collectively share education and support (Gatson et al., 2007). To facilitate effective sister circle,s moderators and/or developers of the group will share identity or specific experience with the group, as well as incorporate African-centered curriculum that reinforce the cultural values of women of African descent and prioritize healing and

physical and mental wellness (Neal-Barnett et al., 2011; Gilbert, Harvey & Belgrave, 2009).

Emphasizing mental health and wellness, sister circles have also been utilized as group therapy (Neal-Barnett et al., 2011; Gatson et al., 2007). Women in the group share connection through their shared mental health diagnoses or concerns (Neal-Barnett et al., 2011). Popularized by psychotherapist Julia Boyd (1993), the therapeutic use of sister circles has been used to assess Black women's self-esteem and how it impacts relationships, work, and other aspects of life. In every session, members reflect on the multiple roles of Black women, family legacy, images of Black women, and the importance of the shared history of Black women (Neal-Barnett, 2011; Boyd, 1993).

Despite the widespread use of sister circles among Black women, empirical research is limited in its investigation of their feasibility and effectiveness (Neal-Barnett et al., 2011; Gilbert er al., 2009; Gatson et al., 2007). The research that is available provides anecdotal data that indicate the effectiveness of sister circles to promote healthy eating, substance abuse prevention, and raising self-esteem (Black Women's Health Imperative, 2010; Gatson et al., 2007). However, extremely few studies have either used or examined the use of sister circles in collecting perceptions of phenomena to illicit actionable change (Neal-Barnett et al., 2011; Black Women's Health Imperative, 2010). With their environment encouraging trust and relationships, sister circles can serve as an effective non-traditional and culturally relevant form of both investigation and healing, that is essential in capturing the nuanced data on Black women's experiences (Neal-Barnett et al., 2011; Gatson et al., 2007; Gilbert et al., 2009).

Black Feminist Thought as Methodology

Patricia Collins (2000) articulates Black Feminist Though (BFT) as "critical social theory," existing staunchly outside of traditional theory and methodology, that emphasizes humanizing, engaging, and including Black women's' experiences in all areas of research methodology and implementation. BFT seeks not only to make Black women's critical consciousness intelligible to Black women and others, it is also opens the possibilities for Black women to resist oppressive forces that limit their self-empowerment and serves as a powerful methodological tool for research by and about Black women (Clemons, 2019; Patterson et al., 2016; Collins, 2000). Derived from a standpoint theory, a feminist materialism that inhibits and expands the critique of capitalism to include all human activity, especially the activity of women, BFT offers insight to the complex history of Black women's social conditions in the United States (Clemons, 2019; Patterson et al., 2016; Collins, 2000). At the center of most general feminist research, the goal is the obligation to act and bring about social change for the social, environmental, and physical conditions of women (Clemons, 2019; Patterson et al., 2016; Collins, 2000). Feminist research aims to give voice to the invaluable, but often, the experiences of women of color are disregarded (Clemons, 2019; Patterson et al., 2016; Collins, 2000). Black Feminist Thought works to created spaces for Black women to share their experiences and contribute their expertise and unique identity to existing phenomena (Clemons, 2019; Patterson et al., 2016; Collins, 2000).

Summary

Nearly twenty years of consistent trends have depicted growing health disparities for Black women in the United States. Maternal mortality and chronic disease rates (e.g.,

cardiovascular disease and diabetes) among this group are higher compared to their white counterparts. Existing literature illustrates the historic systematic influences that have had a direct impact on Black women's level of healthcare utilization. Marginalization and oppression of Black women socially, economically, and physically exacerbate the negative health outcomes that currently exist among the population. Western medicine and traditional healing methodologies have failed to decrease the inequity that exists. Utilizing non-traditional research and therapy methodologies, this study seeks to uplift Black women's voices using a Black Feminist Methodology to ensure that perspectives and lived experiences of participants will add to the gap in literature concerning Black women's self-described experience with the healthcare system and help to develop and implement actionable change to achieve health equity for Black women.

While there have been studies depicting the massive and continually growing health disparity and mortality rate among Black women compared to other racial and gender groups, very few have highlighted the self-identified experiences of Black women within healthcare and the potential factors that may be influencing the various health outcomes. A description of the healthcare atrocities faced by Black women does not address the problems that are pervasive within the healthcare system that are significantly impacting their health outcomes. Black womanhood and subsequent experiences require healthcare professionals and service providers to comprehend the compounded oppression faced by Black women and its influence on potential interactions. While Black women have found strength despite their oppression, there is a need for actionable change to result in all systems in the United States, particularly healthcare, so that the drastic negative impact on the quality of life for Black women can be eradicated.

CHAPTER III

METHODOLOGY

Introduction

The marginalization of Black women in the realm of healthcare is consistent with

other systems of oppression, specifically in the United States (Patterson, Kinlock,

Burkhard, Randall & Howard, 2016; Collins, 2000). Considering various identity

markers, including race, gender, sexuality, class, religion, and more, it is imperative to

use non-traditional research methodologies to center the voices, experiences, and lives of

Black women. Black Feminist Thought (BFT) scholars like Patricia Collins, bell hooks,

and Kimberlé Crenshaw emphasize the significance to combat Eurocentric, western,

positivist paradigms that posit that there is a single absolute truth (Patterson et al., 2016).

BFT and adhering research methodology undergird a process that permits Black women

to be seen and their experiences understood (Collins, 2009). BFT serves as the main

conceptual framework and critical methodology in this study to properly feature the

identities, experiences, and lives of Black women as valuable data. The purpose of this

study is to illuminate and address the experiences of Black women navigating the

healthcare system. Results of this study could potentially be used to improve the

knowledge of the target community, healthcare providers, and researchers, thusly

cultivating positive health outcomes and more holistic and trusting care for Black

women.

Black Feminist Thought as Methodology

Patricia Collins (2000) articulates Black Feminist Thought (BFT) as "critical social theory," existing staunchly outside of traditional theory and methodology, that emphasizes humanizing, engaging, and including Black women's experiences in all areas of research methodology and implementation. At the center of most general feminist research, the goal is the obligation to act and bring about change for the social, environmental, and physical conditions of women (Clemons, 2019; Patterson et al., 2016; Collins, 2000). Feminist research aims to give voice to the invaluable, but often, the experiences of women of color are disregarded (Clemons, 2019; Patterson et al., 2016; Collins, 2000). BFT seeks not only to make Black women's critical consciousness intelligible to Black women and others, it also opens the possibilities for Black women to resist oppressive forces that limit their self-empowerment and serves as a powerful methodological tool for research by and about Black women (Clemons, 2019; Patterson et al., 2016; Collins, 2000). Derived from a feminist materialism that expands the critique of capitalism to include all human activity, especially the activity of women, BFT offers insight to the complex history of Black women's social conditions in the United States by creating spaces for Black women to share their experiences and contribute their expertise and unique identity to existing phenomena (Clemons, 2019; Patterson et al., 2016; Collins, 2000).
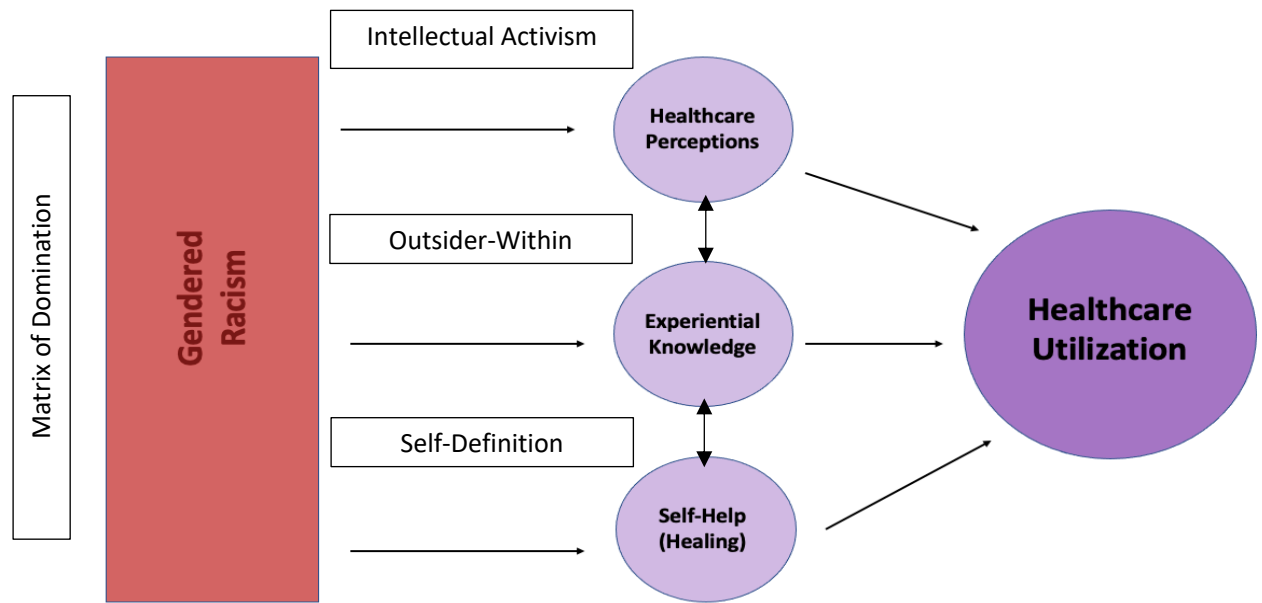
Figure 1. Conceptual Framework of Black Feminist Thought and Healthcare Utilization. Adapted and modified from Collins, Patricia (2009). Black feminist thought: knowledge, consciousness, and the politics of empowerment.

With the Black woman experience in mind, this study utilized BFT as a foundational framework to examine perceptions of and influence on healthcare utilization, by applying the themes of BFT to factors that impact one's intent to seek services (see Figure 1). Gendered racism, a phenomenon coined by sociologist Philomena Essed (1991), lies within the structural domain that functions to organize systemic power and oppression for Black women within the intersections of their oppression (e.g., race, gender, and socioeconomic status; Anderson & Collins, 2004; Collins, 2000). It is theorized to have direct influence on the (1) healthcare perceptions, (2) experiential knowledge, and (3) self-help (healing) that ultimately determines their healthcare utilization. The first of BFT themes, "Matrix of Domination" refers to how the intersections of oppression are systematically organized (Anderson & Collins, 2004; Collins, 2000). It seeks to depict how structural, hegemonic, disciplinary, and

interpersonal domains of power resurface across different forms of oppression (Collins, 2000). Healthcare perceptions fall under the theme of "Intellectual Activism" (IA). IA emphasizes the reclamation of the work and thoughts of Black women that have been "silenced" throughout their contribution to American history, health statistical data-reporting, and lived experiences (Anderson & Collins, 2004; Collins, 2000). Pertinent to this theme is the inclusion of all works (e.g., poetry, music, art, and narrative) of Black women as valid forms of social thought and quality experiential knowledge (Collins, 2000). The "Outsider-Within" theme refers to the unique perspective that Black women hold in the social, political, intellectual, and economic environment in the United States (Collins, 2000). Navigating the healthcare system, Black women have specific experiential knowledge that needs to be captured and requires the expression of their full, intersectional identity, as Black women's experiences differ from those of Black men and white women. Lastly, "Self-Definition," according to Collins (2000), is defined as "the power to name one's own reality" (p. 300). True healing and self-help require safe spaces where self-definition is not clouded by structural objectification and/or silencing (Collins, 2000). Within the same context, affirmation from shared experiences within these safe spaces also plays an important role in self-definition, which aids in the journey from internalized oppression to a free mind—a true healing (Collins, 2000).

This study utilized a qualitative research design and a non-traditional data collection method with two distinct questions and subsequent pertinent aims:

Research Question 1: What are the experiences of Black women navigating the healthcare system?

- Aim 1A: To examine the health and wellbeing of Black women navigating the healthcare system.

- Aim 1B: To identify unique health and wellness resources for Black women when they are navigating the healthcare system.

Research Question 2: What is the role of music in the lived and retold experiences of Black women navigating the healthcare system?

- Aim 2A: To assess the impact of music on the affect and resiliency of Black women navigating the healthcare system.

- Aim 2B: To identify alternative therapeutic resources for Black women when they are navigating the healthcare system.

Qualitative analysis applying the BFT framework of community-engaged data addresses both questions of this study and provides insurance of culturally appropriate interpretations of the results.

Study Design

This study employed a qualitative descriptive case study approach with emphasis on cultural appropriateness and community engagement, guided by BFT and utilizing peripheral, constituent-involving, and sociocultural strategies throughout the research process. Because application of BFT requires inclusive practices, Black women were involved throughout the planning, development, and implementation of the entire research process. The initial phase of data collection consisted of 15 semi-structured interviews conducted with the target population to explore Black women's healthcare perceptions, experiences navigating the healthcare system, self-identified modes of healing (i.e., music and social support), attitudes toward and likeliness of healthcare

utilization, and the conceptualization of a "Sister Circle". Interview questions were developed with guidance of both the BFT conceptual framework and existing literature. However, because traditional forms of data collection (e.g., structured interviews and surveys) are perceived in BFT to pare the exchange of ideas and assume an unequal balance of power, favoring the researcher (Patterson et al., 2016), this study also introduced a non-traditional form of representative data (i.e., oral stories, music, narratives, and spoken word). Steered by the initial findings from the interviews, this study piloted a "Sister Circle," a purposeful collective of Black women that creates a safe space for participants to identify and realize their knowledge, identity, and shared lived experiences (Collins, 2009). The "Sister Circle" served as a mechanism to capture the attitudes towards and likeliness of healthcare utilization, thereby providing a culturally competent, intersectional, community-based model with which to not only capture Black women's experiences, but also to guide a more holistic and trusting form of care.

Researcher Positionality

It is imperative in this research context, that the researcher recognize and account for their worldview that includes ontological assumptions (i.e., an individual's beliefs about the nature of social reality), epistemological assumptions (i.e., an individual's beliefs about the nature of knowledge), and assumptions about human nature and agency (Holmes, 2020). The principal investigator of this study identifies as a Black American cis-gender male—not as a Black woman—and as such, offered to excuse himself from one-on-one interviews according to the participant's preference, so that the research assistant could lead the conversation as a Black woman. He was excluded from participating in the Sister Circle (ensuring safety within the space and validity in data

collection). Additionally, the methods employed throughout the research process ensured that Black women were provided an equitable level of power and decision making in study design, data collection methods, analysis, and reporting.

