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Examining Disrespect in Maternity Healthcare Settings: Lifting Black Women's Voices to Improve Maternal Health Outcomes

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EXAMINING DISRESPECT IN MATERNITY HEALTHCARE SETTINGS: LIFTING BLACK WOMEN'S VOICES TO IMPROVE MATERNAL HEALTH OUTCOMES

By

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APPROVAL PAGE

EXAMINING DISRESPECT IN MATERNITY HEALTHCARE SETTINGS: LIFTING BLACK WOMEN'S VOICES TO IMPROVE MATERNAL HEALTH OUTCOMES

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Dedications

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Author's Statement Page

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Sherry Ann Maxy

ABSTRACT

EXAMINING DISRESPECT IN MATERNITY HEALTHCARE SETTINGS: LIFTING BLACK WOMEN'S VOICES TO IMPROVE MATERNAL HEALTH OUTCOMES

By

SHERRY ANN MAXY

JULY 18, 2024

Background: Black women in the United States experience disproportionately high rates of both maternal mortality and morbidity, compared to women of other racial and ethnic groups, and experience profound inequities regardless of health or social status. Black women are nearly three times more likely to die from a pregnancy-related cause than White women and have a two to three-fold increased risk of experiencing maternal complications/severe maternal morbidity (SMM) or/maternal near miss (MNM). A complex interplay of factors such as preexisting chronic conditions, social determinants of health, racism, bias, and disrespectful care contribute to poor outcomes. Research suggests that disrespectful care during childbirth contributes to severe maternal complications/SMM and MNM.

Purpose of Research: The purpose of this study was to expand our understanding of the birthing experiences of Black women that resulted in a MNM, specifically in relation to understanding their perspectives around experiencing disrespect in maternity healthcare settings.

Methods: A qualitative secondary data analysis was performed using data from Morehouse School of Medicine's national cross-sectional qualitative survey that sought to capture the birthing experiences of women who experienced maternal complications and/or MNM. A practical thematic analysis, utilizing Black Feminist framework, guided the analysis of interview transcriptions and video recordings to identify themes to center Black women's birthing experiences with disrespectful patient-provider encounters.

Findings & Results: A total of 43 women from across the U.S. that identified as Black or African American and reported experiencing a maternal near miss, were selected for analysis. At the time of their interviews, women were between 25-44 years of age. Most reported an annual household income of $50,000 or above and had completed college or a graduate/professional degree. The analysis provided an in-depth understanding of Black women's experiences and revealed critical themes and subthemes, including women feeling unseen when encountering racial bias and discrimination, experiencing a lack of compassion and privacy, insurance discrimination, feeling unheard due to an inability to self-advocate, and suffering from poor outcomes due to not being listened to, and lack of communication and shared decision-making, leaving Black women feeling disempowered to make choices about their care due to a lack of transparency and clear information.

Discussion & Recommendations: The narratives highlight various dimensions of disrespect encountered by Black women and underscore the systemic nature of the issues within maternity care settings and the impact of provider bias and discrimination on patient outcomes. The findings indicate that negative experiences contribute to delays in care, diagnosis, and treatment leading to poorer outcomes. Efforts to transform maternity care systems to provide equitable and respectful care require targeted interventions, policies, and systemic changes in healthcare practice, expanding and diversifying the maternity healthcare workforce by improving training, certification, and reimbursement for clinical and non-clinical providers such as midwives and doulas, and utilizing a trauma-informed care approach with Black women.

Keywords: Black women, disrespectful maternity care, maternal near miss, maternal mortality, maternal morbidity, medical racism, healthcare disparities.

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Chapter 1: Introduction

Despite a complex interplay of factors that influence maternal health outcomes, such as preexisting chronic conditions and social determinants of health, Black women in the United States experience disproportionately high rates of maternal mortality and morbidity, even when controlling for education, social class, and insurance type. For every woman who dies from pregnancy or childbirth-related causes, it is estimated that twenty more suffer from pregnancy-related illnesses/severe maternal morbidity (SMM), or experience a maternal near misses (Kalhan, et, al., 2017). SMM involves unexpected outcomes of pregnancy that result in significant short- or long-term adverse consequences to a woman's health (CDC, Reproductive Health, 2023; Liese et al., 2019). Maternal Near Miss (MNM) refers to a condition when a woman nearly dies, but survives from a complication or SMM occurring during pregnancy, childbirth, or within 42 days of termination of pregnancy. Higher SMM prevalence in a population is associated with an increased risk for a maternal near miss or death. SMM is 50 to 100 times more common than maternal death (Liese et al., 2019), and disproportionately impacts Black women compared to White women (Liese et al., 2019; Creanga et al., 2014). SMM has been steadily increasing for Black women with persistent disparities between Black and White women (Leonard et. al., 2019; CDC, Reproductive Health, 2023; Creanga et al., 2014). Structural racism, in and outside of healthcare systems, is a root cause of these health inequities, often resulting in poorer health outcomes for Black women (Feagin & Bennefield, 2014; Williams et. al., 2019; Chinn et al., 2021).

Background and Significance of Maternal Mortality and Morbidity

The United States is facing a maternal health crisis. While maternal mortality is improving globally, data examined from 1999-2018 show that rates are getting worse in the U.S., making it more dangerous to give birth (Singh, 2021; Declercq & Zephyrin, 2020; Nelson et al., 2018; Neggers, 2016). A maternal death is defined by the World Health Organization (WHO) as, "the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes" (Hoyert, 2022). Maternal mortality deaths are further categorized by the Centers for Disease Control and Prevention (CDC) as: 1) "pregnancy-associated, but not related," which is a death during pregnancy or within one year of the end of pregnancy due to a cause that is not related to pregnancy (e.g., homicide, suicide, drug overdose), or 2) "pregnancy-related," which is the death of a woman while pregnant or within one year of the end of pregnancy from any cause (e.g., hypertension, hemorrhage, infection) related to or aggravated by the pregnancy (CDC, Pregnancy Mortality Surveillance System, 2023; U.S. Department of Health and Human Services, 2020). The U.S. maternal mortality rate, which is the number of maternal deaths per 100,000 live births (CDC, National Center for Health Statistics, 2022), continues to exceed the estimated rate in other high-income countries, such as Australia, Sweeden, Germany, Norway, Canada, and the Netherlands, by two to ten times (The Commonwealth Fund, 2020). Rates have steadily increased over the past few years in the U.S.; in 2021, 1,205 women died of maternal causes, a rate of 32.9 deaths per 100,000 live births, compared with 861 deaths, or 23.8 deaths per 100,000 live births, in 2020 and 754 deaths, or 20.1 deaths per 100,000 live births, in 2019 (CDC, National Center for Health Statistics, 2023). The CDC estimates that four in five, or more

than 80% of pregnancy-related deaths, are preventable, based on review of 2017-2019 data from Maternal Mortality Review Committees (MMRCs) (CDC, Newsroom, 2022).

Maternal health is a key indicator of the health and well-being of a society as it determines the health of the next generation and can impact future challenges for families, communities, and the healthcare system. Although maternal mortality rates are a key indicator, this measure does not give a complete picture of overall maternal health. While maternal deaths in the United States number over 1,200 annually, severe maternal morbidity affects approximately 50,000 to 60,000 women each year (The Commonwealth Fund, 2021). To get an accurate depiction of the impact that poor maternal health outcomes are having on women, especially Black women, it is critical to account for SMM and serious illnesses that occur during pregnancy, such as pre-eclampsia, in the postpartum period, such as cardiomyopathy, (CDC, Reproductive Health. 2023; The Commonwealth Fund, 2021), and "maternal near miss" events resulting from SMM that could have resulted in death.

Black Women and Maternal Health Disparities

Black women in the United States continue to experience disproportionately high rates of both maternal mortality and morbidity, compared to women of other racial and ethnic groups. The rate for Black women is alarmingly high with a death rate of 69.9 deaths per 100,000 live births in 2021, compared to White women (26.6). (CDC, National Center for Health Statistics, 2022). Black women are nearly three times more likely to die from a pregnancy-related cause than White women (CDC, Health Equity, 2023), and have a two to three-fold increased risk of experiencing SMM (Guglielminotti et al., 2021). The CDC developed a list of 25 indicators and corresponding ICD codes to track SMM during delivery hospitalizations, which was recently

updated to 21 indicators that align with the newer version of the ICD-10 codes as outlined in Table 1 (CDC, Reproductive Health, 2023). Data from 2012-2015 estimated that Black women experienced SMM at a rate of 231.1 per 10,000 delivery hospitalizations compared to 139.2 per 10,000 delivery hospitalizations among White women (Admon et al., 2018). Women experiencing SMM during pregnancy, delivery, and the postpartum period experience complications such as embolism, cardiac arrest, organ system failure, sepsis, infection, postpartum hemorrhage and other health problems that often result in extended hospital stays and increased medical expenses associated with blood transfusion, hysterectomy, major surgery, or other major medical interventions (Kuklina & Goodman, 2018; Lazariu et al., 2017). Black women have the highest rates for 22 of 25 severe morbidity indicators used by the CDC to monitor population estimates for SMM (CDC, Reproductive Health, 2023; Howell, 2018; Holdt Somer, 2017). To date, little is understood about the factors contributing to SMM and MNM (England et al., 2019; Kilpatrick & Ecker, 2016; Callaghan et al., 2012). SMM and MNM are recognized as valuable indicators to examine the quality of obstetric care as they have similar risk factors to maternal death (Teshome, et, al., 2022). To improve maternal health, the WHO recommends studying SMM and "Near Misses" as indicators for the evaluation and improvement of maternal health services (World Health Organization, 2011). Improvement in maternal health outcomes can only be achieved when a reduction in the number of deaths is accompanied by a reduction in the frequency of severe complications during pregnancy (World Health Organization, 2011).

Table 1. Severe Morbidity Indicators During Delivery Hospitalizations

Acute Myocardial Infarction	**Puerperal Cerebrovascular Disorders**
Aneurysm	**Pulmonary Edema / Acute Heart Failure**
Acute Renal Failure	**Severe Anesthesia Complications**
Acute Respiratory Distress Syndrome	**Sepsis**
Amniotic Fluid Embolism	**Shock**
Cardiac Arrest / Ventricular Fibrillation	**Sickle Cell Disease with Crisis**
Conversion of Cardiac Rhythm	**Air and Thrombotic Embolism**
Disseminated Intravascular Coagulation	**Hysterectomy**
Blood Transfusion*	**Temporary Tracheostomy**
Eclampsia	**Ventilation**
Heart Failure / Arrest During Surgery or Procedure	

*Excluded, but could be examined separately.

CDC, Reproductive Health. 2023. How Does CDC Identify Severe Maternal Morbidity? | CDC

Structural Racism and SDOH

Structural racism is power that has been used at the societal level to provide White people with advantages, while disadvantaging Black people and other minorities in this country (Yearby, 2018). White people have used structural racism to institute racial segregation and inequities to obtain resources, such as wealth, employment, housing, income, and healthcare, while limiting access to these same resources for Black people and other people of color (Yearby, 2018; Bailey et al., 2017). This unequal distribution of resources has impacted the social determinants of health (SDOH) or nonmedical factors that influence health outcomes (CDC, 2022). SDOH are the conditions in which people are born, grow, work, live, and age, and are shaped by racism in political systems including economic and social policies (CDC, 2022). For example, racial isolation, or living in an economically disadvantaged or racially segregated/isolated neighborhood is predictive of a shorter life, particularly for Black residents.

Researchers have found racial isolation to be associated with higher levels of overall mortality, maternal and infant mortality, along with a range of other poor health outcomes (Yearby, 2018). SDOH play a key role in creating and sustaining health disparities within the U.S. and occur across multiple levels of influence (i.e., individual, interpersonal, community, and societal) (Dagher & Linares, 2022; Crear-Perry et al., 2021; Wang et al., 2020). At the individual level, Black women experience higher rates of chronic conditions such as obesity and hypertension (Brown et al., 2020). Studies show a strong link between these comorbidities and aggravation of conditions during pregnancy, which increase the risk for severe maternal morbidity or mortality (Robledo et al., 2017; Thomas et al, 2017). However, individual-level factors tend to be influenced by community and societal SDOH such as poor quality of care, bias and discrimination in healthcare, poor neighborhood conditions, poverty, lack of transportation, and type of health insurance (Noursi et al., 2021). Black women with lower-incomes are less likely to attend prenatal care visits (Howell et.al., 2017) and women who receive no prenatal care are 3 to 4 times more likely to die of pregnancy-related complications as compared to women who receive adequate prenatal care (Reddy et al., 2021). Consequently, lack of access to quality care during preconception, pregnancy, and postpartum care hinders the identification and management of chronic medical conditions and other factors that increase risk for maternal mortality. Wang et al., (2020) found that low neigborhood socioeconomic status (SES) or low median household income by zip code, and public insurance coverage were associated with higher risk of SMM. Other researchers also highlight that SDOH and systemic factors contribute equally if not more than preexisting chronic illness, to pregnancy-related deaths and poor health outcomes compared to healthcare related factors (Crear-Perry et.al., 2021; DiBari, 2014; Henderson, 2016; Howell, 2018). The disproportionate burden of chronic illness and maternal

morbidity and mortality among Black women is more likely to stem from inequitable policies and structures that perpetuate social disadvantage, low-quality care, and limited access to health resources (Dagher & Linares, 2022; Noursi et al., 2021; Wang et al., 2020).

To understand the influence of structural racism and SDOH on maternal health disparities, researchers must examine the exposure of SDOH over time, and how the interplay of racism, segregation, discrimination, and poor quality healthcare have impacted Black women (Dagher & Linares, 2022). A growing body of research shows that centuries of racism in the U.S. has had a profound and negative impact on communities of color (CDC, Minority Health, 2023). Data consistently show that Black people and other people of color experience higher rates of illness and death across a wide range of health conditions, including diabetes, hypertension, obesity, asthma, and heart disease, when compared to their White counterparts (CDC, Minority Health, 2023). On average, Black Americans have a life expectancy four years lower than White Americans (CDC, Minority Health, 2023). To explain the impact of health disparities on Black Americans' health, Geronimus (2006) proposed the "weathering" hypothesis, which posits that Blacks experience early health deterioration due to repeated experiences of racism associated with social, economic, and political injustices and other social determinants of health (Geronimus, et, al., 2006; Wakeel & Njoku, 2021). This framework illuminated health disparities, particularly for Black women and mothers, to help explain the differences in maternal and infant mortality disparities. The study looked at whether Black individuals experience early health deterioration, by measuring allostatic load, or biological markers, of the cumulative burden of chronic stress and life events and the impact on health outcomes (Guidi et, al., 2022; Forde et, al., 2019; Geronimus, et, al., 2006). This physiological impact of weathering can be measured by biological markers (such as increases in stress hormones—cortisol and adrenaline,

and diastolic and systolic blood pressure) that show increased rates of cardiovascular disease, which is the leading cause of maternal mortality and morbidity in Black women (Bond et, al., 2023, CDC, Reproductive Health, 2023). The weathering hypothesis can also help explain how a Black woman's constant exposure to repeated or chronic stress over a lifetime can impact her health.

At every point along the pregnancy continuum, Black women experience more severe maternal morbidity, and these disparities persist regardless of age, income, and education (Liese et, al., 2019). For example, The Commonwealth Fund found that while educational attainment is typically a protective factor associated with better health outcomes, that doesn't hold true for Black women. Education exacerbates rather than mitigates Black–White differences in maternal deaths (Declercq & Zephyrin, 2020). Five times as many Black mothers with a college education die as White mothers with a college education (Declercq & Zephyrin, 2020). Research shows that maternal deaths are more common among Black mothers with a college education than they are among White mothers with less than a high school education. A Black woman with a college education is at 60 percent greater risk for a maternal death than a White or Hispanic woman with less than a high school education (Declercq & Zephyrin, 2020). Although racial disparities in birth outcomes appear to be worsening between Black and White women, the higher rates are consistent with historical trends. Black-White disparities in maternal mortality have existed for over 100 years. For example, in 1915, the maternal mortality ratio for Black women was 1.8 times higher than that of White women. Currently, Black women are three to four times more likely to die than White women, a disparity that has been consistent since the early 1970's. In 2018, the Black–White maternal mortality ratio was 2.5, reflecting a rate of 37.1 for Black

women compared with 14.7 for Whites. The 2018 rates for Black and White women mirror the disparity seen in the 1940s (Declercq & Zephyrin, 2020).

Medical Racism in Maternal Healthcare

Medical racism can be traced back to the days of slavery when medical doctors, such as Thomas Hamilton, were "obsessed" with proving physiological differences between Black and White people to justify slavery (Silverstein, 2019). Hamilton, a doctor and plantation owner, conducted painful medical experiments on a Black slave to understand how "deep black skin went" to prove that black skin was thicker than white skin, thus able to withstand the "whippings" received in slavery. Additionally, scientists believed that Black people had large sex organs and small skulls, equating to promiscuity and lack of intelligence, a higher tolerance for heat (working in the fields), lower lung capacity (for which forced labor could correct the problem), and immunity and susceptibility to certain illnesses (Villarosa, 2019).

One of the most persistent myths was that Black people had higher pain tolerance. For example, a 1787 manual developed by a British doctor, Benjamin Moseley, claimed that "black people could bear surgical operations much more than White people" and that "what would be the cause of insupportable pain to a White man, a Negro would almost disregard" (Silverstein, 2019). This misconception of pain led J. Marion Sims, a physician known as the father of modern gynecology, to perform unconscionable operations on enslaved black women without the use of anesthesia to perfect obstetric procedures (The New York Times, 2019; Prather et al., 2018; Thorpe, 2017). In Sims autobiography, "The Story of My Life," he described the agony the women suffered as he cut their genitals again and again to improve a surgical technique to repair vesicovaginal fistula, a complication of childbirth (Silverstein, 2019). Per Sim's diary

entries in 1845**,** he claimed to obtain their consent and noted that they were enthusiastic participants in the procedures, which was unfounded and not true (Thorpe, 2017). The autonomy of Black women to make healthcare decisions was stripped away years ago, as it is commonly today. Nevertheless, these fallacies were published in medical journals, which provided support for racial stereotypes and discriminatory policies that provided substandard access and quality of care for black people (Bailey et al., 2021). This pain ideology, which posits that black people have a higher immunity to pain, continues to permeate medical education and practice to this day, more than 150 years after the end of slavery (Mathur et al., 2022; Feagin & Bennefield, 2014). These myths continue to be perpetuated in healthcare by way of curricula in medical schools, the marked under-representation of black physicians working in healthcare, and the disrespect and discrimination manifesting in the care provided for Black women (Ray, 2022; Feagin & Bennefield, 2014). The systematic disinvestment in healthcare within predominately Black neighborhoods, tied to redlining and racial residential segregation, has also resulted in lower resourced hospitals that typically provide substandard care (Bailey et al., 2021; Crear-Perry et al., 2020). For Black women, these factors are compounded by systemic discrimination and implicit racial bias in medical treatment that can lead to suboptimal care (Bond et al., 2021).

Contemporary Racism and Inequities in Maternal Health

There is a growing body of evidence supporting causal links between systemic racism and morbidity and mortality inequities of Black Americans, especially in maternal health outcomes (Cobbinah and Lewis, 2018). Further, Cobbinah and Lewis (2018) note that racism affects health at different levels, including the structural and institutional systems that create disparities in accessing quality care, the clinical encounters between provider and patient that are

negatively impacted by racial stereotypes and implicit bias leading to poorer outcomes, as well as the impact of internalized racism on patient mistrust and adherence to medical treatment recommendations. The historical failure to adequately treat Black people for pain remains a contemporary issue, as some doctors continue to inadequately treat Black people for pain across a range of medical issues, including childbirth (Macgregor et al., 2023; Knoebel et al., 2021; Morales & Yong, 2021). Research also shows that medical students and physicians continue to endorse myths surrounding physiological differences between Black and White patients, such as "black patients feel less pain and black people's nerve endings are less sensitive than White people." (Mende-Siedlecki et al., 2019; Hoffman et al., 2016; Hollingshead et al., 2016). This false and biased thinking often leads to healthcare professionals not recommending appropriate treatment (Aronowitz et al., 2020; Miller et al., 2020; Tait & Chibnall, 2014), resulting in increased severe maternal morbidity, maternal near misses, and maternal deaths. The historical belief that Black women have larger genitals and are more promiscuous has also generated many stereotypes relevant to pregnancy and motherhood, which continue to fuel racist bias by healthcare providers. Rosenthal and Lobel (2020) noted the unique oppression that Black women experience due to the intersections of race/racism, class, and gender/sexism known as "gendered racism." This form of racism causes women to experience stereotype threat, which involves being concerned with confirming "the angry black woman," which characterizes Black women as aggressive, ill tempered, illogical, overbearing, hostile, and ignorant without provocation (Ashley, 2014). Further, this leads to women being judged based on those stereotypes ("single mother," "welfare mother," "multiple baby daddies," or "uneducated") (Rosenthal & Lobel, 2020). When stereotype threat is applied to healthcare, it is associated with delays in seeking

medical care among Black people and greater anxiety about seeing a doctor among Black women (Rosenthal & Lobel, 2020).

Conceptualizing the causes and potential solutions to racial disparities in maternal morbidity and mortality requires clinicians and public health professionals to understand medical racism, which examines the discriminatory interactions that women face within the maternity care system and how bias and racism manifests in these experiences (The Commonwealth Fund, 2020). Failing to acknowledge the underpinnings of medical racism and the explicit and implicit bias that is derived from these early scientific fallacies and discriminatory practices leads to continued discrimination in maternal healthcare (Prather et al., 2018). This inevitably shifts blame to the patient for misconceived "racial" biological differences and a misunderstanding of how black people respond to medical advice due to systemic and institutional discrimination and inequities.