Study Sample

This study utilized purposive sampling to invite the participation of Black women who have had a moderate to extensive experience with the local healthcare system (i.e., clinics, hospitals-private and public, and primary care physicians). This gradient of experience with the healthcare system included those who have both direct and indirect experiences (e.g., as caretakers). Purposive sampling, also referred to as selective or subjective sampling, is a sampling technique that researchers use to pinpoint elements or characteristics within a group or population. Homogenous sampling, a subcategory of purposive sampling, was utilized to focus on a particular subgroup in which all the sample members are similar. Black women, who share both race and gender identities, made up the sample population. Following the initial 15 interviews, 10 additional Black women living in Louisville, Kentucky, were invited to participate in a Sister Circle, utilized in this study to collect additional qualitative data that amplify the voices of Black women.

Inclusion Criteria

To participate as a study participant, an individual must:

- Identify as a Black woman;

- Be over 18 years of age;

- Reside in Louisville, Kentucky; and

- Have experience (i.e., direct or indirect) navigating the healthcare system.

The need for a safe space was crucial in this study to ensure that participants had an opportunity to lift their voices and share their lived experiences.

Exclusion Criteria

If participants aligned with the inclusion criteria, they were not excluded from the opportunity. However, participants of one-on-one interviews were excluded from the Sister Circle. Screening for criterion was executed by community partners and the research team via a pre-screener document.

Recruitment

Community engagement and participation are key to ensuring that the research process follows BFT as a methodology. In the research context, community engagement allows for the incorporation of perspectives from the population that the research outcomes will impact and involve the most (Yale School of Medicine, 2021). Therefore, throughout the research process, Black women were equal partners. This was imperative because this research sought to pilot a methodology/tool to investigate healthcare perspectives and introduction/familiarization to alternative healing and research concepts (i.e., Sister Circles and music). As such, a local Black women-led non-profit organization, The Hope Buss, was selected as a community partner to help with recruitment and participation. The Hope Buss is a 501(c)(3) organization that works to bridge the gap between local organizations and the community by attacking hopelessness at its core (The Hope Buss, 2022). They serve the community by combatting food injustice and responding to other basic needs by hosting health fairs, community conversations centered on mental health, farmer's markets, and school supply giveaways.

Leaders of The Hope Buss and their decided constituency were provided with full insight into the research, influencing the decision-making in reference to interview questions and "Sister Circle" format. The Hope Buss agreed to promote the research opportunity to the community through social media (i.e., Facebook, Instagram, and Twitter), pre-existing social programming and market the opportunity through the community/volunteer and newsletter listserv. Members of the organization also pre-screened participants via the pre-screener document (see Appendix A) to ensure eligibility. The Hope Buss had multiple locations from which they provided services, which allowed the Sister Circle session to be held at familiar and convenient community location; the Sister Circle was held at the site of The Hope Buss's community food pantry, Saint John Lutheran Church. Members of The Hope Buss staff did not facilitate and/or lead any data collection, however, they did choose to participate.

 In addition to the direct connection through The Hope Buss network, the researcher promoted the opportunity for participation in the study by word of mouth and social connections throughout Louisville. Women from across the city were given the opportunity to participate on a first come, first served basis. The 15 participants who completed personal interviews were compensated $50 for their time commitment. All participants of the "Sister Circle" were compensated $100 for their time commitment of two hours.

Human Subjects Protection

This study was approved by the University of Louisville Institutional Review Board. Prior to the start of each interview and following the initial welcome into the Sister Circle, participants were led through the informed consent process by a

Collaborative Institutional Training Initiative (CITI) trained investigator, group facilitator, and/or research assistant. Details about the research were presented verbally and in written materials to ensure appropriate comprehension of risks, benefits, and voluntary participation status.

Personal Interviews

Providing a foundational response for both the research questions and Sister Circle session, 15 personal interviews were conducted with women living in Louisville. The Hope Buss pre-screened all participants to determine eligibility via the pre-screener document. All participants completed a demographic survey (see Appendix B) to capture socioeconomic characteristics. With all interviews conducted virtually, informed consent documents were signed and emailed back to principal investigator via pdf format. Interviews were conducted by the principal investigator, unless participants declared a sense of uneasiness. If uncomfortable, participants were given the option to be interviewed by the research assistant, with whom they shared identity (i.e., Black woman). Interviews lasted 45 – 60 minutes and were directed by the interview guide (see Appendix C).

Sister's Circle – A Qualitative Method

With the continued rise in negative health outcomes for Black women, regardless of their socioeconomic status, it is imperative that non-traditional methods are used to capture their experiences navigating the healthcare system (Collins, 2013; Visvis, 2008). Like the "talking cure" developed by Sigmund Freud and Josef Breuer, Black music, and social narratives, according to BFT scholars like Toni Morrison and Judith Herman, are perceived to be efficacious as both a data collection and a therapeutic tool for Black

women and their lived experiences (Visvis, 2008, Frame, Williams & Green, 1999).

Patterson et al. (2016) aligned with their predecessors by specifically naming a Black

women's collective and/or Sister Circle as a methodological research tool framed in BFT

that promotes the sharing of Black women's lived experiences. In this study, the "Sister

Circle" session lasted approximately 120 minutes.

The session was facilitated by a local licensed music therapist who identifies as a

Black woman and was compensated for her work on the project. She was accompanied

in the session by a research assistant, who also identifies as a Black woman. Both the

facilitator and research assistant had prior experience in research, had completed CITI

training in human subjects' protection, and participated in project training (i.e.,

qualitative research methods) by the principal investigator to ensure strategy and

comfortability following the research protocol. To establish research justice, equity, and

accurately recorded narrative was collected in the Sister Circle session, the investigator

was not present due to their disparate identity. Both facilitator and research assistant,

who share identity with participants, facilitated data collection by moderating discussion,

recording the session, and taking field notes, but also immersed themselves in the

conversation (i.e., developing trust).

Although not required to facilitate a Sister Circle, music was an added component

that aligns with BFT and its scholars as a "second location where Black women can have

their voice." Additionally, art and music have historically been unique in behavioral

health and sharing due to their ability to influence feelings and knowledge (American

Music Therapy Association, 2021; Collins, 2009, p. 19). The music therapist facilitating

the Sister Circle helped to create the environment required by BFT to enable the

expression of feelings, which promotes empowerment, stress management, and wellness, while additionally working toward several health and educational goals (American Music Therapy Association, 2021). With a background in both behavioral health and music therapy, the facilitator was equipped to operate and prepare for the potentially triggering content shared in the session.

Combatting Eurocentric, traditional research methods, the facilitator did not have a pre-determined set of questions, but rather a topic guide (see Appendix D) and was versed in the aims of the study. The Sister Circle provided a forum for the open exchange of stories and employed creative techniques (i.e., music therapy tools) to depict personal experiences. The facilitator provided a foundation of content for data collection purposes, with discussion prompts guided by the conceptual framework, the research questions, and initial findings from personal interviews. Prompts targeted healthcare utilization experiences (i.e., positive, and negative), types of healthcare utilization (e.g., community clinics, emergency room, primary care physician, disease/case management), and the role of music in the lived and told experiences of the women.

In addition to the discussion prompts, the Sister Circle session utilized several tools and methods appropriate to a music therapy group session to capture attitudes, knowledge, and perceptions concerning identity, emotional intelligence, health, and wellness, as well as methods to assist in emotion sharing and neurofeedback. Participants began the Sister Circle session with an icebreaker, which promoted comfortability and trust among the women. Additionally, to provide a starting point of self-awareness and actualization, each participant completed a self-assessment questionnaire and engaged in a song sharing activity. The questionnaire was developed by the researcher, community

partners, and facilitator based upon initial findings from the interviews and foundational literature concerning the phenomena.

Conversations were guided by the facilitator; however, Sister Circle participants were free to express themselves regardless of content. To ensure emotional and psychological safety within the Sister Circle, participants were informed of their power position throughout the process. Comfort and therapeutic opportunity were important aspects of the session, equal to data collection. Although the music therapist served as a facilitator, the dynamics of the Sister Circle relied on a partnership between the facilitator and participants to maintain a safe space where potentially traumatic experiences were able to be shared and discussed.

Utilizing music and artisan interventions, the facilitator centered the experiential sharing space in BFT core themes (i.e., family, work, sexual politics, motherhood, political activism, and self-definition). The therapeutic interventions utilized in the Sister Circle session included:

1) Drum circle: sharing of beat patterns to engage the motor and limbic system of participants.

2) Song share: self-created playlists based on and/or centered around a particular mood or affect (e.g., resilience, healing).

Steadfastly holding to BFT and the non-traditional data collection methodology needed to capture culturally relevant and accurate information from this population, the interventions created a space for sharing that was both uncommon and unique to research protocol and practice.

Data Analysis

To capture all conversations during the interviews and the Sister Circle, sessions were audio-recorded. Recordings were transcribed verbatim by Microsoft Teams, which offers a transcription feature in the Microsoft Office Suite contracted through the University of Louisville. Both set of transcripts (i.e., interviews and Sister Circle session) were reviewed by the research team and partners to certify accuracy and coded to remove personally identifying information and employed a numeric system for tracking each participant's contributions to discussion. For the Sister Circle, the facilitator completed an initial review, then forwarded transcripts to the principal investigator to review the breadth of the data and initiate subsequent analytic steps. Data were saved on dually password-protected software and computer at the University of Louisville. The computer was located within a secured office within the School of Public Health and Information Sciences.

With assistance from the facilitator and research assistant, the principal investigator manually extracted data segments from the transcripts and began the analysis process. Ensuring that no relevant data segments were excluded and/or unclear, the investigator consulted with the facilitator on each extraction dedicated to emphasizing the voice of the participants. Utilizing an in vivo coding process, the investigator identified poignant subject matter and allowed emerging codes to present themselves. This was completed first with interview data as it was collected, to determine any relevant information that would benefit from follow up in the Sister Circle. Sister Circle data was then added to interview data for full analysis. Participants' numeric ID was maintained with data excerpts to differentiate between interview and Sister Circle participants in

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analysis, allowing the research team to watch for conceptual differences that arose during distinct methods of data collection.

The researcher and assembled team of Black women then continued analysis by developing codes and themes from the data provided in both the interviews and Sister Circle. The following data analysis methods were utilized: 1. inductive thematic analysis, 2. narrative analysis, 3. respondent validation, and 4. multiple coders. Most advantageous for this study was the use of *inductive thematic analysis*. In inductive analysis, themes and explanations are derived primarily from a close reading of the data, without trying to fit that data into pre-existing concepts or ideas from theory (Green & Thorogood, 2018). An interpretive approach is crucial to providing research justice and equity to this specific group. *Narrative analysis* provides very different approaches to analysis. Although it is a less traditional method in qualitative research, narrative analysis allows the researcher to recognize the role of stories in health and healing as ways to understand illness in the social context, and through which researchers and healthcare providers offer service to their participants/patients. Because of the historical silencing of Black women's stories through oppression, it was imperative to utilize this form of analysis in alignment with BFT. Moreover, the Sister Circle offered a mechanism for adding music as an alternative venue for storytelling, and narrative analysis complimented this nontraditional data collection method by honoring the stories of Black women and further uplifting their voices.

Participants and partners in this study had the final say in what was revealed and how their stories were presented. The methods of respondent validation and multiple coders refer to the strategies employed by this study to ensure reliability and validity.

Also referred to as "member validation" or "member checking," *respondent validation* involves taking the findings back to the participants or representatives of the target population to ensure that researcher interpretation aligns with the statements and intent of the participants (Green & Thorogood, 2018). Following analysis, the research team returned to individual participants with the assistance of The Hope Buss team, to ensure that the data/results reflected the true meaning and or message that participants were attempting to convey. Again, this allowed for study participants to be the authors of their own stories. Due to the personal nature of the context, the research team withheld data deemed too sensitive to release via participant consensus. *Multiple coders* refer to the use of a research team in the analysis process, rather than relying on a single person, and enhances the reliability of study findings. Specifically in inductive approaches, it is not expected for two or more researchers to identify the same themes or codes in data, however, a focus on reliability is still necessary to make sure that whatever inferences are drawn are credible. Additionally, the rationale for the codes and themes must be identifiable to all those involved in analysis (Green & Thorogood, 2018).

The investigator reported themes that surfaced from the data around healthcare experiences and utilization and the role of music in the lives of the participants, accompanied by written narrative (e.g., written music, story) from participants to provide context. Results were equitably shared and disseminated to all participants and community partners to ensure true liberation prior to public and institutional dissemination and submission. The results of this study will serve the specific community in its decided implications, potential action, and next steps to certify that

actionable change takes place because of the time Black women shared together in the

research space.

CHAPTER IV

RESULTS

Interviews were conducted with 15 Black women residing in Louisville. Ages of interview participants ranged from 18 to 64, with most participants falling into the 25 – 34 age category (47%). All the interviewees had obtained a high school diploma, with nearly three-quarters holding a bachelor's degree or higher (73%). Six participants identified as a caregiver (40%), citing either a familial child or adult as their primary responsibility. Nearly one-half of the participants identified their primary source of health insurance as an employer-sponsored plan (47%), while the remaining signified a combination of Medicare or Medicaid (46%). Related to healthcare workforce experience, most participants described not ever working in a healthcare-related field (67%). Although 11 participants interviewed had a bachelor's degree or higher, 12 reported having a household income of less than $60,000 annually, while six participants interviews reported making less than $20,000 (40%). The demographic characteristics of interview participants are listed in detail in Table 4.1.

A separate group of 10 Black women residing in Louisville participated in the Sister Circle session. Ages of session participants ranged from 18 to 64, with most

participants falling into the 35 – 44 age category (40%). The education level was nearly split with four participants holding a high school diploma, and another four with a master's degree or higher. Over 80% of participants identified as a caregiver, citing a familial child or professional client as their primary responsibility. Over half of the participants described working in a healthcare-related field (60%). One-half of the participants identified their primary source of health insurance as an employer-sponsored plan (50%), while the remaining signified a combination of Medicare or Medicaid (50%). The annual household income ranged among participants, with over half of participants making less than $50,000. Demographics for the Sister Circle participants are presented in Table 4.2.

Table 4.1

Demographics of Interview Participants

N = 15		Frequency	Percent
Age Category	18 – 24	2	13%
	25 – 34	7	47%
	35 – 44	2	13%
	45 – 54	2	13%
	55 – 64	2	13%
	65+	0	0%
Education	Less than high school	0	0%
	High School/GED	1	7%
	Some college/certificate	3	20%
	Associate degree	0	0%
	Bachelor's degree	6	40%
	Master's degree or above	5	33%
Caregiver	Yes	6	40%
	No	9	60%
Worked in Healthcare	Yes	5	33%
	No	10	67%
Health Insurance	Employer-purchased plan	7	47%
	Private – nongovernmental plan	0	0%
	Medicare	2	13%
	Medicaid	2	13%
	State sponsored health plan	3	20%
	No coverage	1	7%
Household Income	Less than $10,000	0	0%
	$10,000 to $19,999	6	40%
	$20,000 to $29,999	1	7%
	$30,000 to $39,999	1	7%
	$40,000 to $49,999	1	7%
	$50,000 to $59,999	2	13%
	$60,000 to $69,999	1	7%
	$70,000 to $79,999	0	0%
	$80,000 to $89,999	0	0%
	$90,000 to $99,999	1	7%
	$100,000 or more	1	7%

Table 4.2

Demographics of Sister Circle Participants

N = 10		Frequency	Percent
Age Category	18 – 24	2	20%
	25 – 34	3	30%
	35 – 44	4	40%
	45 – 54	1	10%
	55 – 64	1	10%
	65+	0	0%
Education	Less than high school	0	0%
	High School/GED	4	40%
	Some college/certificate	0	0%
	Associate degree	0	0%
	Bachelor's degree	2	20%
	Master's degree or above	4	40%
Caregiver	Yes	8	80%
	No	2	20%
Worked in Healthcare	Yes	6	60%
	No	4	40%
Health Insurance	Employer-purchased plan	5	50%
	Private – nongovernmental plan	0	0%
	Medicare	0	0%
	Medicaid	3	30%
	State sponsored health plan	2	20%
	No coverage	0	0%
Household Income	Less than $10,000	0	0%
	$10,000 to $19,999	3	30%
	$20,000 to $29,999	0	0%
	$30,000 to $39,999	2	20%
	$40,000 to $49,999	1	10%
	$50,000 to $59,999	2	20%
	$60,000 to $69,999	0	0%
	$70,000 to $79,999	1	10%
	$80,000 to $89,999	0	0%
	$90,000 to $99,999	0	0%
	$100,000 or more	1	10%

Analysis of raw data from the interviews and Sister Circle resulted in 58 first round codes. However, reconciliation among multiple analysts narrowed these to 49 first round codes. First round codes were then refined to 18 second round codes. These codes were then grouped into six themes. A detailed depiction of the coding to theme grouping process is illustrated in Tables 4.3 through 4.8. The themes that resulted from collaborative analysis highlighted the experiences of Black women navigating the healthcare system by naming barriers to healthcare utilization and presenting their expectations of quality holistic care. Results also cited the perceived invisibility of Black women within the healthcare space, their acquiescence to the current system and their caregiving role for the larger community, and the pervasive resilience among trauma. As the Black women in this study presented a variety of coping strategies, their stories indicate the role of music in their lived and retold experiences.

Additionally, the Sister Circle session elicited a song share list that depicted songs that participants signified represent music of recovery, empowerment, comfort, illness, and spirituality. Participants emphasized the importance of the presence of music throughout nearly every aspect of their lives.

Table 4.3

Theme 1: I AM HERE!

Theme	Second Round Codes	First Round Codes
Black women living in Louisville feel invisible in healthcare	Women reported not being listened to or seen within provider offices, hospitals, and clinics	• Lack of concern • Lack of care • Lack of listening
	Women report that they are pre-judged and not receiving unique, individualized care	• Dismissive providers • Offensive office staff • Body image

Table 4.4

Theme 2: Barriers to Healthcare Utilization

Theme	Second Round Codes	First Round Codes
Black women experience numerous barriers in the utilization of the healthcare system	Access to healthcare facilities is negatively impacted by extended wait times and lack of appointment availability	- Limited access - Scarce appointments - Long wait times
	Uncomfortable provider experiences serve as a barrier to healthcare utilization and quality care	- Dismissive providers - Provider identity - Cultural Competency - Judgement - Racism - Gender discrimination - Stereotyping - Difference in treatment - Comfort with provider - Lack of communication
	Trauma resulting from healthcare leads to adverse perceptions	- Healthcare trauma - ER experiences - Clinic experiences - Historical distrust of healthcare
	Facility quality and lack of personnel are barriers to utilization	- Offensive office staff - Inconvenient office location - Office culture - Healthcare practice standards - Healthcare environment quality - Limited services at a site

	The burden of healthcare navigation is a barrier to accessibility	• Health insurance • Healthcare costs

Table 4.5

Theme 3: Expectations of Quality Healthcare

Theme	**Second Round Codes**	**First Round Codes**
Expectations of Black women to experience quality, holistic care	Access to healthcare facilities is positively impacted by limited wait times and open and increased appointment availability	• Open Access • Available Appointments • Short wait times
	Provider identity, cultural competency, and care can positively influence healthcare utilization	• Ideal provider experience • Provider experience • Provider identity • Cultural Competency • Comfort with provider • Bedside manor/congeniality • Individually catered healthcare
	Positive overall patient experience (i.e., personnel and facilities) can positively impact care and utilization	• Patient experience • Office Staff • Convenient office location • Office culture • Healthcare practice standards • Healthcare environment quality
	Quality insurance will increase likelihood of utilization	• Health insurance

	Intentional provider to patient marketing will increase uptake of services	• Healthcare marketing strategies

Table 4.6

Theme 4: What About Us? What About Me?

Theme	Second Round Codes	First Round Codes
Black women do what they need to for the survival of their community	Black women care for their families and larger community often to the detriment of themselves	• Caregiving • Selfless behavior • Self-neglect • Acceptance of poor healthcare services • Care for community
	Black women display an immense amount of power in self-actualization, resilience, and autonomy	• Resilience • Self-advocacy • Self-awareness • Body Image

Table 4.7

Theme 5: Alternative Healing and Therapy Methods

Theme	Second Round Codes	First Round Codes
Black women utilize formal and informal alternative healing and therapy methods for their wellbeing and rely on them for an appropriate trauma response	Methods used by participants to heal and cope with negative experiences	• Self-help/healing • Coping methods • Safe spaces • Storytelling • Artistic expression
	Shared experiences and social support serve as tools for enlightenment and empowerment	• Sister Circle perceptions • Commonality in experience • Social support

Table 4.8

Theme 6: Music is Life

Theme	Second Round Codes	First Round Codes
Culturally, music serves as a tool for storytelling and rehabilitation in all aspects of life	Music serves as a platform to relate to and tell the lived experiences of Black women	• Music • Storytelling • Music genres
	Music promotes healing and resilience when negative or traumatic experiences occur	• Music therapy • Music representing resilience

Research Question 1: What are the experiences of Black women navigating the healthcare system?

I AM HERE!

Black women living in Louisville feel invisible in healthcare

Consistent across interview and Sister Circle session, the participants reported feeling invisible while navigating the healthcare system. A substantial proportion of women mentioned the lack of care, concern, and listening they received from their provider and their office staff. The women often referred to being "overlooked" and "ignored" when trying to utilize healthcare services. Participants described several varying health issues that were misdiagnosed and/or ignored by physicians until the severity had reached an increased level, despite self-advocacy. One participant summarized Black women's healthcare experiences:

> *I would say that we aren't really taken seriously as African American women when we come into the medical space for treatment. I feel like a lot of times we can be overlooked, or our problems can be like died down to where physicians assume we don't really have these issues, or they're not really a big a deal as we're trying to make it.*

Participants mentioned the pre-judgement that they felt was a result of their identity as

Black women, even prior to speaking to office staff and providers. Furthermore,

participants reported feeling judged for their health behaviors and health outcomes,

coupled by a lack of cultural awareness or the inability to provide context (i.e., social

determinants). For example, the women spoke about experiences of body shaming,

resulting in a heightened awareness of their body image (i.e., how their bodies have been

presently and historically viewed and treated in western medicine). One woman shared:

> *I've gone in and seen doctors who don't even really examine me but determine my*
> *health position specifically because I am an overweight person. You haven't even*
> *talked to me.*

Adding to their perceptions of invisibility was the "factory" mode of healthcare services;

over three-quarters of participants characterized their experiences as "in and out," non-

patient-centered care. One woman detailing this specific experience reported:

> *There are some good providers, and then you have some who just kind of blow*
> *you off, treat the symptoms, keep pumping you full of medication and not really*
> *getting to the root of the issue. So, it's really a hit or miss on the quality of the*
> *physician.*

All women in this study attributed the perceived invisibility in medical spaces to both

racial and gender discrimination, with more than three-quarters prioritizing race as the

most influential factor.

Barriers to Healthcare Utilization

Regardless of the socioeconomic positioning of the participant, all women

reported a minimum of two barriers to healthcare utilization. These barriers ranged based

upon participant preference in provider services and quality of care.

Access to healthcare

When questioned about a negative aspect of their healthcare experience, overwhelmingly, women mentioned the accessibility of their provider. Access encompassed availability of appointments, the burden of planning the appointment, the location of the facility, and logistics of accessing the facility after arrival. Wait times once the patient arrived at care facilities, as well as the convenience of the provider/office hours were also referenced as factors contributing to the feasibility of access. Explaining the importance of office accessibility, a participant reported the desire for:

> *An office that, you know, was accessible past the normal 9:00 to 5:00 or 8:00 to 4:30 type thing, because if you are a working professional or so forth then, you know, you're at work during those times and you're either having to take [time] or plan accordingly, which can be stressful.*

When referencing the process of booking appointments, another woman reported:

> *It's hard enough to even get an appointment scheduled within a month, and then the doctor comes in there for ten minutes, then you're out of the office and it's like, "Well why was I waiting an hour and a half for a ten-minute conversation?"*

A third participant referenced the specific experience of having to wait for your appointment while having a moderately severe health issue:

> *My experience is leaning more on the negative side, just because of the long waiting time and not being able to be seen. Um, I'm, like, in pain, and having to deal with this pain for a long amount of time? Yea, so I would say a little bit more negative.*

Participants' commentary confirms accessibility as a pervasive barrier of seeking and receiving quality patient-centered care.

Uncomfortable provider experiences

When asked about their experiences with providers, 100% of the participants emphasized the importance of the patient-provider interaction. Participants added that factors such as provider identity (i.e., race/ethnicity, gender, and age), inability of the

provider to establish rapport and make the patient feel comfortable, lack of cultural competency, judgement, and lack of clear communication are pervasive barriers to seek out and retain healthcare services with a provider. One woman summarizes her first encounter entering a provider's office:

> *You find yourself in an office or setting where you don't have people who really wanna be there. Where, you know, they're not pleasant when you walk into the office.*

Another participant depicts their experience with stereotyping by healthcare staff and physicians:

> *That perception again, just because you're African American, dressed a certain way, or talk a certain tone of voice, that you can't afford services or support. I have definitely experienced that before.*

Over half participants commented that the negative perceptions, stereotypes, and ultimate discrimination can lead to improper health determinations by physicians:

> *There are times when I feel as though because of our culture, and because I am a Black woman, there are stereotypes that physicians make their determinations on.*

Their reports of discrimination also included perceived acts of differential treatment across race and ethnicity. Although most participants continue to seek care, these total provider experiences have led participants to have a disruption in their continuity of care.

Trauma resulting from healthcare

Nearly half of participants reported some sort of hurtful or traumatic experience while the navigating the healthcare system. These instances have derived from adverse patient and emergency room and clinic experiences that have reinforced distrust among interviewed women towards healthcare providers to deliver quality, holistic care. Within context, adverse experiences refer to negative staff interactions, perceptions of inhumane

treatment and discrimination by providers, lack of acknowledgement of patient perceived severity, and ultimate failure of the provider to deliver positive health outcomes. The trauma described had both psychological and physical impacts. One of the women summarized the foundation of trauma in healthcare for Black women and the subsequent barrier it creates for the uptake of services:

> *I think, in general, Black women definitely want second opinions, just historically being overlooked, being experimented on, you know, the stereotypes and biases about having a high tolerance for pain.*

Describing their current example of healthcare trauma, another participant detailed:

> *My face was swelling, and he put that tube up my nose, and I'm like wincing in pain, and he's not saying, "Oh, I'm sorry, I know it hurts," anything like that. He just shoved it up my nose, and when he took it out, blood just starting gushing, and he looked at me, and said, "Ok, we're gonna send these tests over," and just walked out the door. I'm just there sitting and crying because now I'm frustrated.*

Only three of the participants reported that they never experienced hurt or trauma within healthcare. These participants also fell within the 18 – 24 age category.

Facility quality and lack of personnel

All participants emphasized the need for care facilities to be of both physical and social quality. Their experiences, however, have been the opposite. Approximately 60% of participants desired providers that can offer various specialty services (e.g., general practice, hematology, and cardiology) from one satellite location. They explained that, when a provider offers only limited healthcare services, it is an extreme inconvenience in time management and scheduling around work and family responsibilities, location, and subsequent travel costs. Additionally, dirty and dilapidated provider facilities, as well as rude and unwelcoming office staff and administration are cited as major barriers to the uptake and retaining of healthcare services. When depicting their experience with the

differences in quality of facilities, one of the women emphasized the importance of

patient perception:

> *There is a reason African Americans go to Brownsboro in the East End compared to Norton's downtown. They can't meet our needs. They [East End] are more equipped. Downtown needs to fix their waiting area, you know, just more welcoming, better staff. I would not send nobody there.*

Describing frustrations with the limitations of specific provider services, a participant

stated:

> *Like yea, that's a negative aspect for me. They could tell me what my levels are elevated in some aspect, but they can't necessarily treat me. So, there's a limit to what they can actually do.*

Across the participants interviewed, 34% reported inadequate healthcare staff and

facilities that ultimately forced them to decide to leave the practice and seek care

elsewhere, Resulting in a continuous journey of inconsistent primary care.

Burden of healthcare navigation

Even though every participant denoted having some form of health insurance,

approximately 76% indicated health insurance and out-of-pocket costs as significant

barriers to healthcare utilization. These participants emphasized the burden of having to

navigate the policies surrounding health insurance, as well as the distribution of cost

coverage, depending on the level of service. With the self-owned responsibility of their

family's health and wellness, participants across income level articulated the time burden

that comes with the navigating in- and out-of-network services, the lack of quality

options, and the expense. A participant in the 25 – 34 age category detailed their

perceptions of the financial burden of healthcare for herself, as well as a family member:

> *I am always thinking about what I can and can't afford to get seen about. Umm, which sucks. It has made me not go seek medical attention. Similarly, with my*

dad, he was very sick, and even though it was necessary for us to seek treatment for him, my mom and I worried about all those bills from the hospital visits.

Another woman in the same age category, recently removed from her parent's health coverage, mentioned:

With not, like, having the best insurance, not knowing how to navigate it or having the knowledge, that's where the negative aspects of healthcare come in.

A third participant commented the following regarding her perception on their lack of healthcare options:

If there aren't options, I just have to trust their [provider] judgement. If you don't know you can go somewhere else or seek care elsewhere, what can you do?

All participants were forthcoming that their frustrating experiences negatively impacted their uptake of healthcare services, and as such, were also very clear about what the ideal quality healthcare experience looks like.