Disrespect in Maternity Care Practices

Research has highlighted the experiences of low-income and racial and ethnic minority women who have experienced disrespectful maternity care during childbirth. Morton et al. (2018) identified three overarching forms of disrespectful care including verbal abuse (including threats of poor outcomes, racially demeaning comments, and sexually degrading remarks), stigma and discrimination (e.g., performing extra procedures based on race and ethnicity), and failure to meet professional standards of care (e.g., failing to secure fully informed consent or performing procedures against a woman's wishes). Racial and ethnic minority women have also reported derogatory comments or judgmental remarks about their race or culture in maternity care settings (Mohamoud et, al., 2023; The Commonwealth Fund, 2020). For example, both

Black women and those with Medicaid coverage were less likely than White women and those with private health coverage to say they had autonomy about childbirth decisions and were treated with respect by their providers (Mohamoud et, al., 2023; The Commonwealth Fund, 2020). In addition, this study also noted that support workers such as birth doulas and labor and delivery nurses, reported witnessing disrespectful maternity care (Morton et al., 2018). Racism and racial disparities in healthcare delivery continue to negatively affect the mental and physical health of people of color, preventing them from attaining their highest level of health (CDC, Minority Health, 2023).

The CDC recently released a report highlighting the mistreatment and disrespect that women of color experienced from their healthcare providers. The study described overall maternity care experiences using survey data from more than 2000 mothers who are part of an opt-in community panel. The report found that 1 in 5 women said they were mistreated while receiving maternity care. Women reported not receiving a response to requests for help, being shouted at or scolded, not having their physical privacy protected, and being threatened with withholding treatment or made to accept unwanted treatment (CDC, Vital Signs, 2023). This also led to almost half (45%) of mothers not asking questions or sharing concerns during their maternity care due to fear of being labeled "difficult" (stereotype for Black women), or lack of agreement with provider and feeling rushed and not feeling confident about a topic, so not bringing it up (CDC, Vital Signs, 2023). Mistreatment during maternity care was highest among Black mothers, 30 percent of whom reported experiencing mistreatment during maternity care, compared to Hispanic mothers (29.3 percent) and multiracial mothers (27.3 percent) (Mohamoud et, al., 2023; CDC, Vital Signs, 2023). Black mothers also reported the highest rates of discrimination during maternity care (40 percent), compared to multiracial moms (39 percent),

and Hispanic moms (37 percent). Lastly, mothers with no insurance or public insurance at the time of delivery experienced more mistreatment during maternity care than those with private insurance, at 28 percent, 26 percent, and 16 percent, respectively (CDC, Vital Signs, 2023). Respectful maternity care is a component of high quality care and can be integrated into broader strategies to reduce maternal complications and pregnancy-related deaths.

Theoretical Framework

Black Feminist Theory-Centering Black Women's Voices

Black feminist theory (BFT) is a framework that centers the narratives, experiences, perspectives, and unique struggles that Black women face in society. BFT emphasizes intersectionality, which recognizes that Black women experience multiple forms of oppression and disadvantage simultaneously, as these intersecting identities of race, gender, and class, shape their experiences and perspectives. Additionally, Collins (2022) explains that BFT is a framework designed to understand each Black woman's experience as being unique and different from other "women of color" and White women, by understanding their experiences through their lens and dispelling narratives that have been shaped by others through false stereotypes. Further, the framework examines the intersections of these experiences between and among Black women through diversity of class, age, and other sociodemographic factors to truly understand each unique experience. The utilization of methodological approaches such as qualitative interviews is an important aspect of BFT in gaining insight into the lived experiences of Black women (Brantley, 2023). Gaining insight into the ways that race, gender, and class intersect to negatively impact a Black woman's wellbeing creates a unique opportunity to

differentiate the experiences of Black women from other women. BFT challenges researchers to recognize the link between Black women's history in the U.S. and contemporary structural disadvantages in the healthcare system (Brantley, 2023; Collins, 2022). This will provide a critical lens to better understand Black women's experiences with disrespect by analyzing power dynamics, social inequalities, and systems of oppression, such as healthcare (Brantley, 2023; Collins, 2022).

Conceptual Framework

Institute of Medicine, National Academies of Science: Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare

Almost 25 years ago, in 1999, Congress commissioned the Institute of Medicine (IOM), National Academy of Sciences, to look at racial and ethnic disparities in healthcare outcomes. In 2003, after conducting an extensive literature review of over 100 articles, the IOM committee published their report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care." The committee concluded that "the sources of these disparities are complex, multilayered, rooted in historic and contemporary inequities, and involve many participants at several levels, including institutional racism at the administrative and bureaucratic, health system, healthcare professional, and patient levels" (Institute of Medicine, National Academies of Science, 2003). Overall, the findings demonstrated that Black Americans received poorer quality healthcare for a variety of health conditions (including cancer, cardiovascular disease, HIV/AIDS, diabetes, mental health, and other chronic and infectious diseases) compared to Whites and were less likely to receive needed services, including clinically necessary procedures. Further, they found that racial differences for Blacks persisted even after controlling for factors such as age, income,

education, and access. Additionally, the committee found that clinical encounters, and physician characteristics related to unconscious negative stereotypes of Blacks, were important factors that contributed to these disparities. In many studies, the Implicit Association Test was used, and physicians consistently associated positive terms like "intelligent" with Whites compared to Blacks, used verbal dominance with Black patients, and exhibited disrespect towards these patients. Consequently, these factors were associated with higher levels of morbidity and mortality for Black Americans (Institute of Medicine, National Academies of Science, 2003). The healthcare systems/institutional level examines how healthcare systems are organized and financed, and the availability of services which may impact patient care. The clinical encounter at the provider level examines how bias, stereotyping, prejudice impact how providers make decisions in the context of clinical uncertainty. The patient level examines the factors that may hinder Black patients from seeking medical care or adhering to provider recommendations. The Unequal Treatment report will help to provide a conceptual framework for this research and help to categorize the current sources of healthcare disparities at the healthcare systems/institutional level, the clinical encounter at the provider level and patient level and how they may contribute to racial and ethnic disparities in maternal healthcare.

Study Purpose

Profound racial inequities in maternal health outcomes persist for Black women regardless of health or social status. Upstream social determinants of health, including systemic racism and barriers to access to care, increased rates of chronic diseases, and medical racism in healthcare settings are all hypothesized as causal factors and have been identified as contributors to poor maternal health outcomes. While there is extensive quantitative research highlighting

Black maternal health inequities, there are limited qualitative studies that highlight the birthing experiences of Black women, specifically providing a critical context through their voices and perspectives.

The purpose of this study is to expand our understanding of the birthing experiences of Black women that resulted in a MNM, specifically in relation to understanding their perspectives around experiencing disrespect in maternal healthcare settings. This analysis will also bring a trauma-informed lens to evaluating potential solutions to improve maternal health outcomes for Black women. Trauma-informed care is aimed at being responsive to the impact and perception of racism, improving patient's experiences within the healthcare system, and incorporating strategies to avoid retraumatizing patients through healthcare delivery (Tuyet-Mai et al., 2023; Fani et al., 2021).Trauma-informed care is a tool to transform cultures and assist healthcare providers in providing respectful care and providing opportunities to repair decades of inequity and discrimination (Esaki et al., 2022).

Research Questions

1. How do Black women who have experienced severe maternal complications that resulted in a maternal near miss, perceive disrespect in maternity healthcare settings?
2. What are the specific challenges Black women face in regard to receiving respectful maternity care?

Chapter 2: Literature Review

The history of systemic and structural racism comes from the unjust benefits that White people gained from slavery and the oppression of Black people imposed by a White government (Braveman et. al., 2022; Feagin & Bennefield, 2014). Although Black people have been disenfranchised across all systems, including housing and education, one of the largest institutions rooted in systemic racism is the medical field (Braveman et. al., 2022). Racism is still present and prevalent through the demographics of healthcare providers and decision makers such as hospital governing boards, within healthcare systems (Feagin & Bennefield, 2014). The literature review will assess how medical racism, discrimination, implicit bias, and SDOH, such as access to quality care, contribute to Black women's perceptions and experiences with disrespect in healthcare settings, and how these tend to be more substantial drivers of poor maternal outcomes than proximal factors such as age, education, income, and access for Black women. (Wang et al., 2020).

Systems/Institutional Level Racism

The IOM report highlighted that system-level factors at healthcare facilities impact patient care, such access to care and the availability of services. Black women in particular, and those with public insurance such as Medicaid, often experience barriers to high-quality healthcare services (Brown et al., 2021). Given the intersectionality of Black women's experiences in the healthcare system, it is critical to assess how race, sex, and social class are associated with maternal health outcomes. Zhang et al., (2013) conducted a cross-sectional study using Medicaid data to explore racial and ethnic disparities in adverse pregnancy outcomes among Medicaid recipients. The study looked at over 2 millon women from 14 Southern states

between 2003-2007. Overall, Black women experienced higher rates of adverse pregnancy outcomes when compared to non-Hispanic White women and Hispanic women, despite having the same insurance coverage and meeting the same poverty guidelines for Medicaid. SMM disproportionately affects minority and low-income pregnant women, especially Black women and those with Medicaid coverage (Fingar et al., 2018). Black women were more likely to experience SMM including preeclampsia and placental abruption, which can be precursors for maternal death (Zhang et al., 2013). Black women tended to be younger, more likely to have a cesarean section (36%) compared to White women (30.9%) (Holmes et al., 2020), to stay longer in the hospital and to incur higher Medicaid costs (Wallace et al., 2022; Phibbs et al., 2022; Okwandu et al., 2022; Black et al., 2021; Antoine & Young, 2021; Stark et al., 2021; Vesco et al., 2020; Tangel et al., 2019; Chen et al., 2018; Gibson et al., 2017; Min et al., 2015; Zhang et al., 2013; Edmonds et al., 2013).

A population-based, cross-sectional study using New York City discharge and birth certificate data from 2010-2014 examined racial and ethnic disparities in severe maternal morbidity. The study investigated Black-White and Hispanic-White differences in maternal outcomes within the same hospital, and assessed if the differences were associated with the type of insurance, comparing Medicaid to private insurance. Black and Hispanic women were at higher risk of severe maternal morbidity than White women, which was not associated with differences in type of insurance. Severe maternal morbidity was higher among Black women (4.2%) and Hispanic women (2.9%) compared to White women (1.5%) and among women insured by Medicaid (2.8%) compared to those commercially insured (2.0%). Black women had significantly higher risk for severe maternal morbidity than White women within the same hospital (Howell et al., 2020).

Medicare forced desegregation of hospitals in 1964 under the Civil Rights Act, however, hospital systems in many major cities are still segregated by race in practice. The Lown Institute developed a hospital index report that identified fifteen U.S. cities with racially segregated hospital markets, in which 50% or more of hospitals overserve or underserve Medicare patients from communities of color. Segregated hospital systems within the U.S. have a significant impact on health equity because many of the most-inclusive hospitals in the country are under-resourced, which can lead to poorer quality of care (Lown Institute, 2022). Only a small proportion of Black patients, particularly lower income Black people, receive care in highly-resourced hospitals across the U.S. (Haider et al., 2013). Previous research has noted that predominately Black-serving hospitals are lower quality and tend to provide substandard care, which may be due to inequities in financial resources available to the hospitals (Himmelstein et al., 2023; Eberth et al., 2022; Aggarwal et al., 2021; Howell & Zeitlin, 2017). When hospitals serving Black communities are under financial stress, it's more difficult for them to provide a high quality of care.

For example, lack of access to anesthesia services may also contribute to disparities. Traynor et al., (2016), analyzed data using a 2016 obstetric anesthesia workforce survey to assess availability of anesthesia services. Researchers used a stratified random sample of 1193 hospitals and found that not all hospitals have the resources to provide 24-hour access to anesthesia services. On average, 86% of large hospitals (hospitals with >1500 deliveries a year) provided 24-hour services, while roughly only 1% of small hospitals (hospitals with less than 500 deliveries per year), provided 24-hour access to neuraxial analgesia (Traynor et al., 2016). Smaller hospitals are more likely to be in under-resourced communities, and therefore less likely to provide access to these services (Vaughan & Edwards, 2020). A limitation of this survey was

that it did not explore the race and ethnicity of women delivering at these hospitals. This is critical, as Howell & Zeitlin (2017) found that women from racial and ethnic minority groups give birth in lower quality hospitals that may not have equal access to services such as this, potentially contributing to higher rates of severe maternal morbidity and mortality.

Research has also shown that Black patients undergo surgery at low-quality hospitals more frequently compared to White patients. Dimick et al., (2013) conducted a study to examine the extent to which living in racially segregated areas and living in geographic proximity to low-quality hospitals contributed to the quality of services based on where Black patients receive care. Researchers used national Medicare data for all patients who underwent one of three high-risk surgical procedures in 2005–08. Findings showed that Black patients were consistently more likely than White patients to undergo major surgery at low-quality hospitals despite geographic proximity to the higher-quality hospitals. Black patients were more likely to live closer to higher-quality hospitals than White patients, but were still 25–58% more likely to receive surgery at low-quality hospitals. Researchers also found a strong relationship between racial residential segregation and the use of low-quality hospitals. Black patients were 41-96% more likely to live in racially segregated areas than White patients and to undergo surgery at low-quality hospitals (Dimick et al., 2013). Bailey et al., (2021) highlighted that the systematic disinvestment in public and private sectors (healthcare, education, and businesses) within segregated Black neighborhoods, has led to an influx of low-resourced healthcare facilities with fewer clinicians. Low-resourced healthcare facilities often find it difficult to recruit experienced healthcare providers and specialists, which impacts access and utilization (Bailey et al., 2021).

A recent study examined all Medicare-participating hospitals from 2016–2018 to assess disparities in funding (Himmelstein et al., 2023). The study looked at patient care revenues and

profits per patient day at Black-serving hospitals compared to other hospitals to assess disparities in funding, particularly based on the proportion of Black patients they serve. Of the 574 Black-serving hospitals investigated, an average of 43.7% of Medicare inpatients were Black, vs. 5.2% at the other 5,166 hospitals. Black-serving hospitals were also slightly larger, urban, teaching, and for-profit or government vs. non-profit owned. Patient care revenues were $1,736 and profits averaged $17 per patient day at Black-serving hospitals compared $2,213 and $126 per patient day at other hospitals. They found that to put these hospitals on similar footing, Black-serving hospitals would need to be reimbursed $14 billion in additional payments, or approximately $26 million per Black-serving hospital, annually. The disinvestment and lack of value assigned to the care of Black patients, continues to perpetuate the stark differences in health outcomes, and impedes Black people from having access to equitable care (Lown Institute, 2022). These ongoing funding disparities reinforce inequities in resources from past structural and institutional inequities which contribute to a deficit in the quality of care that Black people receive (Himmelstein et al., 2023).

Clinical Encounter/Physician Level Factors

Research has highlighted the negative impacts of racism and implicit bias and the association with poor outcomes in healthcare systems (Stepanikova & Oates, 2017, Gonzalez et al., 2021). Nong et al., (2020), conducted a cross-sectional survey in 2019 to identify the national prevalence of patient-reported discrimination in the healthcare system. The study found that 21.4% of patients reported experiencing discrimination. Out of these same patients, 72% reported experiencing discrimination more than once. Compared to non-Hispanic Whites (20.3%), Hispanic respondents (22.9%), and Black respondents (22.8%), reported more

experiences of discrimination. Of those reporting discrimination, 17.3% reported experiences related to racial and ethnic discrimination, followed by education or income level (12.9%), weight (11.6%), sex (11.4%) and age (9.6%) (Nong et al., 2020).

Healthcare provider attitudes and behaviors have been identified as one of many factors that contribute to healthcare disparities (Vela et al., 2022). Implicit attitudes are thoughts and feelings that are often automatically activated, outside of one's conscious awareness, and influence human behavior with little control. Implicit bias, which incompasses implicit attitudes, leads to a negative evaluation of a person based on characteristics such as race or gender (Sabin, 2022; FitzGerald & Hurst, 2017). To better understand what contributes to inequities in maternal health outcomes, it's important to understand how implicit bias may show up in stressful healthcare settings such as emergency departments or labor and delivery settings (Saluja & Bryant, 2021). Due to the stressful nature in these settings, relying on automatic or unconscious cognitions to make sound decisions is more likely to trigger stereotypes and unconscious beliefs even when explicit discrimination is not apparent (Vela et al., 2022, Saluja & Bryant, 2021, Gopal et al., 2021). In 2015, Hall et al., performed a literature review to investigate the extent to which implicit racial and ethnic bias exists among healthcare professionals and providers in training, and the impact it has on healthcare outcomes. Researchers searched 10 databases and identified a total of 15 studies that measured and reported results on implicit racial and ethnic bias. Almost all the studies used a cross-sectional research design, convenience sampling, U.S. participants, and the Implicit Association Test (IAT) to assess implicit bias. The IAT is a test that measures the strength of associations between concepts and evaluations or stereotypes to reveal an individual's hidden or subconscious biases. Most healthcare providers appeared to have implicit bias and more positive attitudes toward White people and negative attitudes towards

people of color. Results from this review and other research suggests that implicit bias has a significant impact on patient–provider interactions, treatment decisions, treatment adherence, and patient health outcomes (Gopal et al., 2021, Arif & Schlotfeldt, 2021, Marcelin et al., 2019, Hall et al., 2015).

Additionally, Sun et al., (2022), conducted a cross-sectional study examining medical providers' use of negative patient descriptors in electronic health records to describe patients and their behaviors and to assess if language varied by patient race and ethnicity. They sampled 18,459 electronic health records from January 2019 to October 2020 from an urban academic medical center. Compared to White patients, Black patients had 2.54 times greater odds of having at least one negative descriptor in their record, such as: nonadherent, aggressive, challenging, unpleasant, hysterical, agitated, angry, combative, defensive, and exaggerative.

Unequal treatment of pain/provider bias. As Black Americans are systematically undertreated for pain relative to White Americans, evidence that false beliefs about biological differences between Blacks and Whites continue to shape the way Black people are perceived and treated. Beliefs that Black and Whites are fundamentally and biologically different have been prevalent in various forms for centuries. In the U.S., these beliefs were championed by scientists, physicians, and slave owners alike to justify slavery and the inhumane treatment of Black men and women in medical research (Ray, 2023; Cooper Owens & Fett, 2019; Feagin & Bennefield, 2014). Well into the 20th century, researchers continued to experiment on Black people, based in part on the assumption that the black body was more resistant to pain and injury (Thorpe, JR., 2017). Given the pervasive nature of racial disparities in pain management, Hoffman et al., (2016), sought to understand what contributed to this racial bias. The researchers conducted two studies to examine whether racial bias was related to false beliefs about biological

differences between blacks and whites. The first study recruited 121 participants in which 92 met the criteria of being White, born in the United States, and a native English speaker. Study participants reported the amount of pain they would feel across 18 scenarios (e.g., "I slam my hand in a car door"; scale: 1 = not painful, 2 =somewhat painful, 3 = moderately painful, 4 = extremely painful) and then were randomly assigned to rate the pain of a gender-matched black or white target facing the same scenarios. Participants also rated 15 biological differences between Blacks and Whites as true or untrue (i.e. Blacks age more slowly, are more fertile, have less sensitive nerve endings). White participants who strongly endorsed false beliefs about the biological differences of Black and White people reported lower pain ratings across scenarios for Black targets. The first study found that 73% of participants without medical training held deeply entrenched beliefs and endorsed at least one of the biological differences and or false beliefs between Blacks and Whites (Hoffman et al., 2016). The second study examined racial bias in medical students and residents, understanding bias in medicine by using medical cases like those used in medical training, and the implications for racial bias in pain treatment recommendations. Study participants included a total of 418 medical students and residents. Two hundred twenty-two medical students (first year, n = 63; second year, n = 72; third year, n = 59; residents, n = 28) met the same criteria as in study 1 of being White, born in the U.S., and a native English speaker. Medical participants completed the same measure of beliefs about biological differences between blacks and whites as in study 1, read two mock medical cases about a Black and a White patient, made pain ratings (scale: 0 = no pain to 10 = worst possible pain), and provided medication recommendations (dummy coded for accuracy: 1 =accurate, 0 = inaccurate) for each. Roughly 50% of White medical students and residents endorsed at least one of the biological differences and or false beliefs (e.g., "Black people's skin is thicker than White people's skin", or "Black

people's blood coagulates more quickly than White people's blood") (Hoffman et al., 2016). Further, White medical students and residents reported beliefs that a Black patient would feel less pain resulting in medical professionals making less appropriate pain treatment recommendations 15% of the time for Black vs White patients (Hoffman et al., 2016).

Childbirth is ranked as one of the most intense types of pain experienced in a woman's life (Lange, et.al., 2017). Consequently, because of the disparity in pain management during childbirth, many women suffer needlessly, specifically Black women. Research has well documented the racial and ethnic disparities in the treatment of acute and chronic pain. The Institute of Medicine identified racial and ethnic minorities as being at risk for inadequately treated pain across many healthcare settings, including maternal health (The Institute of Medicine, National Academies of Science, 2003). Neuraxial labor analgesia, which includes epidural, spinal, and combined-spinal epidural analgesia, is the most effective way to manage labor pain, yet many women are precluded from this treatment due to lack of patient knowledge and education, structural and institutional racism due to lack of access or insurance coverage, the type of analgesia administered, or provider implicit bias in decision making (Lange et. al., 2017; Butwick et al., 2016; Traynor et al., 2016; Rust et al., 2004).

Lange et al., (2017) noted that although over 60% of all deliveries in the U.S. use neuraxial analgesia, Black women (63%) are less likely to use or receive it for labor than non-Hispanic White women (74%) (Morris & Schulman, 2014). Almost 20 years ago, Rust et al., (2004), used Georgia Medicaid claims data to measure racial and ethnic differences in patients who received epidural analgesia during labor and delivery to manage pain. The study found that out of the (53.4%) of women who had epidural analgesia, the rates were lower for Black women (49.5%) compared to non-Hispanic White women (59.6%). Despite all study subjects having

Medicaid insurance and meeting the same low-income Medicaid eligibility criteria, race/ethnicity remained a significant predictor in the administration of epidural analgesia.