Expectations of Quality Healthcare

Access to healthcare

When asked about a positive aspect of their experience with providers or what an ideal provider experience would look like, over half of participants recognized accessibility and convenience (i.e., appointment availability, wait times, and non-traditional office hours) as the definition of quality. One woman described her experience booking an appointment at her primary care office:

I think the number one positive aspect compared to, like, my other experiences with healthcare, is, like, I always am able to get an appointment fairly quickly. So, I don't really have to, like, worry about, you know, if I can get in, or if I have a pressing concern that I can get in.

Another participant mentioned the availability of her primary care physician:

> *She's very available. She can be reached via messaging, and if it's something that she can take care of quickly, she does that. If I am adamant about wanting to come in, she will accommodate me as well.*

Of note, participants in the highest socioeconomic level shared more positive feedback about provider accessibility. However, despite their experiences, they joined the consensus that participants desire for provider offices to increase their operations beyond traditional business hours.

Provider identity, cultural competency, and genuine care

Although most participants expressed negative experiences of patient-provider interactions, about 30% of participants reported they have had positive experiences with providers who shared their identity (i.e., race and gender), or who were perceived as culturally competent and showed a sincere concern in their health and wellbeing. All participants mentioned the importance of the provider experience and the need for a "bedside manor" to feel comfortable and truly be seen. One participant mentions her primary care physician:

> *One positive is she is a minority, so she understands the struggle that we go through.*

Another participant goes into further detail about the importance of provider identity and culture:

> *The positive I would say is that she's an African American female who gets it. Like, I don't have to give cultural background and context or whatever, like, she understands, and she gets the stereotypes of Black women in the medical field and how our bodies and studies just don't line up. So, it's easier to have conversations and seek care in a manner which you don't feel judged.*

Quality personnel and facilities

Over 60% of participants emphasized the need for provider personnel and facilities to be of pristine quality, both socially and physically. All participants expressed the need for a welcoming healthcare environment and for the totality of healthcare services to be held in a centralized location where travel to different sites is not necessary. One woman summarized what she would like to see concerning provider experience, facilities, and staff:

> *I would like, you know, for the doctor's office to be more equipped. I mean, even if it is meeting everyone's needs the same way. The same way you serve cookies at the East End provider, why can't we get the same baked cookies down here? You know the sodas and stuff? Why can't we have that same vibe that they have, you know with the trees, where I can sit outside at a table. I want welcoming people who are able to understand us.*

Another participant focused on the physical environment and stated:

> *Umm, you know a clean environment. So, I want the office location to be clean, I want to see them practicing cleanliness and live up to quality building and health standards.*

Health insurance and health marketing strategies

With most participants reporting being on an employer-sponsored health plan, a common sentiment shared across the group was the ability to "shop around" for a quality healthcare experience. The group of participants with greater levels of education and income shared a higher level of security with exploring their choices for providers; if one provider did not meet their expectations, they had the confidence to advocate for themselves and the means to seek another opinion. A participant with an advanced degree and an income over $100,000 reported:

I've been pretty satisfied with my experience, and when I haven't, I've been vocal and spoke up because there are too many providers, and my health insurance is too good. I'm just gonna walk away.

Cultural competency and comfortability with the provider are key themes throughout the data. Additionally, nearly half the participants mentioned the need and want to be able to see marketing materials, communications, and strategies targeted to the community from which they come. Thirty percent of participants expressed the sentiment that seeing marketing materials featuring the community with which they identify would increase their sense of belonging and demonstrate the provider's intention for diverse and equitable care. One woman summarized:

I just think it would be perceived better if marketing resembled me and my community, so it would be really nice.

Although the entire population of participants described their ideal provider experience, less than 20% reported being a recipient of this level of quality care.

What About Us? What About Me?

Black women care for their families and larger community

Over 72% of the participants disclosed they serve as caregivers for a familial child, adult, or professional client. However, all participants indicated a cultural responsibility to be leaders within their respective families and social networks. Throughout the data, participants' stories showed consistent acts of selflessness for their families and the Black community. A participant illuminated her plight, expressing she may not bother others about her issues, even when she needs help or assistance:

I have a hard time expressing exactly what's going on and my knee jerk reaction is to say it's fine. That's all a person will know about whatever I'm dealing with. I'm ok, when I'm not.

They were firm on their sense of duty to family and community, and data showed they often prioritize the health of their families and friends over their own. However, similar disparate treatment practices were shared about experiences while caregiving and seeking personal care. A caregiving experience is detailed by one participant that had to negotiate accountability with her father's care team while he transitioned from intensive care to rehabilitation:

> *A lot of that still advocating for care. I've had to refuse to give care to him so that they would provide adequate care to him.*

Likewise, the women described the healthcare needs of the Black community in Louisville, not limiting discussion to their personal expectations for better care. One participant advocated:

> *Black people are struggling with their health…will this study help with the hospital being built down in the West End?*

But even as advocates, nearly half of the participants commented on the acceptance of less than adequate healthcare services, just to stay "healthy enough" to stick around for their families. Acquiescence is a reoccurring sub-theme throughout the data. One participant described her current attitude:

> *I guess this is how it is. This is just how I am supposed to get care.*

Both in interviews and the Sister Circle, a substantial number of participants signified the stress and burden that accompanies the welcomed cultural responsibility to be stewards over their families. Despite this stress, participants showed an immense amount of strength and tenacity.

Resilience, self-actualization, and autonomy

Although most participants reported frustration and negative experiences when trying to navigate the healthcare system, the data also present significant recurrences of tenacity, self-advocacy, self-awareness, and positive body image. Despite the perpetual reported failures by the healthcare system, these participants show immense resilience and self-actualization regarding their positioning within the system. Resilience is personified in this statement by one of the women in the Sister Circle session:

> *It comes to a point where you don't even necessarily clock those microaggressions as much, and you just kind of deal with it, and just get what you need to get done.*

Several participants also touched on violence against Black women's bodies in the historical experimentation and involuntary sterilization, and judgement imposed by the western medicine present-day view on body image and standards of health. These historical violations and personal trauma have taught them to be on guard and poised to take additional steps to ensure their needs are met. Some participants explained the burden of self-advocacy within the healthcare setting. One woman stated:

> *I go in with the attitude that I need to be listened to and taken seriously. I feel like I can take up for myself and advocate for myself if needed.*

 The experiences of these women and their social networks (i.e., serving as sounding boards for their family members and friends) leads them to feel a sense of perceived invisibility. Despite the hardships imposed by systems outside their control, all participants exhibited a tenacity and/or resilience in the face of their individual problems and the problems of their community, not only while navigating the healthcare system, but in daily life. However, due to their intersections of oppression, participants reported

this constant obligation of self-advocacy, produces elevated stress and a need for alternative healing and therapeutic practices.

Research Question 2: What is the role of music in the lived and retold experiences of Black women navigating the healthcare system?

Alternative Healing and Therapy Methods

Methods used to heal and cope with negative experiences

Participants across socioeconomic positions stated that they have experienced some hurtful or traumatic experiences in their lifetime, with approximately 72% identifying the presence of healthcare trauma. All participants provided some self-help/healing and coping methods, including activities of self-care (e.g., massages, manicures), praying, journaling, storytelling, meditation, yoga, drawing and painting, retreating to their safe space, and music. When describing an event that negatively impacted their emotions, a participant detailed their attempt to feel better:

> *I try to, you know, go get my nails done, and get my hair twisted, something to make myself feel good physically.*

Another participant stated what they do when a stressful or traumatic event occurs in their life:

> *Parks and nature are really good. You know just grounding yourself, taking your shoes off and just walking in the grass, and those types of things. Sitting in open space and just taking in the natural air.*

Another significant and frequent mention across participants was that of safe spaces. Each participant detailed their specific safe space. Participant homes were overwhelmingly

referenced as the primary source/space of safety. Security was also mentioned to be found

at church, and with family and friends. One woman stated:

> *I mean basically my safe space is my home. I'm very intentional about the energy that I bring into my home. However, my friends are a truly safe space for me. I go to them for everything.*

Shared experiences and social support

The most cited coping method among the group of participants was leveraging the

support of community with whom they share identity; social support and commonality in

experience helps to enlighten and empower Black women. Participants stated that feeling

psychological safety is the primary condition in which they would feel free to share and

express themselves. One hundred percent of participants confirmed the effectiveness and

necessity of belonging to a Sister Circle. Whether the Sister Circle was a collective of

their friends that gathered informally or an organized group with structured sessions,

participants emphasized the invaluable tool that a Sister Circle is in creating a safe space

where their unique intersection and lived experiences can be heard and uplifted.

Subsequently, all participants confirmed that if granted the opportunity, they would

participate in and recommend a Sister Circle. Relating social support and healthcare

navigation, one participant stated:

> *Absolutely, we talk about these types of things, you know, about our experiences with healthcare providers…asking them is there anyone they recommend or should stay away from.*

Another participant mentioned the importance of her social network and the

communication with them:

> *Like, the first people I called was my friends and texting them throughout the entire appointment…talking to them. They were able to help me think through my thoughts and my other options and navigate what next steps I needed to take.*

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The comfortability of the Sister Circle environment was detailed by a participant who had joined one in the past:

I think a Sister Circle allows you to, like I said, be free, expressive, talk in a way that doesn't feel like someone is judging you.

Socioeconomic positioning had no impact on the perception of the necessity for Black women to incorporate alternative healing and therapy methods. Within these methods, social support and connection with those who share similar identity was pertinent to recovery after traumatic experiences. Depicting their unique experience with a Sister Circle, another participant, who happened to be in a sorority, detailed her involvement:

Different from traditional therapy, there was a connectedness, a freedom. Our stories were intertwined, and until we were in the same space, we didn't know we were all having similar traumatic experiences. It helped us to share, give alternative ways of addressing these things, while supporting each other in our common struggles and commonalities.

Music is Life

Music and storytelling

Every participant attested to the significance of music in their culture and daily lives. When asked about self-help/healing and coping methods, 100% of participants listed music as one of the most effective tools. The list of music genres varied, including, gospel, country, soft rock, k-pop, hip – hop, rap, rhythm and blues, and classical. Participants emphasized the spiritual connection with music. They also underlined the innate relatability of the lyrics that aid in retelling their own similar stories and experiences. Three participants described the presence and impact of music in their lives:

I wouldn't be here. I had a rough upbringing and even adulthood. Music saved my life.

Music is a huge factor in my life. It honestly helps me in so many different ways. I mean, when I'm having a bad day, I can put on gospel and my spirits are lifted. Music is definitely a healer.

Yeah, I think music plays a huge part. Especially just in our culture as well. Certain things that you listen to can shift your mindset and your vibe.

Music therapy

Several participants agreed that music promotes healing and aids in regulating emotions. Nearly all participants reported using music as their primary tool for the level setting of their thoughts and emotions. Detailing how music helped her to settle her emotion, this participant stated:

We have, like, a stationary bike, so when I get angry, I have just put on Beyonce's Renaissance album and ridiculously rode throughout the whole album because I needed to do something or else I was gonna do something I was gonna regret.

Participants reflected on the benefits of music, noting it can uplift their spirits, promote feelings of empowerment, and facilitate resiliency. Interview participants were asked to pick a song(s) or album that helps them feel resilient or lifts them up when they're feeling down or need motivation. The music chosen by participants was all signaled to be major facilitators of affect and emotional change. Song selections are detailed in Table 4.9 in a playlist, which was also shared with all participants following the conclusion of the study.

Table 4.9

Resiliency Playlist

Artist	Song or Album	Quote from Participant
Solange	A Seat at the Table	"I love this album so much; it makes me feel my emotions"
Burna Boy	Twice as Tall	"It makes me feel like can do anything, I also love Nigerian artists"
Jill Scott	Golden	"I love her, I love her music. I love the tone and vibe of her music; the lyrics are everything"
Sinach	Waymaker	"This song just resonates, it does something to me."
Tems	Free Mind	"Have you heard this song before? Don't you feel free?"
Earth, Wind, and Fire	September	"You need to get up and pick yourself up, put this on."
Bloody Civilian ft. Rema	Wake Up	"This song, and the whole Black Panther soundtrack is motivation."
Jonghyun	Shinin	"This whole album really expressed his feelings before his untimely suicide."
SWV	Right Here	"They are on my girls club playlist; it builds up my mood."
Fred Hammond	No Weapon	"Perfect song to pick me back up from feeling sad."
Jazmine Sullivan	Heaux Tales	"One of the things I love the most is this album tells a story."
Kirk Franklin	Brighter Day	"That's always a good one to get you lifted."

| Rev. James Cleveland | God Is | "Whew, I'll cry right now." |
| The Deele | Two Occasions | "This song reminds me of my husband, pure happiness." |

Sister Circle

In addition to the codes and themes derived from the Sister Circle session, participants were asked to assess the quality, feasibility, utility, and effectiveness of the session. All the participants expressed the need for the sessions to continue and to become standard practice to acknowledge and comprehend the stories of Black women before beginning heavy, vulnerable work. According to the women, the music aspect of the session was essential in helping to foster an environment of comfort and trust when sharing potentially triggering and painful stories. A detailed description of participant song share can be seen in Table 4.10. One hundred percent of the participants reported that they felt both heard and seen within the session.

The women confirmed the power in their collective and recommended that programs/sessions like this be enacted regularly. Participants emphasized the demand for a secure space where personal stories can be shared. The single requirement of these sessions was its facilitation by a Black woman, particularly one like their facilitator who had a background in music therapy or some other non-traditional methodology. Institutions who have historically been oppressive to Black women (e.g., healthcare) were not trusted as potential facilitators of these sessions. Rather, non-profit organizations who help and identify with the community they serve were noted as the most trusted entities to continue this practice. One of the session participants wrote an evaluation and placed it on social

media detailing the complete experience of the session. She granted permission for the

study to utilize her words.

> *Friday night I participated in the Sister Circle for Jason's research. Walking in, there was something weighing on me. I just needed community and to share with Black women. To physically use instruments and feel the heaviness leave my body. That space we created truly felt magical to be open and honest, to share painful experiences, to be filled with laughter, and to utilize instruments to transform energy. I cannot stop thinking about it or how to recreate it regularly. Get in spaces that welcome and support your story, stop holding back the painful parts, talk through the shakes in your voice, talk through the tears, embrace every piece of your story. There is healing in the details, there is promise in detail, there is someone who needs to hear your details. Keep telling your story, keep healing, keep pushing through.*

Table 4.10

Sister Circle Song Share

Songs of Illness	Songs of Recovery	Songs of Empowerment	Songs of Comfort	Songs of Spirituality
I hate you so much right now – Kelis	*CLEAN* *Walking Shoes* – Mali Music	*Strength, Courage, and Wisdom* – India Arie	*Pulling me thru* *Good Days*	*Mary Did You Know* *Impossible* – Shontelle
Love Language - Sza		*So What* – Pink *Pretty Brown Skin* – Eugene Kelly *There's Hope* – India Arie *Breathe*	*I am Light* *Closure* *Firm Foundation* – Maverick City Music *Because you loved me* – Celine Dion	*Grateful* – Hezekiah Walker *Back that Ass Up* – Juvenile *Jireh* – Maverick City Music *Man of your word*

At the beginning and end of the Sister Circle session, participants were asked to share a favorite song, as well as songs that describe and illicit specific affects and emotions. Accompanied with the song share, the facilitator asked for the meaning behind participant song selections. Responses ranged from triggering both negative and positive memories, empowerment, comfort, and connection to spirit. Frequently mentioned was the participants' connection to the lyrics of the music. Three participants described their various reasons for their song selections:

This song puts my life and all my insecurities to music. I love the lyrics.