Epidural analgesia is used most often in labor and delivery and is the preferred anesthetic modality for cesarean deliveries (Lange et. al., 2017). Cesarean deliveries tend to be more common among Black and Latina women than White women. Data show that cesarean deliveries lead to more negative health outcomes and are associated with three of the six leading causes of maternal morbidity and mortality, such as hemorrhage, complications of anesthesia, and infection for both the mother and baby (Butwick et al., 2016). Further, maternal mortality is lower among women who receive neuraxial anesthesia (3.8 deaths per million) compared to general anesthesia (6.5 deaths per million) in the United States (Butwick et al., 2016). Butwick et al., (2016), conducted a secondary analysis of (Cesarean Registry) data from a previous observational study to investigate whether racial and ethnic disparities exist for mode of anesthesia (general vs. neuraxial) among women undergoing cesarean sections. Overall, 7.1% of women received general anesthesia, and 92.9% of women received neuraxial anesthesia. The study found, however, that Black women received general anesthesia at a rate of 11.3% compared to 5.2% for White women, and 5.8% for Hispanic women. Additionally, Black women were more than one and a half times more likely (OR 1.7) than White women to undergo general anesthesia for a cesarean delivery, which could be an additional factor contributing to higher rates of maternal mortality. Limitations of this study include its observational design, limiting conclusions beyond associations. Further, general anesthesia is more likely to be used for a emergency C-section if an epidural is not already in place.

Patient Level Factors

Distrust of the healthcare system has been longstanding within the Black community and impacts patient level factors that may contribute to racial and ethnic disparities in healthcare. As previously noted, implicit or unconscious bias can negatively affect the patient-provider relationship and is associated with lower levels of patient adherence to treatment and treatment recommendations, lower levels of trust in healthcare providers and healthcare systems, and can result in Black patients who are more likely to delay care (Nguyen et al., 2022; Maina et al., 2018; FitzGerald & Hurst 2017; Blair et al., 2013). To better understand adherence to treatment, Toledo et al., (2013) conducted a prospective study with 509 women to assess their decision to use or not use neuraxial analgesia during delivery and the racial and ethnic disparities in neuraxial labor analgesia use. Study eligibility included being a White, Hispanic, or Black woman admitted for labor who had not requested or received labor analgesia, or a pre-anesthetic consultation. The women completed a survey indicating the type of analgesia they anticipated using for labor and the type of labor analgesia administered was abstracted from medical records after delivery. 39% of patients expressed concern around the use of neuraxial analygesia such as misunderstandings about neuraxial analgesia, fears about the procedure, and lack of trust in providers. There were also racial and ethnic differences in the anticipated use of neuraxial analgesia. Non-Hispanic White women were more likely to anticipate neuraxial analgesia use (85%) than Black (67%) and Hispanic (51%) women (Toledo et al., 2013). Of the patients who did not anticipate using neuraxial analgesia, 23% desired a natural childbirth and/or control over their labor experience, and 46% noted concerns about the procedure and potential complications (Toledo et al., 2013). These differences could indicate lack of knowledge of treatment options, previous bad experiences with anesthesia, or lack of education from providers on options.

To understand Black women's decision-making process in obtaining sexual and reproductive health services, Thompson et al. (2022) conducted a qualitative research study to explore concerns that may impact or delay seeking care. A community-based participatory research framework was used to conduct six focus-group discussions and twenty-six in-depth interviews with forty-nine Black women living in Georgia and North Carolina between May 2019 and January 2020. Eligibility criteria included being aged 18–49, English speaking, self-identified as Black or African American, and having lived in Georgia or North Carolina for at least two years. Focus-group participants were recruited in urban and suburban centers. Participants discussed structural and individual experiences of racism and how these experiences affected aspects of their reproductive healthcare. Older participants tended to describe more experiences with racism than younger participants. Three primary themes emerged that explained how both structural and individual racism impacted their interactions and decisions to engage with care: access to care (the ability to obtain timely healthcare services), utilization (the quantification or use of the healthcare service), and experience of care (interactions with the healthcare system). Structural racism influenced access to reproductive healthcare services as Black women living in predominantly Black or in low-income areas stated that healthcare facilities were often outside their communities and required having a car or other modes of transportation, which led to additional costs. Further, structural racism influenced participants' utilization of reproductive healthcare services if women had public versus private insurance as they were concerned with limitations on the scope of services covered or offered free. Lastly, structural racism influenced the perceived quality of reproductive healthcare experiences as Black women noted that the combination of being Black and receiving public assistance or having no insurance coverage had a compounded negative effect on their interactions with

healthcare providers and healthcare systems (Thompson et al., 2022). Participants who were insured through Medicaid noted that structural racism affected their finances as they stated that copayment for preventative reproductive services was a financial barrier and resulted in delaying or forgoing care. Additionally, individual experiences with racism resulted in some women electing to receive care only from same-race medical providers (Thompson et al., 2022).

In maternity care, overuse of medical interventions, including cesarean sections, can lead to severe maternal morbidity and mortality for Black women and other women of color. To better understand and quantify the experiences women of color, Attanasioa & Hardeman (2019) examined the relationship between women who refused or declined certain medical procedures, such a cesarean delivery, and the discrimination women faced during childbirth hospitalization. Data from the Listening to Mothers III survey, a web-based survey of 2,400 women aged 18–45 who gave birth to a singleton baby in a U.S. hospital in 2011–2012, were analyzed. Women who declined care for themselves or their infant during the childbirth hospitalization were more likely to report “poor treatment” based on race and ethnicity, insurance status, or having a difference of opinion with a healthcare provider. Among Black women, declining care was associated with a 37% increase in perceived discrimination based on having a difference of opinion with provider, compared to a 20% increase among White women. Both Black and Hispanic women were more likely to experience discrimination if they declined care and were labeled as “uncooperative” or “non-compliant” if they didn’t agree with the healthcare providers recommendations (Attanasioa & Hardeman, 2019).

Okoro et al. (2022) applied an intersectionality lens to understand the experiences of low-income Black women in the healthcare system. Intersectionality refers to the experience of persons with multiple intersecting statuses such as race and gender. Researchers conducted in-

depth one-on-one interviews with 22 women and facilitated two focus group discussions with community leaders and advocates. The thematic analysis revealed four major themes that emerged from the concept of "intersectional invisibility." Women perceived 'not feeling heard' by healthcare providers, they wanted to be an 'expert of their body,' feeling as though their 'preferences are disregarded,' and declared a strong need to 'advocate for self.' Low-income Black women were more likely to experience intersectional invisibility, which results from provider implicit bias, stereotypes placed on them, and systemic structures that enable discriminatory practices in healthcare delivery (Okoro et al., 2022).

Further, Mehra et al. (2020) used an intersectionality framework and biopsychosocial model of health to understand Black pregnant women's experiences of gendered racism during pregnancy. Researchers conducted semi-structured interviews with 24 Black pregnant women in New Haven, Connecticut. Women were asked about their experiences of being pregnant, experiences of gendered racism, and concerns related to pregnancy and parenting Black children. Black pregnant women encountered gendered racism specific to pregnancy which the researchers referred to as "racialized pregnancy stigma." Black women were likely to experience racial stereotypes that stigmatized Black motherhood in most everyday settings such as healthcare, social services, and housing-related settings. Historical stereotypes and assumptions about Black mothers included having low incomes, being a single mother, and having multiple children, occurred regardless of their socioeconomic or marital status. Racialized pregnancy stigma may contribute to poorer maternal and infant outcomes due to constant stress from discrimination, reduced access to quality healthcare, unsatisfactory healthcare interactions, lack of referral to services, resources, and social support, and poorer psychological health (Mehra et al., 2020).

Summary

As reflected in the literature, there are many factors that contribute to poor maternal health outcomes for Black women. Medical racism, discrimination, and implicit bias negatively impact the SDOH and Black women's experiences in healthcare settings, which impact Black women's perceived experience of disrespect (CDC, Health Equity, 2023; CDC, Minority Health, 2023; Dagher & Linares, 2022; Braveman et. al., 2022). The research suggests that disrespectful care during childbirth contributes to SMM and MNM, and is often associated with lack of regard, and dismissiveness of women's concerns. Racism, discrimination, and implicit bias tend to influence the actions and behaviors of providers, which can negatively impact their view of race, cultural and gender differences and lead to disrespectful behavior, even if unconsciously. There are limited qualitative data that help bridge the gap of provider and patient encounters and the role that bias and discrimination play in women experiencing disrespect and, ultimately, worse maternal health outcomes.

Respectful maternity care (RMC) is considered a critical factor for improving maternal health outcomes (Cantor et. al., 2024). There is extensive literature that recognizes RMC as a strategy to reduce maternal health disparities, however, researchers have struggled to operationalize what constitutes disrespect in healthcare settings and there has been no unified definition established (Cantor et. al., 2024). RMC has essentially been defined as the opposite of disrespect and has been primarily explored through quantitative measures such as theoretical frameworks that identify components of RMC, and quantitative assessments and surveys to collect this information from women (Cantor et. al., 2024).

This research aims to fill a critical gap in the literature by adding to qualitative studies that increase our understanding of how Black women perceive and experience disrespect in

maternal healthcare settings. Additionally, these qualitative insights and perspectives will be used to operationalize and define disrespect in maternal healthcare settings as well as used to identify strategies to mitigate disrespect and to improve respectful maternity care while improving maternal health outcomes.

Chapter 3: Methodology

Section 1: Study Purpose

The purpose of this study is to expand our understanding of Black women's birthing experiences through the voices and perspectives of Black women, specifically in the context of disrespectful maternal healthcare encounters and poor maternal health outcomes. A qualitative secondary data analysis was performed using data from Morehouse School of Medicine's (MSM) national cross-sectional qualitative survey that sought to capture the birthing experiences of women who experienced severe maternal complications and/or maternal near misses. A Black feminist framework (BFT) was used to guide the analysis, highlighting the link between Black women's history in the U.S. and contemporary structural disadvantages in the healthcare system and how intersecting identities shape their experiences and perspectives. In addition, the author used a practical thematic analysis approach to analyze themes to center Black women's birthing experiences. This approach sought to illuminate women's lived experiences with the phenomenon of interest and aim to bring deeper insight to understand how they experience the phenomenon. For this study, the primary phenomenon is how Black women perceive disrespect in their birthing experiences. These data will be used to inform respectful maternity care practices in healthcare system interventions, programs, and policies. The analysis will also bring a trauma-informed lens to evaluating potential solutions.

Research Question/s

1. How do Black women who have experienced severe maternal complications that resulted in a maternal near miss, perceive disrespect in maternity healthcare settings?
2. What are the specific challenges Black women face in regard to receiving respectful maternity care?

Section 2: Original Data Source

Study Design

MSM used a qualitative research design to gather the stories and perspectives of women who experienced severe maternal complications and/or maternal near misses. The purpose of their study was to codify the birthing experiences of people of color and to use their unique perspectives and personal stories to influence health policy, clinical practice, and healthcare strategies. In-depth, semi-structured interviews were conducted to give participants the opportunity to talk in detail, providing a description of their birthing experiences and the meaning they assigned to these experiences (Atkinson et al., 2019; Wood et al., 2019; Bloor & Wood, 2006). Learning more about perceptions, attitudes, beliefs, and behaviors through verbal expressions allows for flexibility and adaptability to generate themes from the expressions such as voice, intonation, and body language (CDC, Evaluation Briefs, 2018, Mills, 2014, Opdenakker, 2006). This is particularly helpful for researchers who can't relate or don't fully understand the experiences of Black women in America. Also, understanding how individuals construct their reality and interpret the world is important as it allows for contextual understanding of how seemingly similar individuals experience situations in unique ways (Mills & Birks, 2014). Between July 2021 and April 2022, eighty-seven in-depth interviews were conducted with birthing people to elicit their birthing stories and near-death experiences. Fifty-six of the participants were identified as experiencing a MNM (severe maternal complications that almost led to death), and thirty-one of the participants were identified as experiencing SMM (severe maternal complications that weren't life threatening). The initial sample size goal was 120 interviews; however, interviews were conducted until thematic saturation was achieved. This study initially recruited birthing persons from states with high maternal mortality rates, however,

to increase recruitment, participants were then recruited nationally. The states initially chosen for recruitment included Georgia, Louisiana, New Jersey, and the DMV area (Washington D.C., Maryland, and Virginia). In September 2021, New York, Connecticut, South Carolina, and Mississippi were added to the study to increase recruitment: Alabama, Texas, and Oklahoma were subsequently added to the study in December 2021. In March 2022, after many inquiries from birthing persons outside of the previously included states, the study was expanded to include all states in the U.S.

The study's eligibility criteria included (1) over 18 years old; (2) able to provide consent; (3) self-identify as a person of color (e.g., African American/Black, Latinx, Asian, Native American/Indigenous, etc.); (4) live in or have received maternal care in the United States, and (5) have experienced life-threatening conditions (pre-eclampsia, post-partum hemorrhaging, infection, high blood pressure, blood transfusion) related to pregnancy or childbirth. Participants were instructed to complete a voluntary demographic questionnaire before answering interview questions. Ninety-two forms were submitted, and eighty-seven interviews were conducted. A small percentage of the demographic characteristics reported for the participants may be overestimated due to duplicate or incomplete forms. Seventy-five percent of participants self-identified as Black/African American. The other women self-identified as Latinx (18.5%), Native American (8.7%). Asian (4.3%), or other (4.3). All participants identified as female. 95.7% of participants were 25–44 years old at the time of the interview, 83.7% of participants completed college or a graduate/professional degree, and 61.5% of participants' annual household incomes in the past year were $50,000 or over. Regarding pregnancy-related complications, 46.2% of participants indicated that they suffered from severe preeclampsia; 26.4% indicated they experienced severe postpartum hemorrhaging. 20.9% of participants

selected “other” as their pregnancy-related complication, which they were able to explain through an open-ended response.

Study Procedures

Recruitment

Internal team members created an email account for recruitment purposes and participant communication. A social media toolkit, including graphics and videos that promoted the Maternal Near Miss study and included maternal health educational materials was created and posted on the study Facebook page to assist in recruitment efforts. The research team contacted various maternal health organizations and established partnerships to provide information about the study and other promotional materials to assist in recruitment efforts. Further, some of these organizations participated in conducting interviews. As there is a higher prevalence of SMM for Black American women, researchers collaborated with Black-led community-based organizations to reach their communities to expand recruitment. Participants were screened to determine eligibility, and all participants provided written informed consent and were incentivized with a $100 Visa gift card for their participation. Interviews were scheduled with participants via email or messages through the technology platforms, D-Scout or User Interviews, and they were conducted virtually through Zoom. Recruitment for the study occurred from July 2021 through April 2022.

Interview Protocol

The interview guide was informed by the Three Delays Model, which explains poor maternal health outcomes due to delays in 1) the decision to seek care, 2) reaching a facility, and

3) receiving care, and the International Consortium for Health Outcomes Measurement (ICHOM) Set of Patient-Centered Outcome Measures for Pregnancy and Childbirth, and contained 12 main questions and 13 probing questions. In-depth semi-structured interviews were conducted virtually between July 2021 and April 2022 via Zoom and recorded and saved as encrypted files. Interviewers, who included team members, community partners, and funders of various races and ethnicities, were also trained to ask additional questions that may be relevant to each specific interview. The interviews were transcribed and coded to identify themes and patterns in women's birthing and near-death experiences. Participants were required to complete a screener survey to determine their eligibility prior to scheduling their interview. Additionally, before the interview began, participants were required to complete a consent form, followed by a voluntary demographic form. All the questionnaires were created and published on Research Electronic Data Capture (REDCap), a web-based application designed to capture data for clinical research. Following the completion of interviews, each participant received an email with a virtual gift card code and instructions as compensation for their participation and time.

Procedures

All internal and external team members were required to complete the basic Collaborative Institutional Training Initiative (CITI) course, and the CITI certificates were submitted and approved by the Morehouse School of Medicine Institutional Review Board. Interviewers were trained to ask any additional questions that may be relevant to each specific interview.

Utilizing storytelling and narrative-based medicine (NBM), which shifts the need to problem solve to the need to understand and hold the woman's story central (Zaharias, 2018), the

interview consisted of an icebreaker question, introduction questions, pregnancy questions, a "near-miss" question, probes, follow-up questions, and closing questions. Interviews typically lasted between one to two hours.

Much of the time during most of the interviews was spent answering the "near-miss" question, which is included below: "Tell me about your birth experience. Tell me the story, all the way from beginning to end, describe the setting, who was involved, do you have any pictures you would like to share, please address important timelines…"Another key question of the interview guide employed the Three Delays Model: "How was the process when you arrived at the hospital and how was your complication resolved? Take me through this part. What was said to you? Did you know what was going on?

Section 3-Dissertation Study—Qualitative Secondary Analysis

This dissertation utilizes a qualitative secondary analysis approach to investigate how Black women perceive and experience disrespect in healthcare settings. The study employs existing qualitative data described above, from Morehouse School of Medicine's retrospective narrative-based qualitative study that sought to capture the birthing experiences of women who experienced a MNM. This dissertation is covered under the original IRB and the researcher signed a data use agreement with MSM to use transcripts and videos to conduct this study. This analysis is comprised of qualitative interviews that specifically focuses on capturing the voices and experiences of Black women. In the original study, a total of 87 women of color participated in a semi-structured interview, of which 56 women identified as experiencing a maternal near miss. The dataset that comprised the other 31 women who experienced severe maternal complications was not made available. Of the 56 women interviewed, 43 identified as Black or

African American, and were selected for the final analysis. This analysis excluded the remaining 14 women who identified as Hispanic/Latinx (7), Indigenous (3), Indian (2), and Pakistani (1). This analysis sought to capture the lived experiences and voices of Black women as Black women in the United States continue to experience disproportionately high rates of both maternal mortality and morbidity, compared to women of other racial and ethnic groups. Black women had a death rate of 69.9 deaths per 100,000 live births in 2021, compared to White women (26.6). (CDC, National Center for Health Statistics, 2022). Additionally, Black women are nearly three times more likely to die from a pregnancy-related cause than White women (CDC, Health Equity, 2023), and have a two to three-fold increased risk of experiencing SMM and/or a MNM (Guglielminotti et al., 2021). Further, mistreatment and disrespect during maternity care is highest among Black mothers (30 percent), compared to Hispanic mothers (29.3 percent) and multiracial mothers (27.3 percent) (Mohamoud et, al., 2023; CDC, Vital Signs, 2023). Black mothers also report the highest rates of discrimination during maternity care (40 percent), compared to multiracial moms (39 percent), and Hispanic moms (37 percent) (CDC, Vital Signs, 2023). This analysis will bring voice to Black women's lived experiences of disrespect in a broader context of healthcare inequities and its impact on patient-provider encounters that impact maternal health outcomes.

The research questions formulated to guide the secondary analysis focused on understanding how Black women perceive and experience disrespect in healthcare settings and specific challenges faced in receiving respectful care. Although the dataset did not specifically ask about Black women's experiences of disrespect, the researcher explored the phenomenon through a review of existing literature to operationalize disrespect. For example, BFT draws on past social inequalities and systemic oppression such as discrimination within the healthcare

system, implicit bias among providers, and historical injustices, and how that may influence how Black women perceived disrespect when interacting with healthcare providers. In addition, a priori codes that include various dimensions of disrespect were developed based on the existing literature, conceptual frameworks, and concepts relevant to respectful care models in healthcare settings. The a priori coding framework served as an initial structure for organizing and analyzing the qualitative data in the practical thematic analysis (PTA) ensuring systematic exploration of key themes and patterns (Saunders et al., 2023; Roberts et.al, 2019; Maguire & Delahunt, 2017). Thematic analysis is an iterative process that begins with applying the a priori codes to a segment of the qualitative data by closely examining participant narratives to identify instances of perceived disrespect and relevant contextual factors (Saunders et al., 2023; Roberts et.al, 2019; Maguire & Delahunt, 2017). In vivo coding or emerging codes were added to the code book to contextualize Black women's experiences and voices in this study. The researcher analyzed the dataset to ascertain behaviors, language, or actions that may be perceived as disrespectful in Black women's healthcare encounters, factors influencing perceptions of disrespect, and potential consequences on health outcomes. Themes tend to emerge through the clustering and synthesis of coded data segments, highlighting patterns and underlying meanings, and applying interpretation of themes through theoretical frameworks and contextual insights (Saunders et al., 2023; Roberts et.al, 2019; Maguire & Delahunt, 2017). The Institute of Medicine Unequal Treatment report provided a contextual framework for categorizing themes around how Black women experience disrespect at the healthcare systems/institutional level and the clinical encounter at the provider and patient levels.

Inclusion criteria were used to select and include data from transcripts and recorded videos from Black women who provided relevant responses to specific questions that were

appropriate for addressing the research questions to maintain consistency and enhance the validity of the analysis. The original dataset asked 12 main questions and 13 probing questions were asked only if appropriate for clarification in the qualitative interviews. To be included in this qualitative secondary analysis, comments were extracted from responses to the following seven of the 12 main questions and probing questions if participants were asked to provide clarification (see Appendix A), that were most relevant to understanding perceived disrespect and women's perceptions of specific challenges faced in receiving respectful care, "When you think about the care you received throughout your pregnancy, can you tell me about a negative experience(s) you remember?", "Can you tell me a time(s) during your pregnancy and/or birth experience where you felt discriminated against in a professional health setting?", "Tell me about your birth experience?", "Do you think being a woman of color affected your medical experience giving birth, if so, how?", "What would you like doctors, nurses, payors and others to know?", "What do you wish you had known then that you know now?", and "How does your pregnancy and near-miss experience affect your life today?" The five questions not directly related to the research questions(s) were excluded from the analysis and included "What is the most rewarding thing about being a mother?", "Tell me about yourself and your community?", "What did you like or not like about being pregnant?", "How do you manage the long-term effects of your experience?", and "Why did you choose to participate in this study?" (see Appendix A).

Analytic Process

The researcher conducted a practical thematic analysis, examining women's responses to specific questions that met the inclusion criteria. Practical thematic analysis entailed five main steps: 1) familiarizing self with data within the context of the research questions and theoretical

underpinnings; 2) applying pre-defined a priori codes to the raw data to systematically categorize and organize the information and as coding advances, in vivo/emergent codes will be incorporated; 3) identifying patterns and relationships in the data by grouping related codes into corresponding categories; 4) organizing categories to develop meaningful themes; and 5) reporting findings. For the first step, the researcher read and reread all interview transcripts and viewed recorded videos to become familiar with the data to later engage in interpreting and contextualizing the findings during the qualitative secondary analysis (Saunders et al., 2023; Roberts et. al., 2019; Maguire & Delahunt, 2017). Further, the author reflected on the data and developed an excel spreadsheet that captured "memoing," jotting down reflections, ideas, and interpretations of the data to seek meaning and patterns to further explore and identify how this information answered the research questions (Saunders et al., 2023, Atkinson et al., 2019; Maguire & Delahunt, 2017). This iterative process of reading, reflecting, and memoing help the researcher to gain a deeper understanding of the data, allowing for thorough analysis and interpretation.

For the next step, the researcher served as a single coder using a deductive analysis approach to systematically apply predetermined a priori codes from the codebook (see Appendix B) to the analytic sample to categorize and organize the information. Each response to the questions was reviewed and assigned the relevant code. This process involved careful reading and interpretation of the transcripts, and viewing recorded interviews, looking for instances where Black women described experiences that aligned with the identified codes/concepts. Further, the researcher identified and added new, in vivo, codes (emerging inductive codes), that used language of women (words/phrases), to center Black women's birthing experiences from the transcribed and recorded data. These codes were added to the final code book (see Appendix

B). Examples of a priori codes that represented the overarching concepts that the researcher was interested in exploring related to disrespect included biased treatment, dismissive attitudes, communication challenges, and how this impacted Black women's experiences in healthcare settings.

To ensure the consistency, reliability, and validity of the analytic process the researcher maintained a decision log. A decision log is used for documenting steps, keeping track of data analysis decisions, and providing the rationale behind analytical choices made throughout the research process such as the application of inclusion criteria, developing and applying a priori codes and in vivo codes, and developing themes, etc (see Appendix C). This documentation ensures transparency and allows for reproducibility of the analysis as it outlines the process such as assigning coded data, checking for consistency in theme development, and confirming that the themes accurately reflect the content and context of the data (O'Connor & Joffe, 2020). Additionally, this process is used to maintain consistency as a single rater/coder, to ensure reliability and validity and to help minimize bias and subjectivity in interpreting the data.

For step 3, the researcher/coder identified patterns, concepts, and relationships across the coded data that reflected underlying themes by grouping all codes into categories that were similar (e.g., grouping the codes, "feeling pushed to make a medical decision" and "lack of shared decision-making" into the category of "patient-provider communication ").

Figure 1: Coding/Thematic Process

a priori codes	Categories	Theme	Sub-Theme
*Lack of shared decision-making *Lack of informed consent *Feeling pushed to make a medical decision.	Patient-Provider Communication	**Not feeling communicated with: When I'm not given the opportunity to engage with my provider to make decisions.**	**Not feeling communicated with.**
*Lack of information sharing, and rationale given for medical interventions.	Patient-Provider Communication		**When there is a lack of transparency in information shared**
*Lack of health education/resources provided.	Patient-Provider Communication		**When there is a lack of education provided**

For the fourth step, preliminary themes were refined by organizing and consolidating the grouped a priori codes into more meaningful thematic categories that aligned with the research questions. This process involved developing themes from the a priori codes and in vivo codes, grouping related codes based on similarities, organizing the thematic categories and engaging in an iterative process for theme refinement. Marker quotes and in-line excerpts that exemplified each theme and captured the essence of the data were provided to highlight meaningful insights and interpretations that aligned with the research questions and theoretical underpinnings. Throughout the coding and theme development process, the researcher maintained reflexivity by developing a statement that made notice and applied attention to the researcher's own biases, assumptions, and perspectives that may influence interpretations of the data (see Appendix D). Documenting decisions, reflections, and modifications made to the a priori coding structure ensured transparency and improved the rigor and trustworthiness of the data analysis process (Saunders et al., 2023, Atkinson et al., 2019; Maguire & Delahunt, 2017).

For the final step, the researcher included in-text citations/quotes and developed a matrix to include other quotes in a table format.

Strengths of Qualitative Secondary Analysis

Qualitative secondary analysis (QSA) uses existing data and provides the opportunity to explore Black women's birthing experiences that are linked to the primary research but brings a different focus to the data, such as disrespect in healthcare settings. Accessing a research population that may be deemed 'elusive,' due to barriers that prevent researchers from reaching or speaking to individuals based on the sensitive nature of the topic, can be prohibitive (Long-Sutehall, et. al., 2010). For example, the sensitive nature of this topic, which focused on Black women who experienced SMM and or MNM, has the potential to re-victimize women as they recount their experiences. Using the existing qualitative data in this secondary analysis prevented the need for challenging recruitment efforts and for women to have to reshare their narratives and potentially be re-traumatized. Additionally, these data were particularly valuable as they provide broader perspectives of Black women across the social and economic spectrum, as a large percentage of women were college educated, had higher incomes, and had access to private insurance and healthcare facilities that offered a different level of care. In contrast, the literature primarily highlights research that focuses on Black women who face challenges regarding social determinants of health, such as low income, lower educational attainment, lack of access to quality care, and who utilize public insurance such as Medicaid. This qualitative secondary analysis has the potential to expand on the current literature and inform policy and system level changes that impact all Black women's experiences in maternal healthcare settings. Lastly, this study will expand on quantitative studies that use surveys or other assessment tools to assess

disrespect and mistreatment in maternal healthcare settings, by giving voice, and context to these experiences, which allows for a deeper analysis and understanding of Black women's experiences of disrespect.

Limitations of Qualitative Secondary Analysis (QSA)

The literature notes several limitations to consider when conducting a QSA. Reusing data can result in ethical dilemmas if the researcher is not intentional with the data. The ethical considerations primarily involve privacy and confidentiality of the participants, data integrity and validity, selection bias, how the researcher handles sensitive data, the study design and consent outlining how long participants are protected, and, lastly, how the researcher will obtain consent from participants for the reuse of data (Hughes, K & Tarrant, A., 2023). The researcher is aware of these challenges and in conducting this QSA, the researcher is working closely with the original investigators to maintain the integrity of the data. Access to the chosen dataset was obtained from the primary investigator and the researcher completed a data use agreement with the MSM to ensure compliance with relevant ethical guidelines and data protection regulations surrounding informed consent, confidentiality, and anonymity of participants in the original study, which were adhered to throughout the secondary analysis process. The researcher agreed that the data cannot be further disseminated or shared with any other investigator, collaborator, mentor, student or colleague, or used in any scientific proposal or data analysis to answer related or unrelated research questions aside from the Aims/Hypotheses/Questions related to this dissertation. Also, the dissemination of findings (including publications) resulting from the data collected as part of the Center for Maternal Health Equity (CMHE) study are expected to include CMHE Study PIs. Lastly, the researcher will ensure that marker quotes are anonymized to

protect the confidentiality and privacy of the participants by removing identifying information to conceal the identities of the individuals quoted. Additionally, because the original study was so closely aligned, there was no concern for data validity or contextual misinterpretation of the data. Data initially collected was intended to gather the perspectives of Black women regarding their birthing experience, interactions with healthcare providers, perceptions of quality of care, and the circumstances of their "near miss" experience. This data was valid for answering how Black women experienced disrespect within their encounters with providers. This also minimizes selection bias as the original sample of women represents the population of interest in this study, which was Black women who experienced maternal complications and their perceptions of the paitient-provider encounter.

Reporting

The researcher will provide summary in-text citations highlighting quotes and narratives from women along with descriptive text that explains the significance and relevance of the quotes to the overall analysis. The researcher will create a matrix to include other quotes in a table format, organizing data by final themes and sub-themes that result from initial coding and categorization of data, to provide additional insights into Black women's experiences with disrespect in maternal healthcare settings. Each row of the matrix will represents a participant or a piece of data, while each column represents a theme or concept. The cells of the matrix will be populated with marker quotes extracted from the qualitative data that vividly illustrate and support the themes and sub-themes identified in the analysis, allowing for a structured overview of the data. Marker quotes will directly relate to the themes being explored in the analysis and capture key aspects of the participants' experiences, perspectives, emotions, or insights.

Chapter 4: Results

Study Population

A total of 43 women that identified as Black or African American were selected for the qualitative secondary analysis. The study revealed that 32 out of 43 women reported experiencing various forms of disrespect; 11 women did not report disrespect during their healthcare encounters.

All of the women included in the analysis identified as Black or African American and reported experiencing a maternal near miss. At the time of their interviews, 47.3% of participants were 25-34 years old and 48.4% were 35-44 years old. 61.5% of participants indicated their approximate total yearly household income was $50,000 or above. 9.8% reported having a GED/high school diploma, 6.5% reported attending technical college, 41.3% of participants indicated their highest level of schooling as college, and 42.4% of participants indicated completing a graduate/professional degree. Over 93% of the woman reported having health insurance, although there was no direct question delineating between public vs private insurance.

Coding/Themes

The researcher conducted a practical thematic analysis that entailed the following five steps: 1) familiarizing self with data within the context of the research questions and theoretical underpinnings 2) applying pre-defined a priori codes to the raw data to systematically categorize and organize the information and applying in vivo/emergent codes as they developed. 3) identifying patterns and relationships in the data by grouping related codes into corresponding categories, 4) organizing categories to develop meaningful themes and sub-themes; and 5)

reporting findings. All transcribed data was reviewed, so that the researcher could look for consistent patterns and trends across all participants responses from interview scripts. Transcripts were read line by line and a priori coding, codes established before the data were collected and are based on the literature, were applied to segments of the data. Examples of a priori coding include patient-provider shared decision making (Cantor et.al., 2024) and loss of self-advocacy (Rosenthal and Prather, et.al., 2018). As there was a considerable amount of overlap between the cluster of assigned codes, the researcher created categories of codes. Next, the researcher evaluated the categories, collapsed and combined similar categories, and developed relevant subthemes to label the theme that best described the combination of categories in the thematic analysis in Tables E1, E2, and E3 (see Appendix E). Following is data to support the developed themes and data that address the research questions. Quotes are included both in-text, as well as marker quotes displayed in Tables F1, F2, and F3 (see Appendix F) to provide additional insights into the women's experiences.

Women Who Reported Experiencing Disrespect

Final Themes

The qualitative analysis of the experiences of Black women who perceived disrespect in maternity care revealed several key themes. These themes illustrate the various dimensions of disrespect encountered by Black women and underscore the systemic nature of the issues perpetuating disrespect within maternity care settings and the influence of provider bias and discrimination on patient outcomes. The thematic analysis of interview data identified the following three themes and six sub-themes outlined below and illustrated in a thematic map (see Figure 1). The thematic map shows the connections and interconnections between and among

themes and subthemes and highlights how Black women participating in this analysis perceived and experienced disrespect in maternity care settings and the specific challenges they faced in receiving respectful care. Ultimately, women perceived not feeling seen, not feeling heard, and not feeling communicated with by providers as disrespectful, often resulting in unfavorable birthing and delivery experiences. Additionally, the interplay of biased and discriminatory care was perceived to result from provider's preconceived ideas of Black women and deeply ingrained stereotypes, which women noted on many instances, had an impact on all aspects of their experiences with perceived disrespectful encounters with providers.

Figure 2. Thematic Map

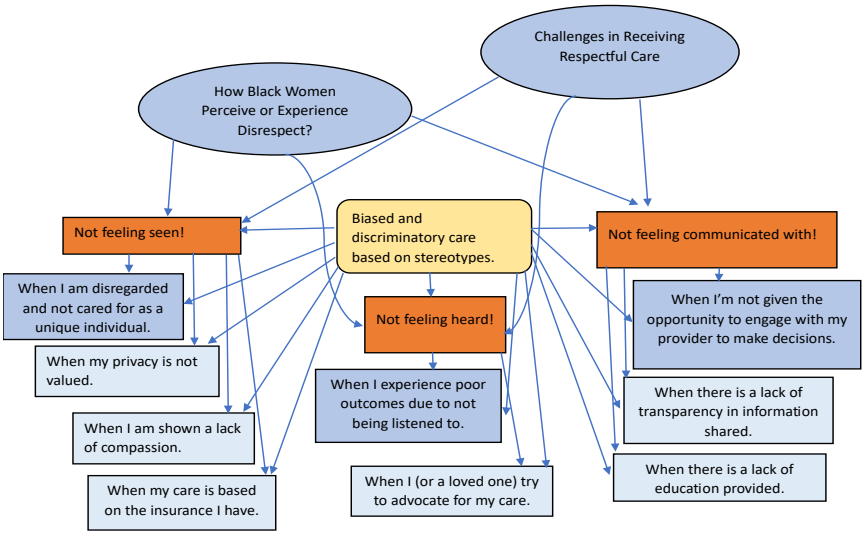

Figure 2. Final thematic map that illustrates the relationships between themes and sub-themes of how Black women perceive and experience disrespect and the challenges women face in receiving respectful care in maternity healthcare settings.

Theme 1. Not Feeling Seen: When I am not cared for as a unique individual. **Sub-theme 1:** When my privacy is not valued; **Sub-theme 2:** When I am shown a lack of compassion; **Sub-**

theme 3: When my care is based on the insurance I have; **Theme 2.** Not feeling heard: When I experience poor outcomes due to not being listened to. **Sub-theme 4:** When I (or a loved one) try to advocate for my care. **Theme 3.** Not feeling communicated with: When I'm not given the opportunity to engage with my provider to make decisions. **Sub-theme 5:** When there is a lack of transparency in information shared; **Sub-theme 6:** When there is a lack of education provided.

Theme One: Not Feeling Seen: "When I am disregarded and not cared for as a unique individual."

Many women reported feeling unseen and disregarded by healthcare providers and felt that provider bias and assumptions impacted how they were seen and the quality of care they received. One woman noted, "I believe I would have received different care if I was a different race. Every time I come, I see how you treat other patients and I see how you treat me. I'm literally begging for all my test results. Like the stuff you offer me, you're not offering her, and it's like a slap in the face, like what you feel like is best for me." Specifically, Black women felt that bias and discrimination exacerbated their disrespectful encounters with healthcare providers and prevented them from being seen as a unique woman, deserving of equitable care. Black women often felt that being viewed through a biased lens, left them feeling looked down upon and judged even if the narratives such as "single mother, with multiple children, and with different baby fathers," didn't fit their unique situation. One woman noted "It's just like, especially with my White friends, if they don't have a husband, nobody looked at them funny. When I had said I had a husband, 'Oh, you're married?' It was almost as though it was a shock that a Black woman could be married to the man she's having a child with." Another woman

recounted when her provider made an about her husband in the hospital, “So my husband walks in the room, and my doctor goes, ‘Why is your boyfriend here? You may not want him in the room.’ I looked at him, I was like, excuse me, that is not my boyfriend, that's my husband. This is his child. I was 23 at the time. They assumed that I wasn't married or that I didn't know who the father of this baby was. It was disgusting.”

Women also felt they were spoken to as if they represented the race, being a Black woman, versus being a unique individual. For example, women felt that language such as “you people,” or “people like her" was a direct insult against their race and being Black. A woman explained her experience of overgeneralized statements about her race in a conversation with a provider stating, "You should have listened to your doctor beforehand. That's what y'all do, y'all don't listen." Women found these statements to be disrespectful and rude. Black women often expressed “If I was a different race, I would be treated more fairly.” Many women expressed being treated differently from White women that they observed in the office and consequently denied care. One woman stated that “I felt a lack of connection, the White nurses, didn’t look at me as a woman, I didn’t feel seen.” Many women had sentiments of “not trusting the medical field” as they continued to experience bias and discrimination and that “it’s tough to put your trust in someone who doesn’t or never had your best interest.” Consequently, many women expressed an interest in seeing same race providers or support workers such as Doulas to improve their encounters. One woman stated, “Now when I go to doctors, most of the time I make it a point to go to Black doctors,” stating her provider race preference after her previous healthcare interactions with medical providers. Another woman noted, “It just made me even less trusting of the medical space in general a bit. Especially when it comes to pregnancy, like if I ever have another child, I would probably look more for doulas or birth workers.”

Sub-theme 1: When my privacy is not valued.

Some women expressed feeling disrespect when their privacy was not valued. A woman stated, “So it was just like disrespect of the birthing space, you know, me having to come out of my meditative space to tell people to shut up and using expletives because they're being rude, coming in my birthing room, not introducing themselves, and distracting me from my labor.” Black women described situations where their privacy was not respected, leading to feelings of indignity and vulnerability. This was a recurring theme as women demanded a consistent care team and requested that a limited amount of people be allowed in their room with permission. One woman expressed,

> “I was very firm. I don't wanna see one damn student. Don't bring me, I don't care if it’s [inaudible] in the corner. They're not allowed in my room, in my space. I will only see my own OBs. I don't wanna see anybody that isn't fully qualified, and I want the same people. I don't want a constant revolving door. It doesn't work for me. I'm not comfortable with that down to my nurses, I don't want 75 nurses. Stop, pause, introduce yourself. Who are you? Talk first, touch after XYZ, and so they dealt with me differently because after the first couple people came through the door, they all explained to the rest.”

Another woman stated that “residents and students were not allowed in the room without asking my permission, and this felt like an invasion of my space and privacy because I, my body, was like exposed and vulnerable on the table.” Another woman felt like her privacy was being violated in her neighborhood clinic, noting ‘When I got there, I noticed they were sending me students instead of my regular physician or even an attending. I was like, Nope, if you don't need

to be in the room, you got to go. I hate to say, I knew I was an experiment, and I was a teachable moment, and I didn't want to be a teachable moment in labor and delivery." Women felt that bias and stereotypes about Black women may influence their provider's decision to ensure privacy as they view them as less sensitive or in an experimental light and depending on where a woman delivers, Black women often receive care in teaching hospitals based on income, insurance, and geographic location.

Sub-theme 2: When I am shown a lack of compassion.

Black women perceived disrespect when there was a lack of compassion and genuine care from providers. Women frequently described their providers as "lackluster, having no real compassion or empathy, and noted that humanity was missing from healthcare." One woman expressed,

> "I felt a lack of empathy with White providers. When these White nurses saw me, they didn't see someone that they could empathize with. You would think that, okay, you're a woman, even if you've never had a child, you've most likely had a menstrual cycle. You know what pain is like in a woman's body, but when they saw me, it was as if my body was different. I had a different body that wasn't the same. The empathy was not there at all. Whereas when I did encounter a couple of times, and I did encounter Black nurses, the treatment was different. It was like they could see me, and there weren't but a couple of instances when I did experience the Black nurses. She was much more patient in explaining things, showing me, held my hand throughout it."

Further, some women felt their pregnancies weren't celebrated as compared to other women as a woman noted, "I feel like my pregnancy was not celebrated and instead I was asked how many other kids do you have, do you plan to have anymore, get on something to prevent more babies. Not, oh congratulations and speaking in a happy joyous manner." Following a similar sentiment, a woman noted "They did ask if I wanted birth control, I'm like, Dude, I don't know. I'm just having a baby now. It was almost like they were starting to give me reasons why I needed to start birth control, or I needed to get my tubes tied, it was never a question of if that's what I wanted."

Narratives didn't convey that women necessarily expected their maternal healthcare providers to act in a role of mental health therapist, however, they wanted to "feel completely cared for" and seen as a "whole person." A woman expressed "I didn't feel like they were helping me relieve any of that pressure or providing any level of emotional care. It was like I was completely obsolete and only my placenta and cervix were being treated. It's not what I expected. I thought I was going to be really taken care of, everything was going to be okay, but it wasn't like that. It was really disappointing." Women often expressed that the assumption that Black women are inherently strong "Strong Black Woman" and need little support impacts providers level of compassion and empathy shown when they experience maternal complications, lose a baby, or even desensitized to how Black women are traumatized and revictimized in bias institutions such as healthcare settings.

Sub-theme 3: When my care is based on the insurance I have.

Black women often felt unseen, treated unfairly, and/or disrespected by providers because of their insurance status. A woman who was covered by Medicaid shared that she

received “inconsistent care and a lack of continuity of care” as she had to see multiple providers throughout her pregnancy. She mentioned attending two separate facilities for her check-ups and ultrasound appointments, and that there was a lack of communication between the two facilities. Additionally, other women reported being frustrated with not having a choice in the provider they saw or hospital/clinic they visited due to being on Medicaid. One woman further noted, “I was going to the clinic that was literally like right next door to my old apartment, and it was predominantly Caucasian doctors. If I would've been a White girl with Medicaid, I would probably been treated like a little princess because this is our own, we're going to do good for our own.” Another woman shared that options weren’t provided to her based on having Medicare as she recounts, “However, because I didn't have private insurance, I had Medicaid, they would prescribe me these big old horse heart pills that were prenatal vitamins and when I inquired about the Tricare, the soft purple gel prenatal vitamins, I was told no because I didn't qualify for that, and they can only give me a few samples. I feel like they talked to me with disrespect because they think I was young and poor and could not afford the other medication.”

Whereas, women who had private insurance, noted their experiences were better in that regard, “I feel that because I had good insurance, and not on Medicaid, that I got better care. They were more attentive to my pain and needs.” Although, some women had positive experiences with private insurance, most women experienced perceived discrimination despite the type of insurance they had. Women felt that providers saw them as financially unstable, provided substandard care and didn’t explore treatment options. As one woman explains, even though she had private insurance, “providers still assumed that she was on Medicaid and attempted to inform decisions based on that. I constantly got the question do you have Medicaid? She stated that a provider said ‘Oh, we can't do the 3D ultrasound because your insurance won't

cover it.' I'd be like, Why? 'She's like, Medicaid doesn't cover those things.' I don't have Medicaid, it literally got so frustrating."

Theme Two: "Not feeling heard: When I experience poor outcomes due to not being listened to.