Because of what I've been through, it speaks to the foundation of who I am.

It's a good memory of my daughter turning one, also a solo trip that I went on. It also reminds me that I am free to be me.

This study examined the lived experiences of Black women navigating the healthcare system, as well as the role of music throughout this specific navigation and their general daily life. The results of this study illuminate potential factors that contribute to the continued disparate health outcomes of Black women compared to their counterparts. Additionally, results provide introspection into feasible and effective strategies (e.g., music, Sister Circles) that may be necessary to provide Black women with a safe space to tell their stories and ultimately, aid the healthcare system and general practitioners in providing a quality and holistic care, thereby improving health outcomes. Examining this phenomenon qualitatively has given voice to this population, who often cited being silenced in many spaces. Further, data provides researchers and healthcare providers with a direct and privileged insight into the lived experiences of Black women, the barriers and facilitators of healthcare utilization, and the need for an innovative

transformation of the common practices that have failed to advance health equity for this population. As impactful as this study was for participants, these data need to be utilized in future research for the assessment and reconstruction of local and national public health policy and practice.

CHAPTER V

DISCUSSION

The National Center for Health Statistics reports that Black women in the United States have been experiencing substantial improvements in their health over the last century, however health disparities persist (Chinn et al., 2021). With a higher burden of chronic conditions, higher rates of maternal mortality, and shorter life expectancy, these health outcomes do not occur sovereign of the social conditions in which they exist. This study investigated the experiences of Black women while navigating the healthcare system and the role of music in their lives, posing the following questions:

Research Question 1 (RQ1): What are the experiences of Black women navigating the healthcare system?

- Aim 1A: To examine the health and wellbeing of Black women navigating the healthcare system.

- Aim 1B: To identify unique health and wellness resources for Black women when they are navigating the healthcare system.

Research Question 2 (RQ2): What is the role of music in the lived and retold experiences of Black women navigating the healthcare system?

- Aim 2A: To assess the impact of music on the affect and resiliency of Black women navigating the healthcare system.

- Aim 2B: To identify alternative therapeutic resources for Black women when they are navigating the healthcare system.

This study underscored the structural inequities that contribute to the lived experiences of Black women within and outside of the healthcare system and highlighted the uniqueness of their intersecting identities in how they have come to cope with systems that repeatedly fail them. Consistently present throughout the data was the self-identified sense of duty to carry the burden of caregiving for the family or acting as head of household. Culturally, this phenomenon was signified by participants of this study and other Black women outside of this study frame to be a responsibility that is accepted with pride (Chinn et al., 2021; Barnett et al., 2011; Frame et al., 1999). However, the burden of family coordination and healthcare navigation and acquiescence of healthcare quality for self-preservation were noteworthy dynamics throughout this research.

Another critical aspect of the study is the reference to the "Sister Circle" in the informal context. Black women rely on friends and family to serve as a sounding board for all issues, including healthcare navigation. A trustworthy social network provides a sense of security that allows Black women to share for healing and research purposes. Additionally, non-traditional, and innovative methodologies should be considered in providing a safe space to heal from trauma, as well as capture accurate data that helps in repairing the historical contexts that have accumulated in the United States to influence Black women's health. Transformation in public health policy and practice needs to take place to combat the individual and institutional levels of racism and perceived discrimination that impede health improvement among Black women.

The Experiences of Black Women Navigating the Healthcare System

Like the literature, this study reflected that, despite adverse experiences within healthcare, Black women in Louisville are seeking provider services, however,

experience a plateau of improved health outcomes (Chinn et al., 2021; Barlow & Johnson, 2020). Three themes remained consistent throughout the population: perceptions of differential treatment, judgement, and discrimination. The results of analysis revealed both barriers and facilitators to the uptake of services among the population. It is important to highlight that over three quarters of participants have reported never having received quality, holistic care and expressed minimal trust that they will encounter an equitable experience in the future. With that, the women asserted that they deserve and expect higher standards.

Participants were concerned with the quality of the physical and social elements of the provider facilities and the comfort they feel in encounters with providers, front office staff, and administration. Relying on someone to take your life in their hands requires an immense amount of trust and comfort, which the healthcare system presently and historically has failed to gain with this community. The impact of judgement and bias is pervasive among this specified group (i.e., Black women). Participants presented story after story about the adverse experiences they had when navigating the healthcare space, because they were unable to get the care they knew they needed and deserved. Discrimination was reported in the form of perceived invisibility, which was rooted in staff inhospitality, brusque provider interactions, and disparate provider view of Black women's bodies. Participants felt they were ignored and depicted a lack of "bedside manor" across experiences. They described harmful interactions with office staff and administration as frequently as they spoke about care professionals. More specifically, participants witnessed staff frequently present with judgement towards patients. Due to the history of this culture, and its marginalization, interactions laced with bias and

microaggressions are a strong deterrent of healthcare utilization, trust building, and comfort with provider services. These experiences have cultivated a lack of trust and comfortability within the setting and perpetuated the deterioration of the patient – provider interaction that is essential in achieving positive health outcomes (Chinn et al., 2021; Erves et al., 2019; Levin, 2009).

Interactions with the provider were mentioned as both a barrier and facilitator to the uptake of health services among this sample of participants. Stratifications in socioeconomic positioning (i.e., level of education and annual household income) among participants showed a difference in perception regarding the need for proximity of office location, healthcare costs, and availability and cost of health insurance. Yet, regardless of socioeconomic positioning, a trend among all participants was the need to advocate for themselves while in the provider's office. Self-advocacy was reported to be a burden while in the assumed "safe space" of healthcare.

Every participant described a negative and positive aspect of their experiences with providers. During the Sister Circle session, several participants noted a need for them to share identity with their provider to increase comfortability; they felt that the shared understanding between Black women eliminated some of the burden of self-advocacy. Interestingly, they also shared the perception that younger generations of providers present with less judgement. Other factors that impacted trust and comfortability with the provider included cultural competency, availability, relevant healthcare communication, and the ability to convey genuine care for their wellbeing. . Adversely, if the provider is not trusted, or does not share identity (i.e., race and/or gender), patients are less likely to adhere to

recommendations of positive health behavior and healthcare utilization decreased (Chinn et al., 2021; Barlow & Johnson, 2020; Erves et al., 2019).

In response to RQ1, the results of this study depict a full view of the experiences of Black women navigating the healthcare system. Both negative and positive experiences were captured, ranging from barriers and facilitators to the uptake of healthcare services, perceptions of invisibility, provider-patient interactions, and expectations of quality care. All participants reported the current state of their health and wellbeing was a result of their own self-advocacy, tenacity, and natural supports. Additionally, participants' stated expectations of quality care practices aided in identifying health and wellness resources for the women that align with their needs and intersecting identity, within their cultural context.

Despite best practices and evolving technology, nationally, the health and wellbeing of Black women is steadily declining (Chinn et al., 2021). Therefore, it is imperative that other influencing factors are considered when attempting to combat health disparities among the population. As healthcare trauma is significant among Black women, it is imperative that non-traditional and alternative methodologies are used for subsequent healing from the trauma, as well as the collection of narrative, provision of healthcare services, and therapy (Dobkin, 2016; Barnett et al., 2021; Frame & Williams, 1996). Ongoing research must continue to examine factors that facilitate the uptake services to increase the positive perceptions of healthcare and decrease the negative health outcomes that result from poor healthcare experiences.

Alternative Research, Healing, and Therapy Methods

Incorporating non-traditional methodologies is essential when servicing marginalized and oppressed populations (Dobkin, 2016; Barnett et al., 2011; Levin, 2009). Historically and perpetually, traumatic events have led these populations to a level of distrust that deters them from engaging with institutions that have victimized them repeatedly and participating in research. Black women have been violently abused by healthcare institutions and research practices. This qualitive case study sought to capture perceptions and experiences of Black women navigating the healthcare system. Unique to this study is the conceptual framework (i.e., Black Feminist Thought), and the utilization of a Sister Circle as both a data collection method and therapeutic tool, ensuring a safe space for participants to express themselves.

Sister Circles have primarily been used in psychotherapy settings and led by a mental health professional to promote health behavior change . Within this study, a Black woman licensed music therapist facilitated the session with a music and a therapeutic lens, with the goal to provide a safe space and capture real life stories of the women involved, within and outside of the healthcare setting. Ensuring psychological safety was the top priority. Using drums and instruments in the circle setting allowed the participants to channel their thoughts and energy and create community with one another. This is significant, as both interview and Sister Circle participants cited social support and their friend networks as safe spaces, and a tool they use to cope with uncomfortable situations and emotionally regulate.

Similarly, music was referenced repeatedly regarding its ability to change affect and mood of the participants. African culture is founded in music and beats. It is reported

that music holds a place in the spiritual dimension and has a direct connection to the spirit (Frame, Williams & Green, 1999; Frame, Williams & Green, 1999a). Research question 2 (RQ 2) was satisfied by participants who confirmed in the interviews and throughout the Sister Circle session that music is transcendent, and not only helped them to share in the research setting, but also was present in every aspect of their lives. The self-designated influence that music has on the emotions of participants confirms the need for music to be increasingly incorporated as a tool for therapeutic purposes for this population. Overwhelmingly, within the session that utilized music therapy, the women expressed their desire to continue the sessions, not only to continue the safe space, but to build community and heal from past traumas that were revealed during the session after listening to the shared experiences of their peers.

This study highlights the social complexities that Black women inherit by way of their intersecting identities (i.e., race and gender). Factors that influence the barriers and facilitators of healthcare utilization among this population are compounded by the social context of racism and discrimination. The study also challenged the traditional ideas surrounding research and practices of western medicine. As an institution that has been extremely violent and immoral towards people of color, specifically Black people, clinical and social research has created an intergenerational distrust of its practices and purpose (Erves et al., 2019). Marginalized populations require safe and creative methodologies within research that attempt to heal and mend the trauma inflicted, as well as accurately captures data that is validated by the population which it attempts to serve. Utilizing a community-engaged research approach, a conceptual framework that details the unique identity intersections of Black women, and a research tool (i.e., Sister Circle)

that centers healing and therapy, this study introduces methods that break the concept of traditional healing practices, as well as conventional research and data collection (Barnett et al., 2011).

Within western medicine, health and wellness is subjective (Ramirez et al., 2019; Conti, 2018; Dobkin, 2016). Who gets to determine what health and wellness looks like for the entire population, and why? All humans share the same biological foundations. However, the social context (e.g., income, housing, education, and racism) in which we live, learn, and play has a direct impact on our health outcomes (Chinn et al., 2021; Levin, 2009). The results from this study provide evidence that classical practices of western medicine are not particularly impactful among Black women. Quality, holistic care for this group requires non-traditional, independently crafted care models that center the patient and meets them exactly where they are. Concentrated on Black Feminist Thought, music and spirituality, and safe spaces, this study indicates the need for alternative methods to repair the trauma that practices of research and western medicine have enacted, as well as solve the persistent health disparities for Black women.

Public Health Policy Implications

The Centers for Disease Control and Prevention (2020) released an infographic in 2020 describing the top two contributors of mortality: pregnancy and cardiovascular disease. "Birthing while Black" was placed on the national landscape, in part thanks to the families of several Black women who passed away while giving birth (King, 2019). In 2018, U.S. Representative Jaime Herrera Beutler and Charles Johnson, widower of the late Kira Johnson, sponsored H.R. 1318, the Preventing Maternal Death Act. This bill requires the Department of Health and Human Services to provide grants to all states to aid in

establishing a state-based maternal mortality review committees to determine why women are dying from pregnancy-related deaths (King, 2019). The bill also ensures that each state department of health develop a plan for ongoing healthcare provider education to improve the quality of maternal care (King, 2019).

Conflicting with the evidence that income is the most highly correlated determinant of health, the National Center for Health Statistics (2020) reports that the most educated Black woman has a shorter life expectancy than that of her less educated white counterpart. With the power of legislation being handed to states, the health disparity among Black women persists. Results from this study illustrate the need for the Kentucky legislature and leadership to assess and evaluate the disparate health outcomes of Black women and determine the best practices to act and address them. In the summer of 2022, Governor Andy Beshear joined state lawmakers and healthcare advocates by signing six bills that attempted to improve access to healthcare for all Kentuckians (Staley & Ellis, 2022). These bills called for the implementation of cancer screening programs, insurance company collaborations to ensure cost effectiveness for patients, and the expansion of outpatient treatment and mental health services (Staley & Ellis, 2022). Furthermore, participants of this study emphasize the need for alternative research, healing, and therapy methods, and suggest Sister Circles as a quality option to try and address the problem. House Bill 237, signed by Gov. Beshear expands mental health services and funding, particularly to underserved areas of Kentucky. Additionally, House Bill 525 provides funding and support for community health workers and non-profit organizations who serve the same designated population (Staley & Ellis, 2022). Both pieces of legislation present opportunities to design new strategies, such as Sister Circles

facilitated by mental health professionals and peers who share their identity, as billable services. Development and implementation of such legislation requires representatives from the population which it will be designed to serve, to ensure that the alternative therapies are considered as billable services that support the health of Black women in the way they have asked to receive support.

However, without an equitable voice within the realm of government that advocates for the most disadvantaged populations, resources can be appropriated disparately and or misused to favor one population over another.   This study applied a community engaged approach in which a grassroots organization led by Black women served as a liaison, as well as an expert, on the lived experiences of Black women living in Louisville. The collaboration between Black-serving local non-profits, Louisville Metro, and Kentucky government is essential in creating policies that allocate funds to offices and committees that assess, address, and evaluate healthcare programming, create targeted interventions for healing, and aid in the ongoing growth of cultural competency and education for researchers and healthcare providers. Louisville's local government can and should advocate for their constituencies (i.e., Black women) on a state level and introduce and advocate for the incorporation of targeted interventions and intentional programs (e.g., Sister Circles) into existing legislation and regulatory policies that are purposed for increased access to care, expand the funds and resources for alternative and targeted interventions, revise reimbursement systems and/or incentivize insurance companies that cover the proposed programming and interventions, and promote intentional recruitment strategies that aid private and public institutions in diversifying their workforces.