Many women reported feeling a level of disrespect when they were not heard as their concerns and pain were dismissed, even when faced with severe pregnancy complications. Women also indicated feeling anxiety and frustration due to not feeling heard or being taken seriously. Black women expressed not feeling heard regarding their pregnancy concerns due to pain or other medical complaints and perceived this as being handled carelessly, as one woman recounts "the provider saying 'oh you will be fine,' then I went into cardiac arrest." This often resulted in women experiencing delays in care and treatment such as delay in diagnosis, inadequate treatment or not being referred for follow-up care, delay in scheduling appointments and/or call backs, or the provider not being intentional or timely with sharing or reviewing test results. Black women also expressed feeling disrespect when providers presented with a dismissive demeanor and tone. Women also often felt that providers conveyed unacceptable responses or explanations for their pain or concerns. They were particularly baffled by responses such as it is because "you are young, it's normal because you have multiple children or it being your first child, or something seemingly unrelated such as food choice" which in noted in the following marker quote:

> "The other issue was that I was in significant pain, and the pain was dismissed. Not only was it dismissed, it was misinterpreted as if, you know, this is the third baby, so I know if

> I'm having pain, I can clearly say this isn't a contraction. Right. I can clearly say that what the pain is feeling like. I immediately set up a right quadrant pain, very clear, transparent with what my needs were at that time and what I was going through at the time. It wasn't any miscommunication. It was I am feeling very, very bad. I am in extreme pain. And this is something that I've never felt before in my life. And I was given Maalox. I was told--I mean literally in my medical records it lists patient had a pizza and a banana, so we're going to give her Maalox."

In this example, the woman described how, despite clearly articulating what she was experiencing, medical staff still dismissed her concerns and failed to read her lab work until after her situation became life-threatening. From her recollection, and it was confirmed with medical records from a deposition, the doctor waited an additional four hours before they delivered her baby via cesarean, and as a result her baby died, and she spent several weeks in the ICU due to a ruptured liver. Another woman recalls, "I had to keep pushing for certain things, and keep asking for certain things over and over where I felt that what I was saying in terms of what I was experiencing was just being passed off as normal, and not any kind of insight into like, I know what I'm feeling. Yes, this is the first time that I've been pregnant, so there's things I don't know, but I know when something's not right with my body." Another woman explains "I couldn't even have a C-section immediately after that first night. They had to wait for me to re-stabilize, but I think had they taken my initial pain and onset of pain a little more seriously, I could have avoided the extremely high blood pressure overnight." One woman felt consistently unheard and dismissed as she recounts:

> "I was calling the doctor three times and saying something isn't right, something isn't right and not once did the doctor say you know what go to the hospital just to put your

mind at ease. No, it was you're fine. This is normal, and maybe some things are normal, but after the third call, you should kind of—it should kind of trigger something to say maybe she's going with her gut. Maybe she knows her body more."

Mothers stated that the lack of attentiveness and diligence, and medical staff neglect, led to them experiencing severe maternal complications and unfavorable delivery experiences, such as internal bleeding, severe pre-eclampsia, severe post-partum hemorrhage, sepsis/infection, and emergency c-sections, resulting in a maternal near miss in which they could have died. One woman noted, "I'm thankful to God that this happened while I was in the hospital, because there was no delay in me receiving assistance. I was in the hospital. I was there." Women often felt that assumptions about Black women having a higher pain tolerance, resulted in the undertreatment of their pain and dismissal of complaints by providers. As a woman noted, "No, my pain is the same as a White person's. Just as they would listen to a White person, they need to listen to us as well because we all bleed the same and some people's tolerance might be higher, but when you're screaming or when you're crying or when you're in pain or when you're struggling to move, help that person, listen to that person."

Sub-theme 4: When I (or a loved one) try to advocate for my care.

Black women describe feeling unheard and disrespected when they attempt to advocate for themselves, as it is often ignored or met with opposition as described in the following marker quote:

"They still was not having it, and neither was I, and I told them that, "I am not leaving this facility because I realized that I haven't had a sonogram in months. You're going to

have to call the cops and they're going to have to arrest me because I am not leaving this place until I get a sonogram." I literally was flipping out, getting loud and everything. They, of course, was like, "Oh, just take her in, just take her in, let her get her sonogram."

Black women feeling unheard often impacted their ability to effectively self-advocate. Many women expressed experiencing barriers that prevented them from speaking up or asking questions for fear of being judged or labeled based on “stereotypical behavior of Black woman.” Although many women tried advocating for themselves in the birthing room, they were oftentimes dismissed, as one woman noted, “I think they just felt like I was being difficult.” Another woman recalls, “I had gone to the doctor the day before, and he had told me that there was nothing wrong with me, and that I was actually worrying people. He didn't run any tests or anything like that to confirm.” Many women felt unheard and less likely to speak up on issues for fear of being labeled as a “complaining, whining, nagging, or annoying” patient if they asked questions or asserted themselves in the birthing process. For example, a woman stated “they're seeing a Black woman trying to tell a White male doctor how to do his job, wasn't acceptable. Privilege always falls into place and an unconscious bias fall into those places as well.”

Another woman alluded to feeling judged and stated, “it’s my own kind of internalized racism feeling like I can't really speak up as much as I want because people will think I'm a complaining black woman.” Another woman spoke about how being a Black woman can hinder empowerment and your ability to advocate for youreself as it is often met with opposition from others as well as internalized racism that doesn’t give you the space to openly speak up for yourself. For example, she stated “I think in every day and in every way, we have to fight and advocate for ourselves. We as Black women, and I know, because I was one of them. I was one of them who was taught that it's bad to fight for yourself, to speak up for yourself. I was always

told, you always got something to say, you always talking back, because I was speaking up for myself. I used to get beat for that. Then the world will beat you down for doing that too. You got to take those beatings and fight back, and still talk." Black women in this study perceived that providers often viewed them through a lens of assumptions and stereotypes about Black women, which could skew a provider's clinical judgement. For instance, Black women being labeled as more aggressive or angry, can impact the way a provider receives their feedback, and can subsequently lead to Black women tempering their expressions when interacting with providers.

In addition to women not feeling heard when they advocated for themselves, they also noted a lack of regard when their partner, parent, or other support person tried to advocate for them. One woman stated, "I remember the doctor seeming rushed when giving my epidural, and my mother questioning the dosage of the epidural, and instead of taking the time to explain the dosage, the doctor responded rudely. He told the nurse to tell her if you know, if you can't keep your mouth closed then you gon get put out." Additionally, another women spoke of when her husband had to advocate for her as she was being dismissed by the nurse,

> "I just remember, my husband was demanding. I remember him actually, he hit his fist on my bed and he was like no, something is wrong. I just remember that forcefulness is what I remember and the way the nurse flipped. Her neck was like the exorcist. She just looked back at him. That's when she saw everything. I just remember him being very demanding. He was like, No, she doesn't act like this normally, this is not her. It seemed no matter how many times I kept coming in and out, he kept saying, "This is not her."

Women noted that in response to loved ones advocating on their behalf, providers often didn't listen to their pleas for help, and in some instances, responded rudely or even threatened to have them removed from the room.

Theme Three: "Not feeling communicated with: When I'm not given the opportunity to engage with my provider to make decisions."

Black women expressed not feeling communicated with as there was a lack of collaboration and or partnership with their provider in shared decision-making regarding their care. Women often expressed that a lack of dialogue and deliberation on the best course of action, led women to feel they didn't consent and/or were pushed or forced to make a medical decision or have a procedure. As noted in this marker quote:

> "So, I'm calling. I didn't know what a hysterectomy was. I'm thinking she like just like basically get my tubes tied. That's what I thought until I called my mom and my aunt down and them, and they was like you too young for that, basically. So, when it was time for me to go back in, , I was like my mom said I'm still young for a hysterectomy. She was like, well, you are a high-risk delivery and you're very dramatic, so a hysterectomy would be good, so you won't have to go through this ever again in life. So, I'm like you telling, at this time I was 25, a 25-year-old to remove everything she have to bear a child because she high risk."

This 25-year-old woman felt pressured to have a procedure that she had little information about. She was able to successfully challenge the recommendation after having a conversation with her mother and aunt. If not for the meaningful engagement with her family, she may have felt forced to make a decision that was in the best interest of the provider and not her. Black women also reported feeling little to no decision-making power during labor and delivery. Women expressed interest in being actively engaged and participatory in their care, however, when attempting to engage, some women reported being spoken to in a disrespectful or

condescending manner. Black women reported experiencing challenges with forging a relationship with their provider due to feeling that assumptions and stereotypes about Black women, impacted the engagement. Bias and stereotypes can impede effective communication and interactions between women and their providers. Women expressed feeling that because some providers assumed that Black women were uneducated and not smart enough to have intelligent conversations, providers were reluctant to provide thorough explanations or engage women in dialogue.

Additionally, Black women reflected on how they felt a lack of decision making power when it came to their birth plans, which often resulted in unwanted or unconsented procedures. Women felt that although they had a birth plan in mind, things changed once they arrived at the hospital. This was particularly common in cases where women had ideas of a natural or water birth, but instead, felt that their birth plans were not honored. Several women recalled being pressured into having a Cesarean section. One woman expressed, “It's just very disappointing when you have a plan and literally, absolutely nothing about your plan went right—and your doctor doesn’t want to discuss options—and like make a plan together.” Women who experienced disappointment and perceived the delivery process as unsatisfactory during their first birth, were reluctant to devise a birth plan for subsequent births due to not having their birth plans honored. One woman noted, “Why bother with a plan, No cause my first pregnancy, I made a plan. It didn’t go nothing like I planned it. So I was just like, whenever I get pregnant again, it's out the window. Imma just go with the flow.”

Sub-theme 5: When there is a lack of transparency in information shared.

Women expressed not being communicated with and a lack of transparency about the information provided regarding their care or the rationale for medical interventions being imposed upon them. As described in the marker quote:

> "At that point, I was trying to ask all the questions that I could, but they weren't really being transparent with me. You know how they say ask questions, but they don't really want you to ask questions. So when the preeclampsia started, it advanced very quickly. In many cases, they didn't--my doctor knows that I'm a physician, but I don't know who in her team in the hospital knows that or doesn't know that, but there was no information really being given. It was just like these interventions were happening and I had to really pipe up and say, what is happening. Like you need to tell me what is going on. You need to tell me why you're starting these meds. You need to tell me what meds you're starting. You need to tell me how often I expect to get them."

This woman noted that she didn't feel her doctors or other medical professionals adequately explained or described the care they provided and the reasoning behind the interventions. Due to the lack of communication or the lack of information provided during pregnancy, women indicated not feeling like they were fully informed about their care. This was consistent throughout their prenatal care and birthing experiences. Specifically, women reported receiving inconsistent, delayed, or no communication/information at all. Women reported they were mainly "ordered or told" what they should do instead of having respectful communication. Another woman explained that she had many questions during her routine appointment and was unable to get transparent answer as she noted that she felt dumb for asking questions in relation to the delivery. She noted one of her questions was "How do I push?" and that it was not

answered. Women often perceived that providers made assumptions that Black women are non-compliant/or less likely to follow advice or a treatment plan outlined by a provider, and therefore the provider puts less effort to communicate or provide explanations and/or information about their care.

Sub-theme 6: When there is a lack of education provided.

Black women expressed not feeling communicated with and feeling unprepared for the birthing experience due to a lack of education regarding potential unexpected events that could occur before and during delivery. Many women reported feeling that providers didn't speak in plain language, and they expressed frustration with their lack of understanding of medical terminology related to their procedures, not knowing the signs and symptoms of unexpected or unplanned outcomes, or not having background knowledge on potential complications. One woman noted, "I think one of the things I struggle with is the explanation of why something is happening or what's the cause of something. You get very minimum of the information. You can't tell me, "Oh, you're bleeding", or "Your pressure is low. Your uterus is contracting." All these different things, you're throwing all this jargon at me but you're not explaining to me why, how, or anything. It's like you're just there blind and you're supposed to take this information." Another woman shared her frustration stating, "That is part of your job as a doctor and as a nurse is to educate your patient on what it is that you are diagnosing them with. Don't send them home with a leaflet and expect that to be sufficient. That's part of your job is to explain it to them, and you will get more respect [inaudible]." Another woman stated, "They were explaining, but I didn't understand what they were saying like a postpartum hemorrhage, I've never even heard of that." Consequently, women expressed the need to educate themselves on the signs and

symptoms of pregnancy-related complications as well as understanding what to look for so they could be more prepared and to communicate more effectively with their provider. As noted earlier, women felt their providers didn't bother to explain medical terms or go into detail about their situation, as women felt that providers make the assumption that all Black women come from a lower socioeconomic status, have low health literacy, and wouldn't understand medical terms and conditions or incapable of fulling grasping what they were being told.

Women Who Did Not Report Experiencing Disrespect

Interestingly, 11 women did not report experiencing disrespect during their maternal healthcare encoutners. These women reported receiving care that was respectful, inclusive, collaborative, and attentive. Factors that women identified that contributed to these positive experiences include: having access to hospitals that are known for quality care and high standards of patient care, diverse maternal care team, including having access to doulas and midwives, receiving care from same race healthcare providers (race concordance), and, lastly, having access to care may have influenced one mother's experience, as a mother attributed her respectful care to having private insurance.

Chapter 5: Discussion

The purpose of this study was to expand our understanding of Black women's birthing experiences in maternity healthcare settings through their voices and perspectives. Specifically, looking at how Black women perceive and experience disrespect, the perceived challenges to receiving respectful care, and the opportunities to develop and implement strategies, policies, and system-level changes to improve these experiences. The analysis provided an in-depth understanding of women's experiences and revealed critical themes and subthemes, including feeling unseen due to biased and discriminatory care, lack of privacy, lack of compassion, insurance discrimination, feeling unheard and dismissed, and not being communicated with effectively. The analysis also revealed that some Black women report no experience with disrespect in maternal healthcare settings, reporting contrasting experiences with women who reported experiencing disrespect. For example, women experiencing no disrespect, reported receiving care that was respectful, inclusive, collaborative, and attentive. Women contributed positive experiences and respectful care to having access to hospitals that are known for quality care and high standards of patient care, access to a diverse maternal team including Doulas and Midwives, receiving care from same race healthcare providers, and having private insurance. On the other hand, women who reported disrespect, the themes illustrate the various dimensions of disrespect and provide insights into how these negative encounters impact the health outcomes of Black women. While respectful maternity care (RMC) is considered an important factor for improving maternal health outcomes (Cantor, et. al., 2024), defining what respect looks like for Black women can only be understood based on a deeper understanding of how they perceive disrespect. As Black women are three to four times more likely to die during or after pregnancy

than White women, and experience higher rates of SMM and MNM, their voices are critical in informing changes needed for respectful maternity care to improve maternal health outcomes.

Additionally, there are limited qualitative data to help bridge the gap in our understanding of provider and patient encounters and our understanding of the role this plays in women experiencing disrespect and ultimately worse maternal health outcomes. As maternity care settings can be high-stress work environments that require quick decisions, providers may be unaware that their behaviors or care are being perceived as disrespectful or discriminatory by Black women. As an example, a provider may be concerned about a baby in distress and be very abrupt in pushing a patient to have an emergency C-section. From the provider's perspective, they are prioritizing the health of the mother and baby. From the mother's perspective, the physician hasn't taken the time to explain what is going on, what the treatment options (and associated risks) are and, it feels very disrespectful and coercive—especially in the contexts of systemic racism and a paternalistic healthcare system. Additionally, as the literature highlights, providers often operate based on biases that may affect their interactions with Black women, influencing their behavior and decision-making without their awareness. These biases can lead to differential treatment, such as assuming that Black women can tolerate more pain or are less compliant with medical advice, which can be perceived as disrespectful. It is only by recognizing patient perspectives that providers will be able to begin to improve the nature and quality of their interactions and care with Black women.

Further, while research shows that many women across racial and ethnic groups experience some level of disrespect, such as not feeling heard, concerns not being taken seriously, or feeling dismissed (Long et.al., 2023), the intersection of disrespect and discrimination compound the effects experienced and perceived by Black women (Dagher &

Linares, 2022). Discrimination adds additional layers of disrespect or mistreatment experienced by Black women compared to other women and is often manifested by unfair or unequal treatment based on their race, class, and other characteristics. BFT provides a critical lens in understanding how race, gender, and social identity intersect to shape how Black women may perceive disrespect when interacting with healthcare providers, specifically in the context of past social inequalities and discrimination within the healthcare system, implicit bias among providers, and historical injustices. This multi-layered effect can impact Black women's treatment based on assumptions, biases and preconceived ideas and stereotypes, resulting in poor quality care and/or inadequate medical attention compared to other women.

The following discussion highlights how Black women perceived disrespect in feeling unseen, unheard, and not communicated with by providers in maternity healthcare settings.

Feeling Unseen: Black women frequently described feeling unseen in healthcare settings, often attributing this to **biased and discriminatory care**. Many women recounted instances where they felt disregarded and unseen by healthcare providers as their care and treatment were predicated on assumptions based on racial stereotypes, versus seeing them as **unique individuals**. Black women also felt they received differential treatment as they highlighted instances where they perceived lower quality care was received compared to non-Black women. Black women often felt unseen as they experienced a **lack of privacy** during medical examinations and consultations. Women reported feeling exposed and vulnerable, often without adequate measures taken to ensure their privacy. Women noted having to make repeated requests for providers to ask permission before allowing others in their room, and feeling discomfort when they were seen by students or residents. Women expressed feeling that their care was "experimental" and that they were viewed as a "teachable moment" by students and

residents, versus feeling their space was fully respected and valued. Women also felt unseen as providers showed a **lack of compassion** and empathy throughout their birthing experience. Women often described healthcare providers as cold, dismissive, or indifferent to their needs. This lack of empathy often translated into a poor quality of care, where the emotional needs of Black women were neglected. For example, women noted their pregnancies weren't celebrated or certain providers couldn't empathize with the stress or trauma of giving birth, as they felt providers focused solely on clinical outcomes or performed in a perfunctory manner. And lastly, women felt they were not seen beyond the type of insurance they carried, which resulted in **insurance discrimination**. For example, women felt the type of insurance coverage they had affected the quality of care they received. Many Black women perceived that having Medicaid resulted in a lower standard of care compared to those with private insurance, impacting where they could see providers and their experience of a lack of continuity of care. Futher, the intersection of racial and economic disparities often compounded the negative experiences of Black women in maternity care.

Feeling Unheard: Black women frequently and consistently felt unheard and dismissed by their healthcare providers, leading to poor health outcomes and a lack of self-advocacy by women and their support systems. This theme was prevalent, as many women attributed their severe maternal complications and maternal near miss experiences to providers not listening or acting in a timely manner to address their concerns. Many women reported that the dismissal and minimization of their symptoms and their health concerns being consistently ignored or downplayed, led to delays in receiving appropriate care, delays in diagnosis and treatment—often exacerbating other health conditions. Further, women linked the lack of attentiveness and carelessness to their **negative experiences and outcomes**, including inadequate pain

management, and poor follow up care. For example, several women mentioned that their pain was not taken seriously. This lack of recognition can lead to significant health disparities, as vital symptoms may go unaddressed. Lastly, women noted feeling unheard had a great impact on their ability (and loved ones') to **advocate for their care**. Due to feeling unheard and often silenced when they did attempt to speak up, Black women were often reluctant or felt unable to advocate for themselves. The persistent dismissal of their concerns led to a decrease in self-advocacy, leaving women less empowered to influence their care. Although provider bias and discrimination may impact self-advocacy, BFT helps to explain how internalized racism also has a profound impact on Black women and their ability to self-advocate as Black women often internalize negative stereotypes and beliefs about themselves (Collins, 2022; Thompson et al., 2022; David, et. al., 2019). For example, women noted feeling that internalized racism impacted their willingness to advocate for themselves for fear of being judged or labeled according to stereotypes such as being "difficult, or aggressive." As a result, Black women in this study highlighted how they were fearful of being labeled based on racial stereotypes so they often didn't speak up . Women also felt that their loved ones were also often ignored or even threatened when they tried to advocate for their care.

Feeling a lack of communication: The final theme centered on the lack of communication or engagement from healthcare providers, particularly in terms of shared decision making, transparent sharing of information, and patient education. Black women expressed a desire to have a more **collaborative partnership with providers**, serving as a key decision maker in regard to the care received during pregnancy and their birthing experiences. As this rarely occurred, women felt excluded from decisions about their care and felt they were often not provided with clear, **transparent information** about their health and treatment options.

This also underscored many women feeling that their voices or opinions were not valued or respected in medical settings. For example, many women reported feeling sidelined in discussions about their care, with decisions being made without their input or consent. Women frequently noted that they were not given adequate information about their health conditions or treatment plans, which often led to confusion and anxiety about their care. For example, this left women feeling unprepared for their birth, as birth plans were often not honored, impacting their desire to have future children. Lastly, the **lack of education** about health and maternity care left many Black women feeling unprepared and unsupported during their pregnancies and deliveries as they didn't understand medical terms or what was occurring with their bodies. Women consistently noted that providers didn't explain medical terms in plain language or provide an explanation or education about their conditions, diagnosis, or impending treatment. Women often felt this was a direct result of bias and discrimination as Black women are seen as "less intelligent," "less educated," or "less likely to adhere to treatment plans." This was captured as women didn't feel involved in their care or asked for their opinions about their care and felt forced or coerced into procedures or treatments such as C-sections, hysterectomies, or birth control, as well as experiencing emergencies such as pre-eclampsia or post-partum hemorrhaging.

Summary

The qualitative analysis highlights the pervasive impact of racial bias and discriminatory practices on the maternity care experiences of Black women. The theme of biased and discriminatory care emerged strongly, undergirding all three themes and six subthemes. Biased and discriminatory care based on preconceived ideas of Black women (low education, insurance

type, higher pain tolerance, non-compliant, angry, or difficult), permeated every aspect of Black women feeling unseen, unheard, or not communicated with during their pregnancy and delivery, which ultimately impacted their perceived disrespect in experiences with healthcare providers in maternity care settings. Repeated disrespectful encounters that expose Black women to bias, discrimination, and trauma can exacerbate pre-existing chronic health conditions, contributing to poorer maternal health outcomes. Considering that SMM is more prevalent for Black mothers, including conditions such as preeclampsia, high blood pressure, and post-partum hemorrhage that can lead to a MNM, women expressed that providers should provide more compassionate and respectful care by being proactive in discussing signs and symptoms and monitoring these conditions with patients, rather than dismissing their concerns. Addressing the impact of discrimination and disrespect in maternity healthcare settings requires a comprehensive approach that acknowledges the unique challenges that Black women face. Efforts to transform maternity care systems to be more equitable, respectful, and responsive to the needs of Black women require targeted interventions, policies, and systemic changes in healthcare practices, including ongoing training, accountability measures, feedback mechanisms, protocols and guidelines, that improve respectful care for all women.

The following definition of disrespect is framed based on the experiences of women from this study.

Disrespect: The experience of racial bias and discrimination through a provider's behaviors, language, or actions that results in Black women feeling unseen, unheard, and not communicated with in maternity healthcare settings.

Conceptual Framework

Using BFT and the IOM Unequal Treatment report, as well as information outlined in the literature review, a conceptual framework was developed to help understand factors that contribute to how Black women who have experienced severe maternal complications and maternal near misses perceive and experience disrespect in maternity healthcare settings, as shown in Figure 3. According to Braveman et. al, (2022), systemic and structural racism are pervasive and deeply embedded in systems, laws, and policies that perpetuate unfair treatment and oppression of people of color, leading to adverse health consequences. As such, historical and contemporary racism sets the foundation for medical racism in the healthcare system (unconsented procedures, dismissal of pain), provider implicit bias and discrimination, and patient-level internalized racism (non-adherence, delayed care, mistrust). In addition, inequities in social determinants of health (SDOH) (employment, housing, income, healthcare access, food access, education, transportation) lead to health inequities, such as increased chronic illness and maternity morbidity and mortality. This conceptual model (Figure 3) helps to contextualize the themes and sub-themes reported from the perspectives of Black women in this study to demonstrate how systemic racism together with discrimination and bias at all levels create a system in which Black women are subjected to a structural and societal context that combined with disrespectful and discriminatory care leads to poor healthcare interactions and maternal health outcomes.

Figure 3. Conceptual Model

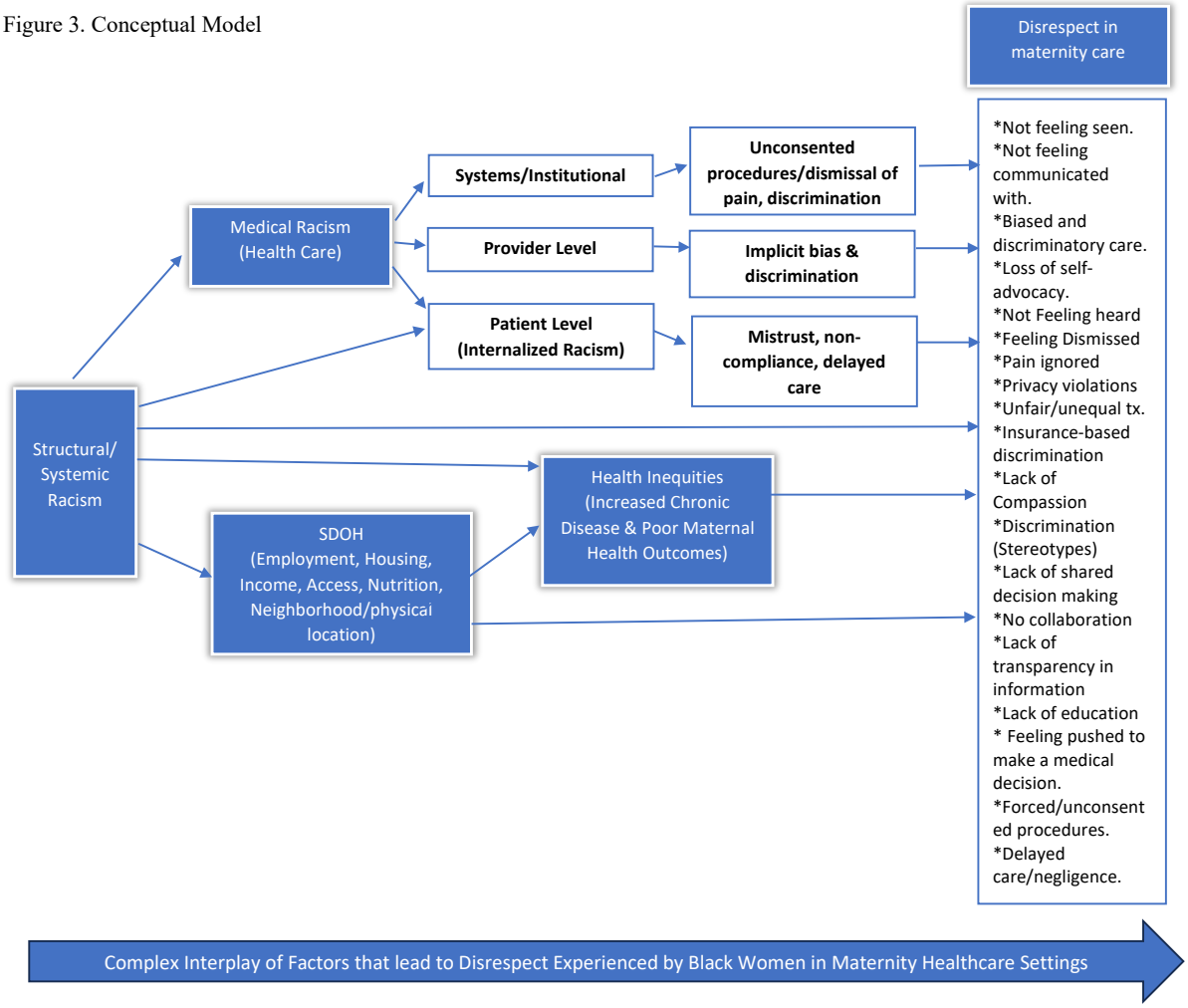

Figure 3. Conceptual model of the causal pathways and results of the impact of racism on disrespectful encounters that result in poor maternal health outcomes.

Institute of Medicine (U.S.) Committee on Understanding and Eliminating Racial and Ethnic Disparities in HealthCare. Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. Smedley BD, Stith AY, Nelson AR, editors. Washington (DC): National Academies Press (U.S.); 2003.

Implications for the field

The findings from this analysis, which provide in-depth qualitative experiences of Black women with disrespectful maternity care, have profound implications for healthcare practice, policy, and future research. The detailed accounts of feeling unseen, unheard, and not communicated with from a biased and discriminatory posture based on assumptions and stereotypes, underscore several critical areas for intervention and change. There is an urgent need

to consider the needs and preferences of Black women and implement strategies that reflect these within clinical settings and encounters with maternity care providers during pregnancy, birth, and the postpartum period to create meaningful solutions and improve maternal health outcomes (Falako, 2023).

In addition, the absence of reported disrespect among some women highlights the variability in maternal healthcare experiences among Black women. It suggests that while systemic issues of bias and discrimination are prevalent, there are also instances where respectful and high-quality care is provided. As respectful care doesn't necessarily preclude maternal complications due to emergencies happening, this variability does underscores the need for best practices to ensure all Black women receive equitable and respectful care to mitigate the potential or foreseeable poor outcomes.

One strategy to mitigate discrimination and disrespectful care has focused on provider and patient encounters, specifically targeting providers, and addressing their own implicit biases to better serve patients. However, research shows that integrating implicit bias and diversity training for current and future healthcare professionals, particularly White providers, does little to reduce bias, and results are often limited and short-term (The Institute of Medicine, 2003, Dobbin & Kalev, 2018). As historical injustices have contributed to medical racism in healthcare settings for centuries, it is not expected that systemic changes such as increasing the diversity of healthcare providers and eliminating racism will happen quickly. However, healthcare organizations can devise strategies to develop and implement policies and practices that explicitly address discrimination and promote respectful care practices, incorporating how Black women perceive disrespect, to inform respectful care models. Additionally, healthcare organizations can implement trauma-informed care practices to educate providers about trauma

and practices to avoid re-victimizing Black women who have experienced a MNM and have repeated experiences with discrimination, bias, and disrespect to improve their physical and emotional well-being. Lastly, expanding and diversifying the maternal healthcare workforce may be a critical lever to improving the quality of care for Black women, and potentially reducing disrespectful and discriminatory maternity care practices while ultimately improving maternal health outcomes.

Reform Healthcare Organizational Policies and Practices

The analysis highlighted instances where Black women felt disrespect in their encounters with providers, such as feeling unseen, receiving biased and discriminatory care and receiving a lack of compassionate care. Additionally, Black women reported not feeling heard, unable to advocate for themselves, and not having the opportunity to engage in shared decision making—are factors that are related to disrespect and areas in which healthcare providers can become more attuned to in understanding the needs and perceptions of Black women. Reconciling the disconnect between healthcare providers' perceptions of their behavior and the experiences of Black women in maternity care settings involves addressing both awareness and systemic issues. Efforts to transform maternity care systems to be more equitable, respectful, and responsive to the needs of Black women will require targeted interventions, policies, and systemic changes in healthcare practices, including ongoing training, accountability measures, feedback mechanisms, protocols and guidelines, to improve respectful care for all women. Healthcare policies can be transformed to increase accountability and transparency in healthcare delivery, with specific measures to address racial disparities and promote equity in maternity care. Additionally, healthcare organizations can outline clear guidelines and policies for addressing racism and

discrimination, promoting diversity within the workforce, and ensuring equitable and compassionate care for all women.

There are many health systems working to address their policies and practices to improve patient-provider relationships and the delivery of respectful care by combatting racism, bias, and discriminatory practices in healthcare. For example, in 2021, the Commonwealth Fund reported on interviews with providers and administrators affiliated with medical centers to learn more about their policy efforts to address racism and discrimination. The University of California Los Angeles (UCLA) Health developed comprehensive equity dashboards to identify inequities and solutions to mitigate them. The dashboards monitor and track metrics across a variety of indicators such as variation in patients' healthcare quality and outcomes by race, gender, age, etc., the health system's hiring, promotion, training and contracting practices, patient and employee grievances, promotions, and selection of vendors providing goods and services (Hostetter & Klein, 2021). Additionally, Penn Medicine piloted a digital platform called, Lift Every Voice, to encourage staff members who have witnessed or experienced racism in the workplace to recognize and report it (e.g., reporting managers that treat Black employees unfairly or reporting if Black patients receive disparate treatment from staff) (Hostetter & Klein, 2021). UCLA, Ohio State University, and Massachusetts General Hospital have all created similar systems for reporting racist and discriminatory behaviors, and consequently, many health systems have hired chief diversity officers to help recruit and promote more clinicians and leaders of color (Hostetter & Klein, 2021). Lastly, academic medical centers are making strides to reform medical education by undoing racist policies and practices that have permeated healthcare and academic institutions. Historically, medical education has taught physiological differences between Black and White people without giving context to environmental and

societal influences and the role of racism in health and strategies to combat it (Hostetter & Klein, 2021).

Expanding and Diversifying the Maternal Healthcare Workforce

Having culturally appropriate patient centered care that incorporates strategies to achieve effective communication, collaboration, joint decision making, education, and overall wellbeing of women is critical to combatting bias, discrimination, and disrespect experienced and perceived by Black women (Constand et al., 2014). Expanding and diversifying the maternal healthcare workforce may be a critical lever to improving the quality of care for Black women, and potentially reducing disrespectful and discriminatory maternity care practices while ultimately improving maternal health outcomes. To achieve new care models, policy initiatives are needed to recruit and retain healthcare professionals from diverse backgrounds that better reflect the communities they serve to improve patient-provider encounters. Improving training, certification, and reimbursement for clinical and non-clinical providers can also improve the provision of quality services for Black women. Women in this study expressed how they felt more supported by Black providers and noted a difference in the level of care they received. Women specifically stated their preference to be seen by race concordant providers, such as Black doctors and midwives, to improve satisfaction and quality of care as well as access to community-based models of care such as doulas to improve respectful maternity care experiences as "they felt heard and supported." The U.S. has failed to adequately increase the number of Black physicians since the release of the Flexner Report of 1910, which asserted that Black medical schools had inferior facilities, access to limited funding, and were "in no position to make any contribution of value." As a result of this report, 10 medical schools that were

.training Black physicians were shut down except for two (Morehouse School of Medicine, 2021). Due to barriers that make it harder for Black people to become physicians, such as the Medical College Admission Test (MCAT), which has not been shown to significantly predict a student's success, establishing a pipeline to improve training and educational opportunities for Black students to be prepared for medical school, and alleviating the burden placed on the four historic Black medical schools to diversify the medical workforce (having graduated more Black physicians over the last 10 years than the top 10 predominantly white medical schools combined). Increasing the number of Black doctors continues to be a challenge (Morehouse School of Medicine, 2021). Consequently, it is critical that efforts to diversify the healthcare workforce be further supported to improve access to Black doctors, as well as other providers and support workers, including midwives and doulas, to improve respectful maternity care for Black women.

Midwives

Midwives are trained professionals with expertise and skills in supporting women during pregnancy, labor, birth, and the postpartum period (American College of Nurse-Midwives, 2016). Certified midwives and certified nurse midwives provide reproductive healthcare and attend births in multiple settings, overseeing the spectrum of maternity care. Midwives have consistently shown positive outcomes for mothers and infants, particularly for those at greatest risk for poor health outcomes due to racial disparities. Midwife-led maternity care results in substantially higher rates of vaginal delivery and lower rates of C-sections, as well as significantly lower rates of preterm births and low-birthweight infants compared with other maternity models (Zephyrin, 2021). Midwives are ideally situated to lead the charge to mitigate

disrespect in maternity care as midwifery professional guidelines demand a high level of quality care for all patients through a relationship-centered approach (Combellick, et.al., 2023; Niles & Zephyrin, 2023). Several studies that assessed models of care and birth settings that influence experiences of respect, autonomy, and decision making, consistently demonstrated a positive association between midwifery care and higher reported respectful care and patient satisfaction (Niles, et.al., 2023; Niles & Zephyrin, 2023; Combellick, et.al., 2023; Vedam, et.al., 2019; Macpherson, et.al., 2016).

Program and policy initiatives are needed to develop specialized training, licensing, and certification guidelines to increase the midwifery workforce, including expanding scope of practice for midwives and increasing reimbursement and coverage for these services. A midwife's scope of practice depends on their certification and licensure credentials, which vary by state (Atkeson & Hasan, 2022). The most common types of midwives include certified nurse-midwives (CNMs), for which licensure requirements include an active registered nurse license, master's or higher degree in nursing, and certification as a CNM from the American Midwifery Certification Board (AMCB) (Atkeson & Hasan, 2022). In recent years, states are increasingly establishing licensure for midwives without a nursing degree, such as certified midwives (CMs), and certified professional midwives (CPMs), to expand the maternal health workforce and improve maternal health outcomes. For example, in 2021, Illinois passed HB 3401, the Licensed Certified Professional Midwife Practice Act, which allows for the certification and licensure of CPMs and the provision to perform out-of-hospital births. This law also formed an Illinois Midwifery Board, which has the authority to recommend revisions to the Practice Act. Regarding Medicaid reimbursement (Atkeson & Hasan, 2022). All states reimburse for services provided by CNMs, and, as of April 2022, 18 states, including Minnesota and Washington,

reimburse both CNMs and licensed midwives (CPMs and CMs) without a nursing degree (Atkeson & Hasan, 2022). In Florida, licensed midwives credentialed as CPMs are reimbursed for Medicaid-covered services such as the care of low-risk pregnant people, including antepartum, delivery, and the postpartum period, and are also reimbursed for Healthy Start prenatal risk screening (i.e., SUD and mental health screening) (Atkeson & Hasan, 2022). As less than 10% of the midwife workforce is Black, having targeted efforts to recruit and train Black midwives can serve as an additional strategy to help diversify the birthing workforce and improve racial concordance in maternity care settings.

Doulas

Research also suggests that doulas are associated with more respectful care, particularly for low-income and Black women, and can help address the lack of racial and socioeconomic diversity in the current birthing workforce by improving racial concordance. Particularly, community-based doulas are trusted individuals, often from local communities, who are trained to provide non-clinical psychosocial, emotional, physical, and educational support for women before, during and after labor and birth, and during the postpartum period. Doulas are well positioned to address upstream factors (i.e., assisting with access to care, food, transportation, and housing options) and by fostering positive relationships and trust, improve patient-provider communication, and ensure continuity of care by linking and referring women to other services (Attanasio et.al., 2021). Research found that women with continuous support during labor were more likely to have spontaneous vaginal births, lower rates of maternal and infant health complications, fewer obstetric interventions, and lower rates of cesarean sections, which are associated with higher rates of maternal mortality (The Center for American Progress, 2020).

Black women who used a birth doula in this dissertation study expressed "feeling completely cared for" and seen as a "whole person" by a professional that understood their needs and were intentional in explaining, educating, supporting, and advocating for the best care for them. Doulas can provide information on the importance of prenatal and preventative care and early interventions to empower women to take control of their health. This highlights the need for policies to support the expansion of coverage (particularly through Medicaid to ensure low-income women have access), educational programs, certification, and job training of doulas to improve maternity care experiences and outcomes (Mallick et al., 2022). As Medicaid coverage of doula services has increased, states have formed doula commissions to inform the creation of doula training, certification, and Medicaid billing structures (National Academy for State Health Policy, 2022). For example, to increase the number of community-trained doulas and support Medicaid reimbursement, New Jersey contracted with HealthConnect One, an organization dedicated to advancing birth equity, to establish a doula learning collaborative. As of July 2021, there were 79 doulas trained and certified through the New Jersey Department of Health (National Academy for State Health Policy, 2022). Additionally, states can also establish credentialing processes for doulas to become Medicaid-eligible providers and receive insurance reimbursement for their services. Virginia created two pathways to become a state-certified doula for doulas fully trained or who have received some training and established criteria and an application process to approve doula training entities to train individuals to become state-certified doulas. Lastly, Oregon was the first state to offer a statewide Medicaid benefit for doula services in 2012 offering a reimbursement rate of $350 per pregnancy. Recognizing the importance of birth doulas as traditional health workers that can lead to improved maternal health outcomes, Oregon amended their Medicaid State Plan in 2022, increasing the fee-for-

service reimbursement to $1,500 per pregnancy, covering two prenatal care visits, care during delivery, and two required postpartum home visits at a minimum (National Academy for State Health Policy. (2022).

Although this research study did not focus on the post-partum period, there are important implications for post birth complications and even death resulting from severe maternal complications and MNM. The impacts of disrespectful care can result in long-term consequences for Black women. Minkoff et al., (2023), highlighted that at least half of maternal deaths occur in the postpartum period. This illustrates the challenges and health risks that can occur after a woman is discharged from the hospital. Women highlighted the need to have support in the postpartum period as another strategy to improve health outcomes as they continue to contend with physical complications long after birth, and needing resources or a provider to connect with to discuss their concerns. As women experience long term physical and mental health complications, doulas that provide post-partum care can provide additional community-based support and linkages to care for Black women after pregnancy. Healthcare delivery models that provide culturally sensitive healthcare after pregnancy are more successful at producing improved maternal health outcomes for Black women (Karbeah et al., 2022, Tucker et al., 2015). This presents additional opportunities to improve provider communication and continuity of care as well as to address emotional trauma when severe obstetric complications occur (Wang et al., 2021).

Strengths

This study adds to the growing body of literature that examines Black women's experiences with disrespect in maternity healthcare settings. This study also operationalizes

disrespect as there is currently no unified definition of disrespect in maternal healthcare settings. Additionally, this study's conteptual model depicts how the complex interplay of factors intersect to influence Black women's experiences in maternal healthcare settings and how they lead to disrespectful encounters with providers. Further, the qualitative approach allows for a rich, contextualized, and nuanced understanding of Black women's experiences of disrespect, that supports the larger number of quantitative studies that have explored this topic. The analysis provides an in-depth understanding of the personal narratives of Black women to provide a more complete picture of how women perceive disrespect through their own voices and experiences, and helps to identify subtle forms of disrespect that may not be easily captured through quantitative measures. For example, the study substantiates how the impact of bias and discrimination shape Black women's experiences with disrespect and poor maternal health outcomes, despite their social status, level of education, or insurance type. This intersectional analysis provides a more comprehensive understanding of how various aspects of identity converge to shape Black women's healthcare experiences. These nuanced insights are essential for understanding the full spectrum of disrespect experienced by Black women in maternity healthcare settings. Finally, it provides real-world context that makes the data more relatable and actionable for policymakers and healthcare providers. These contributions are essential for informing policy, practice, interventions, and future research aimed at improving the quality of care for Black women and providing culturally responsive policy and programmatic solutions.

Limitations

As with other studies, there were important limitations that need to be acknowledged.

While this study provides valuable insights into how Black women perceive and experience disrespect, there are inherent limitations associated with the use of self-reported data. Firstly, there is the potential for bias and subjectivity as women may consciously or unconsciously provide socially desirable answers, or responses based on what the participant thinks is the right answer, rather than their true thoughts, feelings, and behaviors, leading to an overestimation or underestimation of a response. Secondly, recall bias can occur leading women to potentially forget details or misremember events, leading to inaccuracies in the data. Thirdly, women may misinterpret interview questions, which could be due to the wording or development of interview questions, which can lead to incorrect or inconsistent responses. Lastly, women may not be completely honest with their responses which could be influenced by concerns about privacy and confidentiality. Despite assuring women that their responses are anonymous and confidential, they may give false information, especially if questions are sensitive or personal in nature (Kormos & Gifford, 2014; McDonald, 2008). To mitigate participant bias, the researcher used triangulation by gathering data from multiple sources, such as conducting an extensive literature review, comparing coding and themes from the original study, as well as my thematic analysis approach (reading over transcripts multiple times, and revising themes (helped to mitigate this and provided a more balanced and comprehensive understanding of their experiences.