Local government can also focus on improving the social determinants of health by investing in communities of color and ensuring equitable distribution of community resources. Being a historically redlined city, Louisville continues to suffer presently from the structural violence via transportation, housing development, economic and educational resources, and minimal access to healthcare facilities (Poe, 2023). Women in this study claimed their homes as a safe space, yet homelessness disproportionately impacts Black women. Louisville Metro is called to increase the inventory of affordable housing and remove barriers to homeownership.

Accompanied with the 2020 declaration by the American Public Health Association that racism is a serious threat to the public's health, it is crucial that data are used from this and other associations to inform the development and restructuring of policies, practices, and norms. Centuries of racism have had a detrimental impact on the social determinants of health for communities of color, none more evasive and visually apparent than that of the Black community. In collaboration with all stakeholders of health equity in Louisville, the systems and policies that have resulted in generational injustice have to be confronted and potentially dismantled, socially, and legislatively.

Public Health Practice Implications

A major priority in public health practice is to center the social context from where people are viewing and experiencing the world. Patricia Collins and Kimberle' Crenshaw detail Black women's unique intersection of identities (i.e., race, gender, and sexuality; Crenshaw, 2011; Collins, 2009). Within the public health context of practice, the intersection must be carefully examined and assessed for the development and implementation of programs and interventions to improve the health outcomes of Black

women, and ultimately strive for health equity. Public health has mined and developed data describing the existing health disparities for Black women, however, it has also failed to lift the voices of the community it intends to serve. Numbers are necessary; however, it is imperative that public health practitioners and the bigger field heed our own advice and center our specific population's social context. This study demonstrates that non-traditional methods work for this population and innovative health education and programming is needed to engage and retain their partnerships in achieving health equity.

With the declaration of racism as a public health issue, and the role of racism on the social determinants of health and life course, Louisville Metro Public Health and Wellness and other healthcare leaders must take an integral role in spotlighting new and effective strategies that can potentially increase positive health outcomes for the most negatively impacted communities. Data from this study show the effectiveness of music and Sister Circles as spaces to not only collect pertinent information regarding the improvement of the healthcare system, but also provide a coping method to deal with trauma from within and outside of the healthcare setting. Additionally, local public health officials need to continuously evaluate successful interventions and programming that may impact health outcomes. The patient-centered medical home (PCMH) model is a perfect example of the type of program needed to effectively impact and evaluate the quality of care for historically marginalized populations. The PCMH implements a team at the practice level to coordinate and manage the care of patients across the practice community in all sectors of the healthcare system. This model, state legislated, allows for care to be uniquely designed for individual patients, and allows programs and interventions like a Sister Circle to be utilized and covered under insurance plans. For Black women, a

population that has survived institutional and structural violence, and continued victimization, this model would address the distinctive experience that comes with their unique identity.

Study Limitations

This qualitative study is limited in its generalizability. Although this study focused on a specific population (i.e., Black women), the social context including Louisville residency and differences in socioeconomic position may skew other results. It is important to pinpoint this shortcoming as Black people are not a monolith. To stereotype perceptions and behavior in this group would be problematic and dangerous in the landscape of achieving health equity. Participants were not stratified into different groups based upon demographic data. Over 30% of the women indicated working in the healthcare field in some capacity, however, this was not factored into data analysis. Moreover, analysis did not account for differences in education, income level, and insurance type. These personal circumstances may have potentially impacted the women's experiences and/or how/what they shared in the interviews and group setting. Additionally, the findings of the interview data cannot be credited as empirical evidence of racism, discrimination, and disparate treatment that participants stated they faced navigating the healthcare system.

All the participants in the study reported having some form of health insurance, with a majority belonging to an employer-sponsored plan. Stigma and healthcare costs are factors positively influenced by the possession of health insurance. Barriers to healthcare utilization may be compounded for those without health insurance compared to those who do. A limited study timeline and limitations in resources to support the study may have

also affected the potential for the discovery of new concepts and themes. Lastly, selection bias could have potentially influenced the data collected, as those who are more willing to participate in a study may also be more apt to show resilience in their navigation of the healthcare system, as well as searching for and receiving quality holistic care.

Future Research

Results from this study revealed the necessity to develop, create, implement, and evaluate unique, population-catered interventions and programming that cater to Black women. Expanding on this study, it would be beneficial to evaluate Sister Circles as a culturally appropriate data collecting method. Introducing a different format to Sister Circles traditionally utilized for behavior change, is a unique way to culturally-target this population. More importantly than collecting data, a deeper analysis should focus on the significance of the sessions to foster and retain a safe space for Black women to share identity and experiences. It would also be interesting to stratify Sister Circle participants by socioeconomic positioning and professional with healthcare to determine if there are any differences in the outlook of the navigation of the healthcare system. This study illuminated those experiences with primary care providers and those providers sought out in emergency and specialty situations. Future research should build on this to examine the differences in experiences across healthcare settings (e.g., emergency rooms, specialty clinics, and public and private practices).

Expanding this study nationally to different sites, as well as increasing the number of sessions, allows for an opportunity to not only collect perceptions around healthcare and self-help/healing methods, but also to evaluate the feasibility and effectiveness of the methodology (i.e., Sister Circles and BFT) with insight into the experiences and needs of

Black women in differing social contexts (i.e., location and culture). Additionally, this study was stringent on the participants being American born cis-gender Black women. Opening the population to include both Black trans women and foreign-born women allows for the examination of the similarities and differences among the population in their perceptions regarding healthcare, and ideal safe spaces to share their experiences within and outside of the healthcare system.

The demographic survey captured level of education, type of health insurance, professional experience with healthcare, and income. For future research, separating the women based upon their socioeconomic positioning would be beneficial to see if experiences differ among the population.

Lastly, it would be fascinating to add another level of intersectionality to future research. Black women healthcare workers have a unique positionality in their navigation of the healthcare system. Interviewing this population allows for the researcher to obtain perceptions of provider-patient interactions, and their own navigation of care. It would also be interesting to see if there are differences in perceptions among Black women providers and those that are not to determine whether their privilege in education, knowledge base, and income level has a significant influence.

REFERENCES

Adewunmi, B. (2014). Kimberle Crenshaw on intersectionality: I wanted to come up with an everyday metaphor that anyone could use. Retrieved from www.newstatesman.com/lifestyle/2014/04/kimberl-crenshaw-intersectionality-i-wanted-come-everyday-metaphor-anyone-could

American College of Physicians. (2021). What is the patient-centered medical home? Retrieved from https://www.acponline.org/practice-resources/business-resources/payment/delivery-and-payment-models/patient-centered-medical-home/understanding-the-patient-centered-medical-home/what-is-the-patient-centered-medical-home

American Music Therapy Association. (2021). What is music therapy? Retrieved from www.musictherapy.org/about.musictherapy/

Anderson, M.L., Collins, P.H. (2004). Race, class, and gender: An anthology. *5th Ed.* Belmont, CA: Wadsworth/Thompson.

Anderson, E., Massey, D.S. (2001). Problem of the century: racial stratification in the United States. *Russell Sage Foundation*. New York, NY.

Ashcraft, J. (2020). The four humors: an ancient take on phlebotomy. Retrieved from https://www.northwestcareercollege.edu/blog/the-four-humors-an-ancient-take-on-phlebotomy/

Agyemang, C., Bhopal, R., Bruijnzeels, M. (2005). Negro, Black, Black African, African Caribbean, African American or what? Labeling African origin populations in the health arena in the 21st century. *J Epidemiol Community Health*. Vol. 59: 1014-1018.

Barlow, J.N., Johnson, B.M. (2020). Listen to Black women: Do Black feminist and womanist health policy analyses. *Women's Health Issues.* Vol. 31(2): 91-95

Bechtel, G., Davidhizar, R. (2000). Integrating cultural diversity in patient education. *Semin Nurse Manag*. Vol. 7: 183-197.

Boudreau, J.D., Cassell, E.J., Fuks, A. (2007). A healing curriculum. *Med Ed.* Vol. 41(1): 193-201.

Brach, C., Fraser, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Med Care Res Rev*. Vol. 57: 181-217.

Braithwaite, R.L., Taylor, S.E., Treadwell, H.M. (2009). *Health issues in the Black community. 3rd ed.* Jossey-Bass, San Francisco, CA.

Bridges, Khiara. (2017). Implicit Bias and racial disparities in health care. *Human Rights*. Vol. 43(3): The State of Healthcare in the United States. Retrieved from https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/the-state-of-healthcare-in-the-united-states/racial-disparities-in-health-care/

Browne, M.G. (2000). Autobiography of a female slave. Electronic ed., *Chapel Hill: Academic Affairs Library, University of North Carolina.*

Carr, C., d'Ardenne, P., Sloboda, A., Scott, C., Wang, d., Priebe, S. (2012). Group music

therapy for patients with persistent post-traumatic stress disorder-an exploratory

randomized controlled trial with mixed methods evaluation. *Psychology and*

Psychotherapy: Theory, Research and Practice. Vol. 85: 179-202.

Cassell, E.J. (2013). The nature of healing: the modern practice of medicine.

Oxford University Press.

Centers for Disease Control and Prevention. (2020). Infographic: Racial/ethnic

disparities in pregnancy related deaths – United States, 2007-2016. Retrieved

from https://www.cdc.gov/reproductivehealth/maternal-mortality/disparities-

pregnancy-related-deaths/infographic.html

Centers for Disease Control and Prevention. (1986). Premature mortality in the United

States: public health issues in the use of years of potential life lost. *MMWR*. Vol.

35(2): 1-11.

Chinn, J.J., Martin, I.K., Redmond, N. (2021). Health equity among Black women in the

United States. *Journal of Women's Health.* Vol. 30 (2): 212-219.

Collins, C. (2013). African American women's life issues today: vital health and social

matters. Santa Barbara, California: *Praeger*, an imprint of ABC-CLIO, LLC.

Collins, Patricia. (2009). Black feminist thought: knowledge, consciousness, and the

politics of empowerment. *Routledge*, 2nd ed.

Conti, Andrea Alberto. (2018). Historical evolution of the concept of health in western

medicine. *Acta Biomed*. Vol. 89 (3): 352-354.

Conti, A.A. (2017). From informed consent to informed dissent in health care: historical

evolution in the twentieth century. *Acta Bio Medica*. Vol. 88: 201-203.

Conti, A.A. (2013). Albrecht von Haller: an encyclopedia cosmopolite in the history of

Swiss medicine. *Clin Ter.* Vol. 164: 445-448.

Conti, A.A. (2011). Reconstructing medical history: historiographical features, approaches and challenges. *Clin Ter*. Vol. 162: 133-136.

Conti, A.A. (2010). Physicians, patients, and society: a long and complex history. *Fam Med*. Vol. 42: 159-160.

Crenshaw, K. (2011). Black women still in defense of ourselves. *The Nation*. Retrieved from   www.thenation.com/article/black-women-still-defense-ourselves

Dain, B. (2012). A hideous monster of the mind: American race theory in the early republic. *Harvard University Press: Cambridge, MA*. 19-25.

Davidson, Alan. (2019). Social determinants of health: A comparative approach. *Oxford University Press.* 2nd ed.

Davis, J.L., Green, B.L., & Katz, R.V. (2012). Influence of scary beliefs about the Tuskegee Syphilis Study on willingness to participate in research. *ABNF J*. Vol. 23(3): 59-62.

Dobkin, P.L. (2016). Healing in western medicine. *International Journal of Whole Person Care*. Vol. 3(2): 1-2.

Eppes, J.W., Jefferson, T. (1953). Jefferson's farm book: with commentary and relevant extracts from other writings. *Princeton, NJ: Princeton University Press*. P. 46

Erves, J., Deakings, J., Mayo-Gamble, T., Kelly-Taylor, K., Miller, S.T. (2019). Factors influencing parental trust in medical researchers for child and adolescent patients' clinical trial participation. *Psychology, Health & Medicine*. Vol. 21(6): 691-702.

Erves, J.C., Talbott, L.L., O'Neal, M.R., Ivankova, N.V., Wallston, K.A. (2016).

Development of a theory based, sociocultural instrument to assess black maternal

intentions to vaccinate their daughters aged 9 to 12 against hpv. *J Canc Ed*. Vol.

31: 514-521.

Erves, J.C., Mayo-Gamble, T.L., Malin-Fair, A., Boyer, A., Joosten, Y., Vaughn, Y.C.,

Sherden, L., Luther, P., Miller, S., Wilkins, C.H. (2017). Needs, priorities, and

recommendations for engaging underrepresented populations in clinical research:

a community perspective. *J Community Health*. Vol 42. 472-480.

Essed, Philomena. (1991). Understanding everyday racism: An interdisciplinary theory.

Thousand Oaks, CA: Sage.

Farmer, D.F., Jackson, S.A., Camacho, F., Hall, M.A. (2007). Attitudes of African

Americans and low socioeconomic white women toward medical research. *J

Health Care Poor Underserved*. Vol. 18(1): 85-99.

Fett, S.M. (2002). Working cures: healing health and power on southern slave

plantations. *Chapel Hill and London: University of North Carolina Press*.

Frame, M.W., Williams, C.B. (1996). Counseling African Americans: Integrating

spirituality in therapy. *Counseling & Values*. Vol. 41(1): 16-29.

Frame, M., Williams, C., Green, E. (1999). Counseling groups for African American

women: a focus on spirituality. *The Journal for Specialists in Group Work*, Vol.

24(3): 260-273.

Frame, M., Williams, C., Green, E. (1999a). Balm in Gilead: Spiritual dimensions in

counseling African American women. *Journal of Multicultural Counseling and

Development*. Vol. 27: 182-192.

Fry, G.M. (2001). Night riders in Black folk history. *Knoxville, TN:*

The University of Tennessee Press

Gates Jr.., H.L. (1987). To be raped, bred, or abused. *New York Times Book Review*. P.
    12.

Geronimus, A.T. (1992). The weathering hypothesis and the health of African American
    women and infants. *Ethn Dis*. Vol. 2: 207-221.

Graves Jr, J. (2001). The emperor's new clothes: biological theories of race at the
    millennium. *New Brunswick: NJ. Rutgers University Press*. 113-114.

Green, J., Thorogood, N. (2018). Qualitative methods for health research. *SAGE
    Publications*. 4th Ed. p. 252

Gross, C.P., Sepkowitz, K.A. (1998). The myth of the medical breakthrough: smallpox,
    vaccination, and Jenner reconsidered. *Int J Infect Dis*. Vol. 3 (1): 54-60.

Guy-Sheftall, Beverly. (1995). Words of fire: An anthology of African American
    feminist thought. *New York: NY. The New York Press.*

Hardeman, R.R. (2019). Disparities and social determinants of maternal mortality.
    Lecture presented at *Future Research Directions Workshop: Rockville, MD.*

Holmes, Andrew Gary D. (2020). Researcher positionality- A consideration of its
    influence and place in qualitative research – A new researcher guide.
    International Journal of Education. Vol. 8(4): 1-10.

Harrison's Principles of Internal Medicine. (1998). *New York: McGraw Hill*: 2568-
    2569.

Haleprin, E.C. (2007). The poor, the Black, and the marginalized as the source of
    cadavers in United States anatomical education. *Clinical Anatomy.* Vol. 20: 489-
    495.

Katz, R.V., Green, B.L., Kressin, N.R., Kegeles, S.S., Wang, M.Q., James, S.A.,
McCallum, J.M. (2008). The legacy of the Tuskegee Syphilis Study: assessing its
impact on willingness to participate in biomedical studies. *J Health Care Poor
Underserved*. Vol. 19(4): 1168-1180.

Karamanou, M., Panayiotakopoulos, G., Tscoulas, G., Kosoulis, A.A., Androutsos, G.
(2012). From miasmas to germs: a historical approach to theories of infectious
disease transmission. *Inf Med.* Vol. 20 (1): 58-62.

King, E.Y. (2019). Widowed father works with congresswoman on legislation to
prevent maternal deaths. *ABC News.* Retrieved from
https://abcnews.go.com/Health/widowed-father-works-congresswoman-
legislation-prevent-maternal-deaths/story?id=59846228

Krueter, M.W., Lukwago, S.N., Bucholtz, D.C., Clark, E.M., Sanders-Thompson, V.
(2002). Achieving cultural appropriateness in health promotion programs:
targeted and tailored approaches. *Health Education & Behavior*. Vol. 30(2):
133-146.

Kreuter, M.W., Griffith, D.J., Thompson, V., Brownson, R.C., McClure, S., Scharff,
D.P., Clark, E.M., Haire-Joshu, D. (2011). Lessons learned from a decade of
focused recruitment and training to develop minority public health professionals.
American Journal of Public Health. Vol. 101(S1): S188-S195.

La Rue, Linda. (1976). The Black movement and women's liberation. *Female
Psychology: The Emerging Self.* 1st ed.

Lang, R., Kelkar, H.M., Byrd J.R., Edwards, C.L., Pericank-Vance, M., Byrd, G.S.

(2013). African American participation in health-related research studies:

indicators for effective recruitment. *J Public Health Manag Pract.* Vol. 19(2):

110-118.

Leary, J.D. (2005). Post traumatic slave syndrome: America's legacy of enduring injury

and healing. *Joy DeGruy Publications.*

Levin, A. (2009). Adhering to western medicine may limit healing potential.

Psychiatric News Online. Retrieved from https://psychnews-psychiatryonline-

org.echo.louisville.edu

Marshall, T. (1995). Murdering to dissect: Grave-robbing, Frankenstein and the

anatomy literature. *Manchester: Manchester University Press.*

Mount, B.M. (2006). The 10 commandments of healing. *Journal of cancer education:*

the official journal of the American Association for cancer education. Vol 21(1):

50-51.

Murphy, S.L., Xu, J.Q., Kochanek, K.D., Arias, E., Tejada-Vera, B. (2018). National

vital statistics report: final data for 2018. *National Center for Health Statistics.*

Vol. 69(13).

National Center for Health Statistics. (2019). Health, United States, 2018. Retrieved

from https://www.cdc.gov/nchs/data/hus/hus18.pdf

National Library of Medicine. (2013). The world of Shakespeare's humors. Retrieved

from https://www.nlm.nih.gov/exhibition/shakespeare/fourhumors.html

National Research Council. Institute of Medicine. (2013). U.S. health in international

perspective: shorter lives, poorer health. *National Academies Press.* Retrieved

from https://www.ncbi.nlm.nih.gov/books/NBK154469

O'Dell, M.L. (2016). What is a patient-centered medical home? *Missouri Medicine*. Vol. 113 (4): 301-304.

Office of Disease Prevention and Health Promotion. (2022). Social determinants of health. *Healthy People 2030.* Retrieved from https://health.gov/healthypeople/priority-areas/social-determinants-health

Office of Disease Prevention and Health Promotion. (2020). U.S. Department of Health and Human Services. *Healthy People 2020*. Retrieved from https://www.healthypeople.gov

Patterson, A., Kinloch, V., Burkhard, T., Randall, R., Howard, A. (2016). Black feminist thought as methodology: examining intergenerational lived experiences of Black women. *Departures in Critical Qualitative Research*, Vol. 5 (3): 55-76.

Poe, Joshua. (2023). Redlining Community Dialogue. Retrieved from https://louisvilleky.gov/government/redevelopment-strategies/redlining-community-dialogue

Porter, R. (1997). The greatest benefit to mankind: a medical history of humanity from antiquity to present. *London: Harper Collins.*

Ramirez, M., Kamal, R., Cox, C. (2019). How has the quality of the U.S. healthcare system changed over time? *Peterson Center on Healthcare.* Retrieved from https://cdc.gov/brfss/annual_data/annual_data.htm

Reeves, R.V., Matthew, D.B. (2016). 6 charts showing race gaps within the American middle class. *Brookings Institute.* Retrieved from https://www.brookings.edu/blog/social-mobility-memos/2016/10/21/6-charts-showing-race-gaps-within-the-american-middle-class/

Resnicow, K., Baranowski, T., Ahluwalia, J., Braithwaite, R. (2000). Cultural sensitivity in public health: defined and demystified. *Ethnicity and Disease*. Vol. 9: 10-21.

Risse, G.B. (1970). The Brownian system of medicine: its theoretical and practical implications. *Clio Med*. Vol. 5: 45-51.

Roberts, D. (2000). Killing the Black body: race reproduction, and the meaning of liberty. *Vintage Books.*

Savel, R.H., Munro, C.L. (2015). From Asclepius to Hippocrates: the art and science of healing. *AM J Critical Care.* Vol. 23(6): 437-439.

Savitt, T.L. (2002). Medicine and slavery: the diseases and health care of Blacks in antebellum Virginia. *Urbana: University of Illinois Press.*

Sillman, J., Gerber, M., Ross, L., Gutierrez, E. (2016). Undivided rights: Women of color organizing for reproductive justice. *Chicago, IL: Haymarket Books.*

Skloot, R. (2018). The immortal life of Henrietta Lacks. *New York: Random House*.

Shavers, V.L., Lynch, C.F., Burmeister, L.F. (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol*. Vol. 12(4): 248-256.

Shavers, V.L., Lynch, C.F., Burmeister, L.F. (2001). Factors that influence African Americans willingness to participate in medical research studies. *Cancer*. Vol. 91(1 Suppl): 233-236.

Silvano, Giovanni. (2021). A brief history of western medicine. *Journal of Traditional Chinese Medical Sciences*, Vol. 8: 510-516.

Smedley, B., Stith, A., Nelson, A. (2003). Unequal treatment: confronting racial and ethnic disparities in healthcare. Washington, DC: *National Academies Press.*

Smith, A., Stewart, A.J. (1983). Approaches to studying racism and sexism in Black

women's lives. *Journal of Social Issues.* Vol. 39: 1-15.

Staley, C., Ellis, S. (2022). Gov. Beshear signs bills promoting better health care in

Kentucky. *Commonwealth of Kentucky.* Retrieved from

https://www.kentucky.gov/Pages/Activity-

stream.aspx?n=GovernorBeshear&prId=1407

Steinke, H. (2005). Irritating experiments. Haller's concept and the European

controversy on irritability and sensibility. *Amsterdam-New York: Editions*

Rodopi. 1750-90.

Suliman, Tina. (2021). Black maternal mortality: "it is racism, not race". *John Hopkins*

Bloomberg School of Public Health. Retrieved from

https://ccp.jhu.edu/2021/05/17/maternal-mortality-black-mamas-race-

momnibus/?gclid=CjwKCAjw6fyXBhBgEiwAhhiZsqYIPk_h5BqE71gIhqsMsW

Ji2IqMqLT9AO3XD182jB_hIV6jxoATZxoCXM4QAvD_BwE

The Hope Buss. (2022). Real resources, real people, real results: Hope reimagined.

Retrieved March 15, 2023 from https://www.thehopebuss.org/

Visvis, V. (2008). Alternatives to the "talking cure": black music as traumatic testimony

in Toni Morrison's song of Solomon. *African American Review*, John Hopkins

University Press, Vol. 42(2).

Washington, H.A. (2006). *Medical apartheid: the dark history of medical*

experimentation on Black Americans from colonial times to present. New York:

Doubleday.

Waters, M. (2002). The social construction of race and ethnicity: some examples from

demography. *Albany, NY: State University of New York Press*. 25-49.

Weeks, A. (2008). Paracelsus (Theophrastus Bombastus von Hohenheim, 1493-1541).

Essential Theoretical writings. Leiden and Boston: Brill.

Williams, D.R., Sternthal, M. (2010). Understanding racial-ethnic disparities in health:

sociological contributions. *J Health Soc Behav*. Vol. 51(Suppl): S15-S27.

Williams, R.A. (2011). Healthcare disparities at the crossroads with healthcare reform.

Springer-New York: 1st ed. 7-21.

Wingate, T. (1929). Anthropology and Negro slavery. *Medical Life.* Vol. 102: 166.

Yale School of Medicine. (2021). Benefits of community engaged research. Retrieved

from https://medicine.yale.edu/intmed/genmed/eric/cbprguidebook/principles/

Zaragovia, Veronica. (2021). Trying to avoid racist health care, Black women seek out

Black obstetricians. *NPR*. Retrieved from https://www.npr.org/sections/health-shots/2021/05/28/996603360/trying-to-avoid-racist-health-care-black-women-seek-out-black-obstetricians

Zekeri, A.A., Habtemariam, T. (2006). African American college students' perceptions

of psychosocial factors influencing racial disparities in health. *College Student Journal*. Vol. 40(4), 901.

APPENDICES

Appendix A: Prescreening Document

(*Adjust language as necessary*)

Hello _____. I hope you are doing well. My name is _____ and I am reaching out because you have been referred to or have expressed interest in participating in our sister circles. To move forward to see if you are eligible for our project and the compensation there are a few things we need to know about you.

Questions (to be done via call or in person)

1. Do you identify as Black?

Yes___   No___

2. Are you above the age of 18 years old?

Yes___   No___

3. Do you live in Louisville?

Yes ___ No_____

4. Do you identify as a cis-gender woman?

Yes___ No ___

5. Have you had healthcare experience? (e.g., PCP, clinic, ER, hospital)

Yes___ No ___

Appendix B: Demographic Survey

1. What is your age category? (Please circle)

    o   18-24

    o   25-34

    o   35-44

    o   45-54

    o   55-64

    o   65+

2. What is your highest level of education? (Please circle)

    o   Less than high school

    o   High school graduate or GED

    o   Some college/certificate

    o   Associate's degree

    o   Bachelor's degree

    o   Master's degree or above

3. Are you a caregiver for anyone for whom you have interacted with healthcare providers?

    o   Child

    o   Adult relative

    o   Professional client

4. Have you worked in the healthcare field?

Yes___ No ___

5. What is the current primary source of your health insurance?

    o   Employer –purchased plan

- o Private nongovernmental plan

- o Medicare

- o Medicaid

- o State sponsored health plan

- o No coverage

6. What is your total household income? (Please circle)
   - o Less than $10,000
   - o $10,000 to $19,999
   - o $20,000 to $29,999
   - o $30,000 to $39,999
   - o $40,000 to $49,999
   - o $50,000 to $59,999
   - o $60,000 to $69,999
   - o $70,000 to $79,999
   - o $80,000 to $89,999
   - o $90,000 to $99,999
   - o $100,000 or more

Appendix C: Personal Interview Guide

Experiences with healthcare

- Do you have a regular healthcare provider that you go to? (e.g., primary care provider/clinic)

  - If yes, tell me about the provider?

  - If yes, can you name on positive and one negative aspect of your provider/provider experience?

  - If no, where do you go when you get sick/health issue?

  - If no, why not?

- Besides a regular primary care physician, what other health services have you accessed? (e.g., ER? Hospital? Clinic?)

  - How often?

  - Have your experiences been positive or negative? Why?

- Do you serve as a personal caregiver?

  - If yes, to who?

  - Difference in treatment?

  - Have your experiences been positive or negative? Why?

- (If Applicable) Do you have children? If so, what healthcare services have you accessed for them?

  - Have your experiences been positive or negative? Why?

- What do you look for when choosing a healthcare provider or office? (e.g, staff, administration, location)

Healthcare Perceptions

- When visiting a healthcare provider, historically, how satisfied have you been with your experience?

  - Why or why not? What shaped your experience?

- When accessing healthcare services do you feel like you have been listened to and/or seen?

  - Why or why not? What shaped your experience?

- Do you feel like Black women's health issues are reported correctly and/or taken seriously within the healthcare system (e.g., among providers, administrators)?

    o Why or why not?

- Among your friends, family, and associates who share identity with you (i.e., Black women), have you heard about their experiences navigating healthcare?

    o If yes? What have those experiences been? How did they feel afterwards?

- Within the healthcare setting (e.g., PCP, ER, reproductive health, specialty care, caregiving) have you ever felt discriminated against based upon your race? Gender?

    o Tell me about one of those experiences.

- Generally, when accessing healthcare services do you trust the physicians and staff to provide you a quality holistic care?

    o If yes? What built your trust?

    o If no, what factors led to the mistrust?

Self-Help (Healing) Music

- When hurtful or traumatic experiences occur in your life, what do you do to cope? Emotionally regulate?

- Do you have a safe space to regulate your emotions? Explain. What is it?

- Have you ever experienced hurt or trauma navigating the healthcare system?

    o If yes, what did you do to cope?

- What role does music play in your life?

    o Have you ever listened to music to express your emotions? (e.g., hurt, anger, happiness)

- Do you feel that music helps to relate and retell your lived experiences?

- What genres of music do you most enjoy? (e.g., Gospel, R&B, Hip-Hop) Why?

- Have you ever heard of a "Sister Circle"? *Sister Circle explanation*

- As a safe space to share your experiences, would you ever consider participating in a Sister Circle?

- Do you think a Sister Circle could be beneficial in telling the stories of Black women?

Appendix D: Sister Circle Session Guide

I. Welcome/Introductions
   a. What brings you here?
   b. Purpose

II. Self-Assessment
   a. Individual completion
   b. Group share

III. Baseline Topics
   a. Healthcare experiences
      i. Tell me about a time you had to navigate the healthcare system? Positive or negative experience? Why?
      ii. What does the ideal healthcare experience look like to you? Resource accessibility? Experiences with administration (i.e., front line)? Experiences with nurses? Providers? Affordability? Bedside manor?
   b. Music Resiliency
      i. Let's talk about what role music plays in your life. How do you utilize music to operate in your life? Connection with family? Friends? Celebrations? Hardships?
      ii. Tell me about a time when music has inspired you? Changed you? Helped you?