The use of a single rater/coder can potentially introduce bias and subjectivity into the research process, affecting consistency and objectivity of the coding process and results. Relying on one rater/coder can limit the diversity of perspectives and interpretations which multiple coders can bring to enrich the data analysis. Additionally, the use of a single rater/coder precludes the ability to assess inter-rater reliability, which is a measure often used in coding to improve consistency and reliability in qualitative research. Also, human error without the checks

and balances of multiple coders, has the potential to produce coding errors, analytical oversights, or ethical dilemmas. Lastly, the inherent subjectivity of a single rater/coder can reduce transparency and reproducibility of the analysis by other researchers (Cofie et.al., 2022 & O'Connor & Joffe, 2020). To ensure the consistency, reliability, and validity of the coding process the researcher maintained a decision log, documenting all steps in the analysis such as decisions made and rationale used in the process of theme development, and revisited the coded data multiple times to check for consistency in theme iterations, and confirming that the themes accurately reflected the content and context of the data. Additionally, throughout the coding, theme development, and analysis; the researcher maintained reflexivity, with attention to the researcher's own biases, assumptions, and perspectives that may influence interpretations of the data.

By exclusively focusing on Black women's experiences of disrespect in maternity healthcare settings, this study fails to highlight and compare the experiences of White women and other women of color. A comparative analysis could provide valuable insights and a more nuanced understanding of the similarities and unique challenges faced by Black women, White women, and other women of color and how they experience disrespect and/or discrimination in maternity healthcare. As a result, the findings are not able to draw conclusions about the extent and variation of disrespect and discrimination across different racial groups. Future research could include comparative analyses by incorporating women from various racial and ethnic backgrounds. This would enable researchers to identify specific challenges faced by Black women in contrast to other groups and to understand the broader patterns of disrespect in maternity healthcare settings.

There were also limitations due to the sample of Black women as they tended to be highly educated, with higher incomes. This presents potential limitations with generalizability, homogenity, diverse perspectives, social desirability, issue prioritization, and an overrepresentation of certain perspectives. Due to a greater chance of homogeneity, in terms of having predominately highly educated Black women, presented specific limitations. For example, this sample may exhibit similar attitudes, behaviors, and experiences, which could reduce the variability and range of perspectives from a spectrum of Black women, therefore threatening the generalizability of the results. Also this group may interpret or articulate their experiences or prioritize issues in a way that differs from less well educated or lower income women. For instance, higher educated women may be more familiar with this topic from watching the news or having an existing understanding of the data which could sway the way they discuss the topic. This could also be influenced by social desirability and understanding of social norms, resulting in being more versed and educated on the topic, and providing socially acceptable responses versus their true feelings or experiences. Future research could focus on designing a more robust recruitment strategy to ensure there is representation of women that span the income and education spectrums to provide a more diverse range of perspectives on this topic.

Qualitative methods have been criticized for their lack of generalizability, or the extent that the results or findings can hold true outside of the context in which they were researched (Bloor, M., & Wood, F. (2006). This study used a data set with a select sample of Black women who experienced MNM and therefore has limits to its generalizability, however the richness of the qualitative data, nonetheless, helps to inform and contextualize the perspectives of Black women. These findings are also consistent with other research describing the historical and

contemporary experiences of Black women in the healthcare system (Bloor, M., & Wood, F. (2006). Future studies could employ mixed-methods approaches, combining qualitative insights with quantitative data from larger, more diverse samples. This can help to further validate qualitative findings and provide a more comprehensive understanding of disrespect in maternity healthcare settings and its implications. Lastly, as roughly 25% of participants reported a exclusively positive healthcare experience, future qualitative studies can assess why some Black women reported no experience with disrespect to understand their perception of disrespect and how these practices can be adopted more widely, and to develop strategies that could inform policies and interventions to improve respectful care.

Conclusion

In conclusion, this dissertation study contributes valuable insights into how Black women who experienced a MNM perceive and experience disrespect in maternity healthcare settings. This dissertation study also highlights both the negative experiences of disrespect and the positive instances of respectful care in maternal healthcare settings for Black women. Through a qualitative lens, the voices of these women illustrate the multifaceted and intersectional challenges they face in maternity healthcare settings. The narratives shared by Black women highlight a consistent pattern of disrespect that compromises their health and overall well-being. The themes of feeling unseen, encountering racial bias and discrimination, experiencing a lack of compassion and privacy, feeling unheard due to an inability to self-advocate, and suffering from poor outcomes due to not being listened to, paint a vivid picture of a break down in patient-provider encounters and engagement and the systemic inequities that impact respectful care.

Additionally, the lack of communication and shared decision-making further exacerbates these challenges, leaving Black women feeling disempowered to make choices about their care. These experiences are not isolated incidents but indicative of broader structural and systemic issues within maternal healthcare systems. Lastly, the stark reality that bias and discrimination due to assumptions and stereotypes about Black women impact pregnancy and delivery experience throughout their entire maternity care journey, demands reform of policies to address racism and underlying systemic issues.

By amplifying the voices and perspectives of Black women, this study aims to advocate for systemic and policy changes to foster a healthcare environment that provides equitable, respectful, and compassionate care for all women. In healthcare practice, there is an urgent need for policy, practice, and system-level reforms to improve respectful care through the development of accountability measures, feedback mechanisms, and protocols and guidelines. Also, expanding and diversifying the maternal healthcare workforce may be a critical lever to improving the quality of care for Black women, and potentially reducing disrespectful and discriminatory maternity care practices, while ultimately improving maternal health outcomes. As Black women continue to experience repeat exposure to bias and discrimination in maternity care settings utilizing a trauma-informed care approach is critical to addressing adverse health outcomes and their long term consequences. Future research should continue to explore disparities in maternity care practices and associated adverse outcomes to gain a comprehensive understanding of the impact of disrespectful care.

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Appendix A

Included_Excluded Interview Questions

Table A. List of Questions from the MNM Interview Guide and selected questions for analysis.

Included Questions	Excluded Questions
1. When you think about the care you received throughout your pregnancy, can you tell me about one positive/one negative experience you remember? (Related to research question(s) as it highlights/references the provider-patient encounter during pregnancy and birth and experiences associated with the interaction).	1. What is the most rewarding thing about being a mother? (Not directly related to research question(s)).
2. Can you tell me a time(s) during your pregnancy and/or birth experience where you felt discriminated against in a professional healthcare setting? (Doctor appointments, hospital visits/stays, during birth, etc.). (Related to research question(s) as it highlights/references the provider-patient encounter during pregnancy and birth and experiences associated with the interaction).	2. Tell me about yourself and your community? (Not directly related to research question(s)).
3. Tell me about your birth experience? Tell me the story all the way from the beginning to end, describing the setting, who was involved, etc. (Related to research question(s) as it highlights/references the provider-patient encounter during pregnancy and birth and experiences associated with the interaction). **Probing Questions:** 1. Describe complications that arose while pregnant. 2. When did you suspect something was not going right with your pregnancy. 3. How was the process in seeking immediate help. 4. Process of getting to the medical services needed. 5. Differences or similarities that existed between when sought care and what you expected to happen. 6. How was the process when arrived at hospital and how was complication resolved?	3. What did you like or not like about being pregnant? (Not directly related to research question(s) as it was a personal expression of the pregnancy).

4. Do you think being a woman of color affected your medical experience giving birth, if so, how? (Related to research question(s) as it highlights/references the provider-patient encounter during pregnancy and birth and experiences associated with the interaction).	4. How do you manage the long-term effects of your experience? (Not directly related to research question(s) as it focuses on the post-partum period beyond pregnancy and birth and individual elf-care).
5. What would you like doctors, nurses, payors, and others to know? (Related to research question(s) as women recounted what they needed in the pregnancy/birthing encounter(s) with providers).	5. Why did you choose to participate in this study? (Focused more on personal experience of participating in study, not directly related to research question(s)).
6. What do you wish you had known then that you know now? (i.e., gave insight into women's perspectives/experiences and highlighting the importance of advocating for self, having support persons in the room, researching pregnancy/birth on their own, seeking support from other healthcare providers such as doulas/midwives).	
7. How does your pregnancy and near-miss experience affect your life today? (Looked at the long-term implications of MNM and long-term consequences experienced by women although they survived the MNM and informs trauma related care that is needed and how it could potentially impact the perception of subsequent encounters with providers).	

Appendix B

Final Code Book_A Priori_In Vivo Codes

How Black Women Perceive Disrespect in Maternity Healthcare Settings

Qualitative Secondary Analysis Codebook

Definition of Disrespect: The experience of racial bias and discrimination through a provider's behaviors, language, or actions that results in Black women feeling unseen, unheard, and not communicated with in maternity healthcare settings.

Concepts/Components	A Priori Codes & Definitions
Medical Racism: Refers to historical/contemporary systemic discrimination and bias that Black Women face in healthcare settings.	
	• **Historical/Contemporary: Medical experimentation/Forced/Unconsented procedures; Lack of patient autonomy/agency over body in reproductive rights:** description/examples of Black women experiencing forced and unconsented medical experiments and ongoing issues of women undergoing unwanted medical procedures or unnecessary medical interventions i.e., c-section. (Prather, et.al., 2018; Thorpe, J.R., 2017; Silverstein, J., 2019). • **Historical/Contemporary: Myths about physiological differences pertaining to pain levels/Dismissal of pain:** description/examples of historical (physiological differences between Whites/Blacks) and ongoing issue of healthcare providers dismissing or underestimating the pain/symptoms reported by Black women. (Macgregor et al., 2023; Knoebel et al., 2021; Morales & Yong, 2021; Mende-Siedlecki et al., 2019;

	Hoffman et al., 2016; Hollingshead et al., 2016). • **Historical/Contemporary: Public, Nude Physical Auction Examinations to Determine Reproductive Ability:** Hyper sexualization/media portrayals/slavery/exposed (Silverstein, J., 2019; Prather, et al., 2018; Thorpe, J.R., 2017). • **Historical/Contemporary: Provider bias/discrimination:** description/examples of providers providing care based on deeply entrenched biases, and historical and contemporary racism against Black women. (Rosenthal and Lobel, 2020; Prather, et al., 2018).
Discrimination: Refers to a situation when someone is treated differently or unfairly based on their personal characteristics. (i.e., gender, social status, class)	
	• **Racial Discrimination:** description/examples of unfair or unequal treatment of individuals based on their race (Rosenthal and Lobel, 2020; Prather, et al., 2018; Nong et al., 2020). • **Preconceived Ideas of Black Women (Stereotyping):** description/examples of instances where healthcare providers make assumptions or judgments based on racial stereotypes about Black women (Mehra et al., 2020). • **Intersectionality:** description/examples of how Black women discuss how factors such as race, gender, socioeconomic status, and education level intersect to influence their experiences of disrespect in maternity care (Brantley, 2023; Collins, 2022; Okoro et al., 2022). • **Internalized Racism:** Conscious and unconscious acceptance of a racial hierarchy in which Whites are consistently ranked above people of color (belief in negative stereotypes about their race/gender, etc., i.e., “strong Black woman”, adaption of White cultural

	standards, etc. (Thompson et al., 2022; David, et. al., 2019). • **Insurance-Based Discrimination:** description/examples of being judged/or treated in an unfair manner based on insurance type i.e., private vs. public insurance (Mohamoud et, al., 2023; Brown et al., 2021).
Components of Non-Respectful Care	
Verbal or Physical Abuse	• **Disrespectful language:** description/examples of healthcare providers speaking to Black women in a condescending or dismissive manner i.e., rude, harsh, aggressive language (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018).
Informed Consent	• **Lack of informed consent:** description/examples of instances where Black women have been subjected to medical procedures without their full understanding of a procedure or consent i.e., options presented, or discussion of risks (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018).
Privacy & Dignity	• **Violations of privacy and dignity:** description/examples where Black women experience violations of their privacy or dignity during childbirth, i.e., unnecessary exposure, lack of privacy, or multiple or unknown providers present during care (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018; Prather, et.al., 2018).
Communication & Shared decision-making	• **Patient-provider shared decision-making:** description/examples of how Black women's perception of their role and agency in a shared decision-making process regarding their care (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018). • **Information sharing:** description/examples of Black women highlighting communication challenges with healthcare providers and provision of information shared to facilitate informed choices (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018).

	• **Power dynamics:** description/examples of how power differentials impact communication between healthcare providers and Black women. (Paternalistic/race dynamics/provider education) (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018; Nimmon & Stenfors-Hayes, 2016).
Autonomy & Advocacy	• **Loss of patient autonomy:** description/examples of how Black women aren't given agency or autonomy to make choices in their care i.e., birth plans, etc (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018; Prather, et.al., 2018; Thorpe, J.R., 2017; Silverstein, J., 2019). • **Loss of self-advocacy:** description/examples of how Black women face challenges in asserting their preferences, asking questions, or challenging medical decisions made by healthcare providers (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018; Prather, et.al., 2018; Thorpe, J.R., 2017; Silverstein, J., 2019).
Safety	• **Unsafe care environment:** description/examples that highlight an unsafe healthcare environment (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018).
Support	• **Lack of support:** description/examples of Black women expressing a lack of support from healthcare providers (Cantor et.al., 2024; CDC, Vital Signs, 2023; Morton et. al., 2018).
Perceptions of Care: Refers to how a woman perceives their care, negatively or positively, during their pregnancy and birthing experience; negative perceptions of care only/encounters with providers	**In-Vivo Codes: Using women's actual words; supported by the literature.**
	• **Not feeling heard (listened to):** description/examples of Black women not feeling heard or listened to when voicing concerns, perspectives, or opinions on what they would like to happen with their bodies (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022).

	• **Not feeling seen or treated a certain way based on race:** description/examples of Black women not feeling seen or treated a way based on the color of their skin (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Stereotyped/assumptions made for being a Black woman:** description/examples of Black women feeling like assumptions are made about them because they are Black (Mehra et al., 2020). • **Lack of compassion:** description/example of a Black woman not feeling that a healthcare provider has a feeling of concern, sympathy, or empathy for them (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Lack of attentiveness:** description/example of a Black woman feeling that a healthcare provider is not being attentive (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Feeling rushed:** description/example of a Black woman feeling like they are being rushed by healthcare staff in a clinical encounter (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Feeling pushed to make a medical decision:** description/example of a Black woman feeling like they are being forced to make a decision with limited information or context, c-section, hysterectomy, loss of control over birth plan (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022 Prather, et.al., 2018; Thorpe, J.R., 2017; Silverstein, J., 2019). • **Poor bedside manner:** description/example of a Black woman feeling like a healthcare provider has poor interpersonal or soft skills (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Lack of cultural competence/humility:** description/example of a Black woman feeling like a healthcare provider lack understanding of the unique needs and perspectives of black women, not providing

	culturally appropriate information, or advocating for equitable healthcare (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022). • **Discriminated based on Insurance:** description/examples of Black women not feeling heard or listened to and/or receiving subpar care based on the type of insurance they had/or perceived to have (Medicaid vs. Private Insurance) (Mohamoud et, al., 2023; Brown et al., 2021). • **Perceptions of disparities in care:** description/examples of how Black women perceive their level of care i.e., neglectful care, delay in diagnosis, handled carelessly, inadequate treatment, lack of follow-up care (Washington & Randall, 2023; Okoro et al., 2022, Peahl, et.al., 2022; Nong et al., 2020; Rosenthal and Lobel, 2020; Prather, et al., 2018).

Appendix C

Decision Log

Research Project: "How Black Women Perceive Disrespect in Maternity Healthcare Settings"
Date: June 24, 2024
Researcher(s): Sherry Maxy, MS, MPH
Decision Log: This decision log provides a systematic record of the analytical decisions made throughout the research process, including the rationale behind each decision. It serves as a reference for ensuring transparency, accountability, and rigor in the data analysis process.

1. Decision: Decided not to use software for qualitative data analysis.

Rationale: Chose to manually code data as sample size was small.

2. Decision: Familiarization with data.

Rationale: Researcher thoroughly read and re-read interview transcripts and viewed recorded videos to become intimately familiar with the data which helped to understand context before developing a priori codes. The researcher used a excel spreadsheet for memoing, jotting down reflections and impressions of the data.

3. Decision: Development of initial codebook. (A Priori Codes)

Rationale: This qualitative secondary analysis used a deductive approach, formulating a priori codes based on existing knowledge in the literature and research questions of how Black women perceive and experience disrespect in maternity healthcare settings. In developing the codebook, the researcher explored the phenomenon of disrespect through a review of existing literature to operationalize disrespect or what factors contribute to non-respectful care. For example, BFT draws on past social inequalities and systemic oppression such as discrimination within the healthcare system, implicit bias among providers, and historical injustices, and how that may influence how Black women perceived disrespect when interacting with healthcare providers. Further, examining research that has highlighted components of respectful and non-respectful care were developed into a priori codes. Lastly, codes that include various dimensions of disrespect were developed based on existing literature and conceptual frameworks that illustrate a Black woman's perception of care through patient-provider encounters.

4. Decision: Inclusion criteria and Data selection for analysis.

Rationale: Applied inclusion criteria to select qualitative data from women who identified as Black or African American, and who provided relevant responses to interview questions that discussed their pregnancy and birthing experiences and perceived disrespect in maternity healthcare settings. Interview questions were identified to ensure that the data answered the research question/s and to analyze responses that characterized disrespect as it was not explicitly asked in the initial study. The analysis focused on seven of the original 12 interview questions

and six probing questions from the initial study that highlighted women's overall pregnancy and birthing experiences (See Appendix A).

To be included in the qualitative analysis, interview recordings and transcriptions of the recorded interviews were carefully reviewed, and the researcher systematically applied the inclusion criteria. The responses must include one of four inclusion criteria: report a less than favorable or biased interaction/encounter with a healthcare provider, response must include a negative perception of care, interaction/encounter must occur during pregnancy and or delivery, and responses that notably use the term disrespect to describe their healthcare encounter. Responses will be excluded if participant meets one of three criteria: exclusively reported positive interactions/encounters with healthcare providers, exclusively presented a positive perception of care, or if encounter occurred entirely in the postpartum period.

The data was analyzed specifically to understand patient-provider encounters and what factors led to a perceived disrespectful experience. This helped to contextualize Black women's experiences and interactions and gain an understanding of how these factors impacted the overall relationship, perceived care received, and outcomes. This also allowed for the exploration of various dimensions of disrespect and how it has manifested historically and how it is reflected in the voices and narratives of Black women currently.

5. Decision: Allocation of data segments to a priori codes.

Rationale: Assigned a priori codes to identified segments of data that were relevant to the research questions. To maintain consistency, the researcher checked codes/coded data against other excerpts that were similar in nature to ensure that codes were consistently applied.

6. Decision: Addition of In Vivo Codes (Emerging Codes).

Rationale: The researcher included in vivo codes to the codebook as codes/themes emerged. This was done to capture the voices and experiences of women who participated in this study to help contextualize their narratives with perceived disrespectful encounters and experiences with healthcare providers that resulted in them experiencing poor outcomes from their perspectives.

7. Decision: Creation of Preliminary Themes.

Rationale: The codes were grouped into potential themes. The researcher developed overarching themes based on patterns and similarities identified in coded data, and created themes based on the meanings that the women assigned to the data.

In this phase, the researcher began to look for themes and patterns in the data based on the identified codes in the data. The initial themes captured something significant or interesting about the data and how it related to the research question/s. As the researcher looked for themes, there was a considerable amount of overlap between assigned codes across the initial four themes that emerged. Themes across the data highlighted a loss of control, power, basic human rights,

and lack of quality care as a result of bias and discrimination and not feeling heard or ignored when Black women had encounters and experiences with providers in maternity care settings.

The codes were examined and put into themes that appeared relevant to the concept, despite appearing in several themes. For example, perceptions of care resulted in women feeling unheard, dismissed, feeling pushed to make a medical decision, etc., which appeared to be related to a woman having a loss of control or agency in her care, or lacking power in the patient-provider dynamic, and women stating this as neglectful care. Additionally, there was overlap of non-respectful care based on how Black women described their experiences.

The themes identified were predominately descriptive, i.e., they described patterns in the data relevant to the research question. Table 1. shows all the preliminary themes that are identified from the transcripts, along with the codes that are associated with them. Most codes are associated with more than one theme and are highlighted in Table 1.

8. Decision: Creation of Categories for Refinement of Themes.

Rationale: Due to the overlap in the initial coding of transcript data, to further delineate concepts, the researcher created categories to better manage the categorization of data before further refining themes. This helped to grouped frequently expressed sentiments (coded data) and identify patterns and similarities between the coded data which related to communication and decision making, racial bias, advocating for self and having support from others such as family and doulas, perceptions of care received, feeling a lack of compassion, and not feeling seen or valued by medical professionals.

During this next phase the researcher reviewed the themes to ensure they accurately captured the data and made decisions to either merge or discard themes to ensure themes were comprehensive. The preliminary themes identified in the previous phase were vetted by asking "Do they make sense?" As there was considerable overlap of the codes, it was necessary to gather all the data that was relevant to each theme and create broad categories to define what each concept/theme meant or was trying to convey. Other considerations made: Am I trying to fit too much into a theme? If themes overlap, are they really separate themes? Are there themes within themes (subthemes)? Are there other themes within the data? This helped to assign clear and descriptive themes attached to the coded data.

In Table 2. Five broad categories/themes were identified: racial discrimination/bias, patient-provider communication, dehumanization/devaluation, loss of advocacy, and expectations of expected care vs. care received. The researcher re-read the data several times to determine if it was associated with each theme and considered whether the data really did support it. The data associated with each theme is noted as "example." Also, in this phase, sub-themes began to emerge.

For example, the researcher felt that Black women weren't necessary concerned with "control or power struggles" with providers, it was more so the necessity to advocate for one's care and have shared decision-making and collaboration with providers in making decisions about their care.

This led to the development of the Loss of Self-Advocacy and Patient-Provider Communication theme/s, as the researcher didn't feel that the preliminary theme, Loss of Agency and Lacking Voice and Power in Patient-Provider Relationship worked as themes. Some of the codes included here (Forced/unconsented procedures, Feeling pushed to make a medical decision, Lack of informed consent) seem to relate to a separate issue of women wanting to be involved in decisions made. Therefore, the researcher didn't feel it was about power and a new theme Patient-Provider Communication was created with three subthemes: Not feeling heard or listened to, Lack of collaboration/partnership with provider in decision-making, and Lack of education/ information about care options.