IV. Music Interventions and Therapy Alternatives (**utilize for data collection as well**)
   a. Drum Circle
   b. Song Share
   c. Song writing
   d. Song performance

V. Closing
   a. Meditation
   b. Network

CURRICULUM VITAE

Jason A. Deakings

Email: (p) **stonejd1121@gmail.com** **(**w) **jason.deakings@louisville.edu**
Phone: (412) 251 – 6002
LinkedIn: linkedin.com/in/jason-deakings-msph

EDUCATION

University of Louisville	8/2018 – Present

Doctor of Philosophy – Public Health – HPBS
Dissertation title: "Our Story, Our Song:
Assessing and Addressing Black Women's
Healthcare Experiences"

Meharry Medical College	8/2016 – 5/2018

Master of Science Public Health
Thesis title: "Assessing the Roles of Knowledge, Attitude,
and Trust in African American College Students'
Willingness to Participate in Medical Research"

University of Phoenix	8/2012 – 12/2015

Bachelor of Science Biology (EVS)

Slippery Rock University	8/2004 – 1/2006

RESEARCH EXPERIENCE

University of Louisville – SPHIS	2/2022 – Present

Project Title: Our Story, Our Song: Assessing and Addressing Black Women's
Healthcare Experiences
Role: Principal Investigator
Responsibilities:

- Utilizing a community-engaged approach in collaboration with Black Feminist
  Thought, evaluate healthcare perceptions and healing methods among Black
  women.

University of Louisville – SPHIS   07/2020 - Present
Project Title: Fighting Injustices Among African American Youth (F.I.A.A.Y.)
Role: Research Team
PI: Jelani C. Kerr, MSPH, PhD
Responsibilities:

- Assist in organization of key stakeholders, development of instruments, recruitment, evaluation of program, quantitative and qualitative data analysis, and manuscript development.

Change Today, Change Tomorrow   04/2021 – 07/2021
Project Title: Assess the Change: A Community Needs Assessment
Role: Principal Investigator

- Utilizing a community-based participatory research approach, helped to develop and implement a community needs assessment (i.e., mixed methods), analyze, disseminate, and assess study results to engage in strategic program planning.

University of Louisville – SPHIS   07/2021 – 07/2022
Project Title: Understanding African American parental concerns about child protective services involvement to
        improve access to pediatric medical and social care
Role: Research Team
PI: Amber Pendleton, MD; Ryan Combs, PhD, MA
Responsibilities:

- Assisted in organization of key stakeholder, recruitment, study implementation, evaluation of program, qualitative data analysis, and manuscript development.

University of Louisville – SPHIS   06/2019 – 08/2019
Project Title: Depicting Hope in Healthy Communities: Humana Foundation
Role: Research Team
PI: Brandy Kelly-Pryor, MA, PhD
Responsibilities:

- Organized and analyzed qualitative data gathered by the Humana Foundation and participants. Evaluation of project and manuscript development.

University of Louisville – SPHIS   01/2019 – 08/2019
Project Title: Elucidating the stories of wellbeing in the West Louisville community: A
        Phenomenological study
Role: Research Team
PI: Meera Alagaraja, MS, PhD

Responsibilities:

- Assisted in organization of key stakeholder, development of instruments, evaluation of program, quantitative and qualitative data analysis, and manuscript development.

University of Louisville – SPHIS   01/2018 – 06/2018

Project Title: Entry into prenatal care: An evaluation of Family Health Center's process
              and outcomes
Role: Research Team
PI: Muriel Harris, MPH, PhD
Responsibilities:

- Assisted in organization of key stakeholder, development of instruments, evaluation of program, quantitative and qualitative data analysis, and manuscript development.

Meharry – Vanderbilt Alliance   01/2016 – 08/2018

Project Title: Assessing Views of Immunization Neighborhood to Improve HPV Vaccine
Rates
Role: Extern
Responsibilities:

- Assisted in recruitment of community partners, scheduled, and conducted interviews, data analysis, development of intervention and manuscript

Project Title: VICC Education Pilot
Role: Extern
Responsibilities:

- Assisted in designing, implementing, and evaluating a community-informed public health intervention among underrepresented populations in research

Project Title: Comparative Effectiveness Study of Patient – Centered Interventions to
              Improve HPV Vaccine Rates among African – American adolescents
Role: Extern
Responsibilities:

- Assisted in collaboration of key stakeholders, grant writing and development of a manuscript

PI: Jennifer Erves, PhD, MAEd, MS, CHES

TEACHING EXPERIENCE

University of Louisville   Spring 2021
PHPB 300: SOC FNDTNS OF PUB HLTH
Instructor

PHPB 300: SOC FNDTNS OF PUB HLTH   Fall 2020

Co-Instructor

PHPH 301: GLOBAL PUBLIC HEALTH	Fall 2020
Graduate Teaching Assistant	
PHPH 301: GLOBAL PUBLIC HEALTH	Spring 2020
Graduate Teaching Assistant	
PHPB 615: ADV PROGRAM EVAL	Spring 2020
Graduate Teaching Assistant	
PHPB 614: CRIT THINK, PLAN & IMPL	Fall 2019
Graduate Teaching Assistant	

Meharry Medical College

MSPH 71401: EPIDEMIOLOGY II	Spring 2018
Graduate Teaching Assistant	
MSPH 70001: EPIDEMIOLOGY I	Fall 2017
Graduate Teaching Assistant	

Guest Lectures

PHPH 301: GLOBAL PUBLIC HEALTH	Fall 2021
"Men's Health: National and International Statistics"	
PHPH 301: GLOBAL PUBLIC HEALTH	Spring 2022
"Men's Health: National and International Statistics"	
PHPH 301: GLOBAL PUBLIC HEALTH	Spring 2023
"Men's Health: National and International Statistics"	

PROFESSIONAL EXPERIENCE

University of Louisville   8/2018 – Present
Diversity Fellow
Graduate Research Assistant
School of Public Health and Information Sciences

Change Today, Change Tomorrow   3/2020 – 12/2021
Research & Development Specialist
- Developed and implemented process and procedures utilized in the daily operations of the organization
- Developed operational and procedural documents
- Lead grant writing efforts to support all programming of the organization
- Lead all research initiatives, both organization led and through collaborations

Meharry Medical College   8/2017 – 6/2018
Teaching Assistant – Epidemiology I & II
- Assisted professor in classroom instruction, record keeping, and exams
- Collaborated with fellow teaching assistant to instruct classroom lectures

Highmark Inc.   3/2013 – 7/2016
Associate Case Management Coordinator
- Entered relevant information into the clinical information system
- Monitored an inbound call queue and direct inquiries appropriately
- Monitored and distributed tasks/cases from the clinical information system
- Assisted in telephonic contact to members for patient support

Philips Respironics   8/2012 – 3/2013
Customer Service Representative
- Provided excellent health-related customer service
- Provided technical support to external customers for medical equipment
- Resolved customer service events by leveraging Philips tools/resources as needed

CIGNA Group Insurance   1/2006 – 9/2010
General Clerk Associate
- Executed automated reports and compiled and printed listing
- Managed a database, retrieved data and conducted status inquiries
- Received, stored and issued material and supplies
- Determined appropriate methods for processing of mail, files and supplies
- Answered incoming customer inquiries dealing with Life Insurance policies
- Coordinated production and daily workflows

Pittsburgh Community Food Bank   1/2008 – 1/2014
     Local Director

Pittsburgh Public Schools – Brown Chapel Church   1/2007 – 8/2012
     After School Program Mentor/Tutor

PROFESSIONAL AFFILIATIONS

American Public Health Association	8/2017 – Present
Kentucky Public Health Association	8/2018 – Present
Division of Public Health Practice Student Association Nashville, TN	1/2017 – 6/2018

PROFESSIONAL SERVICE

Black Graduate/Professional Student Association Executive Chair University of Louisville	8/2021 – Present
Commission on Diversity and Racial Equity (C.O.D.R.E) Student Concerns Committee Chair	8/2019 – Present

University of Louisville

Multicultural Association of Graduate Students Administration Officer University of Louisville	2/2019 – Present
Graduate School Student Ambassador University of Louisville	1/2019 – Present
Graduate Student Council Director of Finance University of Louisville	2/2019 – 8/2021

COMMUNITY PARTNERSHIPS

Goodwill Industries, Inc. Reintegrating Individuals Successfully Everyday (R.I.S.E) Program Sexual Health Educator	2021 - Present
The Hope Buss Research and Grant Consultant Louisville, KY	2020 – Present
National Pan-Hellenic Council, Louisville Chapter Social Action Committee Chair Louisville, KY	2020 – Present
Community Foundation of Louisville Fund for Louisville: Racial Justice Cohort Grant Reviewer Louisville, KY	2020 – 2021
Family Health Centers, Inc. Prenatal Health Program Success among LatinX Women - Program Evaluator Louisville, KY	2018 – 2019
Salt Wagon Community Clinic Director of Quality Assurance and Research Nashville, TN	2017 – 2018

GRANTS AND FELLOWSHIPS

National Trust "Preserving Black Church's" Grant $150,000 direct/1 yr	2023
Graduate Student Council Research Grant $500 direct/1 yr	2022
Graduate Student Council Research Grant $500 direct/1 yr	2021
M.A.G.S Research and Travel Grant $500 direct/1 yr	2022

M.A.G.S Research and Travel Grant $500 direct/1 yr	2021
Metro United Way Community Food Grant $10,000 direct/1 yr	2021
LMPHW Center for Health Equity Community Access Grant $30,000 direct/1 yr	2021
LG&E and KU Energy LLC Community Grant $5,000 direct/1 yr	2020
Metro United Way Community Food Grant $10,000 direct/1 yr	2020
Southern Regional Education Board State Doctoral Program Fellow	2021
HSC Office of Diversity & Inclusion Social Justice Scholar Fellow	2019
University of Louisville Graduate School Diversity Fellow	2018

PUBLICATIONS

Journal Publications

Cunningham Erves, J.C., Kelly-Taylor., Mayo-Gamble, T.L., **Deakings, J**., Forbes, L. *A Physician's Recommendation for HPV vaccination: What makes African American Mothers compliant?* Pediatric Infectious Disease.

Cunningham-Erves, J., Forbes, L., Ivankova, N., Mayo-Gamble, T., Kelly-Taylor, K., **Deakings, J**. (2018, March). *Black mother's intention to vaccinate daughters against HPV: A mixed methods approach to identify opportunities for targeted communication. Gynecologic Oncology*, DOI: 10.1016/j.ygyno.2018.03.047.

Cunningham Erves, J.C., **Deakings, J**., Mayo-Gamble, T.L., Kelly-Taylor., Miller, S. T. (2019, January). *Factors influencing parental trust in medical researchers for child and adolescent patients' clinical trial participation.* Psychology Health Med, DOI: 10. 1080/13548506.2019.1566623.

Journal Reviews

Journal of Health Care for the Poor and Underserved Manuscript Reviewer	2019 – Present

Abstracts and Presentations

Deakings, J.A. (2022). *Assess the change: A community health needs assessment of the west end of Louisville.* Oral Presentation at American Public Health Association Conference. Boston, MA.

Kelly-Taylor, K., Smith, A.B., Earnshaw, V., Turan, J., DiClemente, R., LaJoie, S., Rai, S.N., Burton, K., **Deakings, J.A.,** Bullock, N., Kerr, J. (2022). *The difference in HIV knowledge: A comparative analysis between formerly incarcerated and non-justice involved African American youths.* Oral presentation at American Public Health Association Conference. Boston, MA.

Smith, A.B., Earnshaw, V., Turan, J., DiClemente, R., LaJoie, S., Rai, S.N., Burton, K., Kelly-Taylor, K., **Deakings, J.A.,** Bullock, N., Kerr, J. (2022). *Examining the relationship between incarceration status and endorsement of HIV stereotypes among African American youth in Louisville, KY.* Oral presentation at American Public Health Association Conference. Boston, MA.

Kelly-Taylor, K., **Deakings, J.A.,** Elmore, S., Bullock, N., Story, A., Brown, A., Kelly-Pryor, B. (2022). *Illustrating our story: using photovoice to depict hope and equity in various U.S. communities.* Presented at 2022 KPHA Annual Conference. Bowling Green, KY.

Deakings, J.A., Burton, K., Smith, A.B., Kelly-Taylor, K., Bullock, N., Kerr, J. (2022). *Fight the stigma: translational HIV education for African Americans through art.* To be presented as a poster at 2022 KPHA Annual Conference. Bowling Green, KY.

Deakings, J., Clarke, J. (2021). *Assess the Change: A community needs assessment.* Presented at 2021 Research!Louisville Conference. University of Louisville. Louisville, KY.

Deakings, J., Harris, M. (2019). *An assessment of facilitators and barriers to early entry into prenatal care.* Presented as a poster at 2019 AEMRN Research Conference. Geneva, Switzerland.

Deakings, J., Brown, V.L., Cunningham-Erves, J., Alexander, L. (2019). *Assessing the roles of knowledge, attitude, and trust in African American college students' willingness to participate in medical research.* Presented as a poster at 2019 Graduate Student Regional Research Conference. University of Louisville. Louisville, KY.

Deakings, J., Brown, V.L., Cunningham-Erves, J., Alexander, L. (2018). *Assessing the roles of knowledge, attitude, and trust in African American college students' willingness to participate in medical research.* Presented as a poster at 2018 American Public Health Association. San Francisco, CA.

Deakings, J., Brown, V.L., Cunningham-Erves, J., Alexander, L. (2018). *Assessing the roles of knowledge, attitude, and trust in African American college students' willingness to participate in medical research.* Presented as a poster at 2018 Research Day. Meharry Medical College. Nashville, TN.

Deakings, J., Cunningham-Erves, J., Mayo-Gamble, T., Kelly-Taylor, K. (2017). *Factors influencing Parental Trust in Medical Researchers for Adolescent Participation in Clinical Trials.* Presented as a poster at 2017 American Public Health Association. Atlanta, GA.

Kelly-Taylor, K., Cunningham-Erves, J., Mayo-Gamble, T., **Deakings, J.** (2017). Factors *Associated with African American mothers being more likely to comply with a physician's recommendation for the HPV vaccination.* Presented as a Poster at 2017 American Public Health Association Conference. Atlanta, GA.

HONORS AND AWARDS

University of Louisville

Outstanding Community Engagement Award	2023
DEI Student Leader Award	2022
Social Justice and Inclusion Award	2022
Graduate School Dean's Spotlight Award	2021

Meharry Medical College

Master of Science in Public Health Academic Achievement Award	2018
Master of Science in Public Health Leadership Award	2017
Dean's List	2017