Also, the loss of agency (control) seemed to be more related to a loss of control over a woman's birth plan, not control in the relationship with providers. The Loss of Self-Advocacy was more about a woman having or not having the space to advocate for their needs and what was best for them. The code lack of support was noted as what women needed in terms of advocacy as well as what was lacking from providers, however, the data spoke more to women having support from family, friends, and providers such as doulas, was more important for a woman receiving respectful care vs. from the healthcare provider. This led to the development of the Dehumanization/devaluation theme which highlighted "a lack of compassion" and "lack of privacy/dignity" subthemes as this appears to be what was missing from providers more so than women needing their support per se.

Further, the theme "Racism and Lack of Basic Human Rights Impact Care and Treatment" was retitled to "Racial Bias and Discrimination Impacts how a Black Women is Seen" as the data appeared to be more related to how a Black woman is seen and treated based on initial assumptions and stereotypes before care is ever delivered. The codes of not feeling heard and feeling dismissed continued to reoccur across three themes, "Racial bias and discrimination", "Patient-provider communication" and "Expectations of care and actual care received." The code of not feeling heard was so prominent and an undercurrent in every transcript, that the researcher further explored what this meant to women by rereading all coded data and it was eventually defined in the final theme in Table 3.

Lastly, many of the codes related to perceptions of care were shifted from previous themes as they were more in line with the theme "Expectations of care and actual care received" and women noting that it was more related to poor outcomes vs the relationship with providers and that poor care resulted in neglectful and delayed care, and ultimately poor outcomes.

9. Decision: Iterative Refinement of Final Themes.

Rationale: In this final phase of theme development, as there was still an overlap in codes and themes, the researcher finalized themes by identifying the underlying concept/s that linked the themes. For example, ultimately Black women perceived they received disrespectful maternity care when they were not seen, heard, or communicated with by providers. Therefore, several themes and subthemes were collapsed into these three overarching themes and six sub-themes.

Lack of compassion was listed under the category of dehumanization & devaluation as well as perceived quality of care. Lack of compassion under dehumanization & devaluation alluded more to showing joy for new baby and celebrating Black women's pregnancy or empathizing with mothers' trauma of the loss of their baby, whereas compassion in quality of care looked more at not making compassionate or responsive choice to ensure more favorable outcomes. The theme Dehumanization and Devaluation was eliminated as the data relayed the lack of compassion, empathy, and insensitivity of providers made Black women not feel seen or valued as a woman and was collapsed under the overarching theme of "Not feeling seen" as a sub-theme.

The overarching theme of "Not feeling seen: When I am disregarded and not cared for as a unique individual" noted how Black woman felt that providers level of care was jaded by bias and discrimination and often resulted in women not feeling seen as a unique individual with unique needs as assumptions are often made upon meeting them without getting to know them. The theme also includes two additional subthemes "When my privacy is not valued" as woman didn't feel seen as valuable when their body and space are not dignified and respected, and "When my care is based on the insurance I have" as women reported judgements made about them based on the type of insurance, they caried and receiving substandard care as provider often didn't explore treatment options. And lastly, as noted above, the third sub-theme is "When I am shown a lack of compassion" as women expressed providers showing a lack of empathy, specifically in terms of not validating their pregnancies, neglecting their emotional needs (whole person approach) as well as showing no compassion for the trauma experienced with either losing a child, or experiencing a near death experience.

The re-occurring code/theme of not feeling heard, not listened to, or feeling dismissed was eventually coded as the Theme "Not feeling heard: When I experience poor outcomes due to not being listened to" as the data showed because of not feeling heard often resulted in women feeling that they received neglectful care, delay in diagnosis, handled carelessly, inadequate treatment, and lack of follow-up care which resulted in women experiencing poor outcomes or severe maternal complications which resulted in them experiencing a maternal near miss. Women being dismissed for concerns related to pain and other issues, tended to be ignored or not listened to base on the covert or overt assumption that Black women had a higher pain tolerance. Further, the theme, Loss of Self-Advocacy was included as a subtheme under "Not Feeling Heard" and was retitled "When I (or a loved one) try to advocate for my care" as women often spoke up and advocated for themselves, along with family members advocating for them, however, indicating it was often met with opposition, as providers either challenged or ignored their concerns. In this phase, the researcher collapsed "internalized racism" under this sub-theme and removed it from the racial bias theme, as this had the propensity to impact a woman's ability to advocate for themselves or not, out of fear of embodying assumptions about Black women and being labeled or judged based on stereotypes.

Lastly, the third theme emerged "Not feeling communicated with: When I'm not given the opportunity to engage with my provider to make decisions" as women expressed a lack of dialogue/ discussion with their providers about medical decisions whether it was having birth plans honored, or forced c-sections, and receiving delayed communication. Women felt a bias

from providers noting that they perceive that their providers perceived them as being less educated or not smart enough to have intelligent conversations with to understand medical conditions and terms. This theme includes two subthemes “When there is a lack of transparency in information shared” and “When there is a lack of education provided” which both are more related to women not being provided transparent information and rationale given for medical interventions and lack of education around their symptoms or medical conditions as providers often didn’t speak in plain language/or oversimplified information, which led to women feeling disrespected for not being included in their healthcare and receiving biased care based on provider assumption that they were uneducated and didn’t understand medical terminology.

Interestingly, the one code that undergirds all three themes and six subthemes is “Biased and discriminatory care based on preconceived ideas of Black women/stereotypes.” In every aspect of a Black woman not feeling seen, heard, or communicated with is based on assumptions made about them regarding their skin color, socioeconomic status, educational levels, insurance coverage, pain tolerance, compliance, marital status, and being labeled as angry or difficult, which ultimately impacted their experiences with healthcare providers in maternity care settings and led to perceived disrespectful encounters and poor outcomes.

10. Decision: Review and Validation of themes.

Rationale: As a single coder, the researcher used a technique called triangulation to validate the themes. For example, multiple data sources from the literature were used (BFT, IOM, Medical Racism, Discrimination, Components of Respectful Care, and In Vivo or emerging codes examining women’s words from the study, were cross-checked to ensure consistency in findings and assignment of codes that addressed the research questions.

11. Decision: Use of Marker Quotes.

Rationale: Selected exemplary quotes to illustrate and support each thematic code, providing concrete examples of women’s experiences with disrespect in maternity healthcare settings.

12. Decision: Finalization of Analysis.

Rationale: Reviewed and synthesized the findings to develop a coherent narrative that accurately represents the experiences of Black women with perceived disrespect in maternity healthcare settings.

13. Decision: Documentation of Reflexivity Statement.

Rationale: Drafted and finalized a reflexivity statement to acknowledge and address the researcher's own biases, assumptions, and experiences in relation to the research topic.

Appendix D

Reflexivity Statement

As an African American woman researcher who has personally experienced systemic and interpersonal racism in multiple systems and institutions, I bring a unique perspective to this qualitative analysis. I consider myself an insider to this research as I identify at multiple connection points to the participants in this study. I have first-hand knowledge, accounts, and experiences of intersecting identities such as being Black, a woman, and varying social status identities, as well as personal connections with maternal mortality and morbidity having suffered from severe maternal complications/MNM and having a colleague and friend who died from pregnancy-related complications. My lived experiences serve as a benefit that provide insight and perspective as my life has shaped my worldview and influenced the way I approach research, particularly in terms of the compassion and empathy with which I engage with participants' stories. My own experiences navigating the healthcare system as a Black woman inform my understanding of the complexities and nuances involved in addressing the issue of disrespect. As an insider, I considered self-reflexivity throughout my data analysis and recognize the importance of acknowledging my own biases, assumptions, and emotions throughout the research process. Additionally, I am aware of the potential impact of my own experiences on the interpretation and analysis of the data. I am committed to maintaining reflexivity, remaining objective and impartial, throughout the research process by way of reflective memoing and engaging in multiple rounds of reviewing transcripts, as well applying codes, and developing themes. I approach this research with a deep sense of responsibility and commitment to amplifying the voices of Black women and recognize the importance of centering their experiences and perspectives in the analysis. Throughout the research process, I remain open to

engaging in critical reflection to enhance the rigor and validity of the analysis and strive to recommend solutions that contribute to respectful care practices for Black women in maternal healthcare settings.

Appendix E

Thematic Analysis Tables

Thematic Analysis: Black women's perceptions/experiences of disrespect in maternity care settings.

Table E1. Preliminary Themes

Theme: Lacking a Sense of Agency **Codes** **Medical Racism** *Forced/unconsented procedures. *Dismissal of pain **Perceptions of Care** *Feeling Dismissed Feeling pushed to make a medical decision. *Not feeling heard *Perceived quality of care **Non-Respectful Care** *Violations of privacy and dignity *Lack of patient-provider shared decision-making *Power dynamics/differentials *Loss of patient autonomy *Loss of patient self-advocacy *Lack of partnership/collaboration with provider	**Theme: Racism and Lack of Basic Human Rights Impact Care and Treatment** **Codes** **Medical Racism/ Discrimination** *Racial discrimination *Unfair/unequal care/treatment *Treatment based on preconceived ideas of Black women/stereotypes *Internalized racism *Intersectionality (care based on race, gender, socioeconomic status, and education level) *Insurance-based discrimination **Perceptions of Care** *Feeling Dismissed *Not feeling heard *Lack of compassion *Lack of attentiveness *Perceived quality of care *Poor bedside manner *Lack of cultural competence/humility *Perceptions of disparities in care (neglectful care, delay in diagnosis, handled	**Theme: Lacking voice and power in patient-provider relationship** **Codes** **Medical Racism** *Forced/unconsented procedures. **Perceptions of Care** *Feeling Dismissed *Not feeling heard *Feeling pushed to make a medical decision. **Non-Respectful Care** *Lack of informed consent *Lack of patient-provider shared decision-making *Lack of information sharing *Power dynamics/differentials *Loss of patient autonomy *Loss of patient self-advocacy *Lack of support *Lack of partnership/collaboration with provider *Lack of education-signs/symptoms of disorders/ providers not	**Theme: Neglectful care resulting in poor outcomes** **Codes** **Perceptions of care** *Feeling Dismissed *Not feeling heard *Lack of compassion *Lack of attentiveness *Feeling rushed *Perceptions of disparities in care (neglectful care, delay in diagnosis, handled carelessly, inadequate treatment, lack of follow-up care) *Lack of support *Feeling pushed to make a medical decision.

	carelessly, inadequate treatment, lack of follow-up care) **Non-Respectful Care** *Verbal abuse/disrespectful language	speaking in plain language	

Explanation: In this phase, the researcher began to look for themes and patterns in the data based on the identified codes in the data. The initial themes captured something significant or interesting about the data and how it related to the research question/s. As the researcher looked for themes, there was a considerable amount of overlap between assigned codes across the initial four themes that emerged. Themes across the data highlighted a loss of control, power, basic human rights, and lack of quality care as a result of bias and discrimination and not feeling heard or ignored when Black women had encounters and experiences with providers in maternity care settings.

The codes were examined and put into themes that appeared relevant to the concept, despite appearing in several themes. For example, perceptions of care resulted in women feeling unheard, dismissed, feeling pushed to make a medical decision, etc., which appeared to be related to a woman having a loss of control or agency in her care, or lacking power in the patient-provider dynamic, and women stating this as neglectful care. Additionally, there was overlap of non-respectful care based on how Black women described their experiences.

The themes identified were predominately descriptive, i.e., they described patterns in the data relevant to the research question. Table 1. shows all the preliminary themes that are identified from the transcripts, along with the codes that are associated with them. Most codes are associated with more than one theme and are highlighted in Table 1.

Table E2. Categorization of Themes

Theme: Racial Bias and Discrimination Impacts how a Black Women is Seen and Treated: **Sub-theme: Unfair/unequal treatment based on race/bias associated with preconceived ideas and stereotypes:** *Racial discrimination *Unfair/unequal care/treatment Example: "If I was a different race" *Feeling Dismissed *Not feeling heard *Lack of compassion *Internalized racism *Treatment based on preconceived ideas of Black women/stereotypes. *Perceived quality of care **Example:** uneducated, single mother, multiple baby fathers, aggressive, hostile, on the system, non-compliant *Verbal abuse/disrespectful language **Example:** spoken to in a condescending/dismissive manner/Rude/insensitive comments based on stereotypes: **Sub-theme: Intersectionality:** *Intersectionality (care based on race, gender, socioeconomic status, and education level)	**Themes: Patient-Provider Communication:** **Sub-theme: Not feeling heard or listened to:** *Feeling Dismissed *Not feeling heard *Dismissal of pain Example: medical complaints/dismissal of pain and concerns **Sub-theme: Lack of collaboration/partnership with provider in decision-making:** *Lack of partnership/collaboration with provider **Example:** lack of dialogue/ discussion, delayed communication *Lack of patient-provider shared decision-making **Example:** Lack of agency/loss of control over birth plans *Power dynamics/differentials **Example:** provider knows best-medical training *Lack of informed consent *Feeling pushed to make a medical decision. *Forced/unconsented procedures. **Example:** C-sections/hysterectomy Treatment based on preconceived ideas of Black women/stereotypes.	**Themes: Dehumanization/Devaluation:** **Sub-theme: Not feeling valued or seen as there was no compassion.** *Lack of compassion **Example:** Lack of empathy, Not feeling seen or valued/Lack of validation of pregnancy/devalue of Black body and needs/neglected emotional, physical, and mental needs/trauma, loss of child **Sub-theme: Feeling like privacy is compromised:** *Violations of privacy and dignity *Poor bedside manner **Example:** leave exposed on table/handled carelessly

Example: Intersectionality playing a role in stereotypes as most Black women are "labeled by as being the same." (Black mother's self-acknowledgement of being discriminated against for combined factors, There being a benefit in terms of race/gender/class when highly educated and private insurance, a cost to mothers who lacked those). **Sub-theme: Treated poorly based on type of Insurance.** Insurance-based discrimination Example: Lack of continuity of care, seeing multiple providers, lack of choice in care received.	**Example:** not worthy or smart enough to have intelligent conversations to understand medical conditions and terms) **Sub-theme: Lack of education/ information about care options:** *Lack of education *Lack of information sharing **Example:** (Unplanned emergency/ unexpected outcomes/not being educated about signs/systems of certain disorders/what could go wrong in pregnancy/providers not speaking in plain language)	
Theme: Loss of Self-Advocacy *Loss of patient autonomy *Loss of patient self-advocacy *Lack of support *Internalized racism **Example:** Don't speak up, assert preferences, ask questions, or challenge medical decisions made by healthcare provider for fear of being judged/labeled/receiving poorer care	**Theme: Expectations of care and actual care received.** *Feeling Dismissed *Not feeling heard *Dismissal of Pain *Lack of attentiveness. *Feeling rushed *Poor bedside manner *Lack of cultural competence/humility *Lack of support *Perceived quality of care *Perceptions of disparities in care **Example:** neglectful care/poor outcomes, delay in diagnosis, handled carelessly, inadequate treatment/not referred for care, lack of follow-up care/delay in scheduling appts or f/up's. **Example:** Poor care and outcomes had impact on decision to have future children.	

	*Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Perception of higher pain tolerance.	

Explanation: During this next phase the researcher reviewed, modified, and developed the preliminary themes that were identified in the previous phase, asking "Do they make sense?" As there was considerable overlap of the codes, it was necessary to gather all the data that were relevant to each theme and create broad categories to define what each concept/theme meant or was trying to convey. In Table 2. Five broad categories/themes were identified: racial discrimination/bias, patient-provider communication, dehumanization/devaluation, loss of advocacy, and expectations of expected care vs. care received. The researcher re-read the data several times to determine if it was associated with each theme and considered whether the data really did support it. The data associated with each theme is noted as "example." Also, in this phase, sub-themes began to emerge. For example, the researcher felt that Black women weren't necessary concerned with "control or power struggles" with providers, it was more so the necessity to advocate for one's care and have shared decision-making and collaboration with providers in making decisions about their care. This led to the development of the Loss of Self-Advocacy and Patient-Provider Communication theme, as the researcher didn't feel that the preliminary theme, Loss of Agency and Lacking Voice and Power in Patient-Provider Relationship worked as themes. Some of the codes included here (Forced/unconsented procedures, Feeling pushed to make a medical decision, Lack of informed consent) seem to relate to a separate issue of women wanting to be involved in decisions made. Therefore, the researcher didn't feel it was about power and a new theme Patient-Provider Communication was created with three subthemes: Not feeling heard or listened to, Lack of collaboration/partnership with provider in decision-making, and Lack of education/ information about care options.

Also, the loss of agency (control) seemed to be more related to a loss of control over a woman's birth plan, not control in the relationship with providers. The Loss of Self-Advocacy was more about a woman having or not having the space to advocate for their needs and what was best for them. The code lack of support was noted as what women needed in terms of advocacy as well as what was lacking from providers, however, the data spoke more to women having support from family, friends, and providers such as doulas, was more important for a woman receiving respectful care vs. from the healthcare provider. This led to the development of the Dehumanization/devaluation theme which highlighted "a lack of compassion" and "lack of privacy/dignity" subthemes as this appears what was missing from providers more so than women needing their support per se. Lastly, the theme "Racism and Lack of Basic Human Rights Impact Care and Treatment" was retitled to "Racial Bias and Discrimination Impacts how a Black Women is Seen" as the data appeared to be more related to how a Black woman is seen and treated based on initial assumptions and stereotypes before care is ever delivered. The codes of not feeling heard and feeling dismissed continued to reoccur across three themes, "Racial bias

and discrimination", "Patient-provider communication" and "Expectations of care and actual care received." The code of not feeling heard was so prominent and an undercurrent in every transcript, that the researcher explored further what this meant to women by rereading all coded data and it was eventually defined in the final theme in Table 3. Lastly, many of the codes related to perceptions of care were shifted from previous themes as they were more in line with the theme "Expectations of care and actual care received" and women noting that it was more related to poor outcomes vs the relationship with providers and that poor care resulted in neglectful and delayed care, and ultimately poor outcomes.

Table E3. Final Themes

Theme: Not feeling seen! **"When I am disregarded and not cared for as a unique individual."** *Racial discrimination *Unfair/unequal care/treatment *Intersectionality (compounded effect based on assumptions) **Example:** "If I was a different race" **Example:** Black women are seen and "labeled as being the same." *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumptions or negative perceptions about Black women based on bias, lead to poor care and outcomes. (Uneducated, single mother, multiple baby fathers, aggressive, hostile, on the system) **Sub-theme: When my privacy is not valued:** *Violations of privacy and dignity **Example:** body and birthing space/leave exposed on table/	**Theme: Not feeling heard!** **"When I experience poor outcomes due to not being listened to."** *Feeling Dismissed *Not feeling heard *Dismissal of Pain **Example:** medical complaints/dismissal of pain and concerns *Lack of attentiveness. *Feeling rushed *Poor bedside manner *Lack of cultural competence/humility *Perceived quality of care *Perceptions of disparities in care **Example:** neglectful care/poor outcomes, delay in diagnosis, handled carelessly, inadequate treatment/not referred for care, lack of follow-up care/delay in scheduling appts or f/ups. **Example:** Poor care and outcomes had impact on decision to have future children. *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Perception that Black women have a higher pain tolerance. (Undertreatment of	**Theme: Not feeling communicated with!** **"When I'm not given the opportunity to engage with my provider to make decisions."** *Lack of partnership/collaboration with provider **Example:** lack of shared decision making, lack of dialogue/ discussion about medical decisions, delayed communication *Lack of patient-provider shared decision-making **Example:** Lack of agency/loss of control over birth plans. *Power dynamics/differentials **Example:** provider knows best-medical training *Lack of informed consent *Feeling pushed to make a medical decision. *Forced/unconsented procedures. **Example:** C-sections/hysterectomy

multiple people in birthing space-students, residents) *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Black women less sensitive. Experimental. Hyper sexualization/media portrayals/slavery/exposed **Subtheme: When I am shown a lack of compassion.** *Lack of compassion **Example:** Lack of empathy, Not feeling seen or valued/Lack of validation of pregnancy/devalue of Black body and needs/neglected emotional, physical, and mental needs/trauma, loss of child *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumption that Black women are inherently strong and need little support. Racial bias and assumptions/strong black woman. Neglect of emotional needs. **Sub-theme: When my care is based on the insurance I have.** *Insurance-based discrimination (Lack of continuity of care/seeing multiple providers/sub-par care/lack of treatment options) *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumptions made about insurance type and financial stability/Black women having inadequate health	pain and dismissal of complaints about discomfort or pain) **Sub-theme: When I (or a loved one) try to advocate for my care.** *Loss of patient autonomy *Loss of patient self-advocacy *Lack of support *Internalized racism *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumption that Black women are naturally more aggressive or angry. Don't speak up, assert preferences, ask questions, or challenge medical decisions made by healthcare provider for fear of being judged/labeled- "difficult or angry."	*Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Bias that Black women are less educated/ not smart enough to have intelligent conversations to understand medical conditions and terms. **Sub-theme: When there is a lack of transparency in information shared:** *Lack of information sharing, and rationale given for medical interventions. **Example:** Not given information regarding their care-Unplanned emergency/ unexpected outcomes/or not discuss treatment options. **Example:** Lack of rationale given for medical procedures *Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumption that Black women are non-compliant/or less likely to follow advice or treatment plan/provider put less effort to communicate or provide explanations/information. **Sub-theme: When there is a lack of education provided:** *Lack of education (health education/resources) **Example:** not being educated about signs/systems of certain disorders/what could go wrong in pregnancy/providers not speaking in plain language/provider oversimplify.

coverage/substandard care provided as provider doesn't explore treatment options.		*Biased and discriminatory care based on preconceived ideas of Black women/stereotypes. **Example:** Assumption that all Black women come from lower SES and have less health literacy/assume woman wouldn't understand.

Explanation: In this final phase of theme development, as there was still an overlap in codes and themes, the researcher finalized themes by identifying the underlying concept/s that linked the themes. For example, ultimately Black women perceived they received disrespectful maternity care when they were not seen, heard, or communicated with by providers. Therefore, several themes and subthemes were collapsed into these three overarching themes and six sub-themes.

Lack of compassion was listed under the category of dehumanization & devaluation as well as perceived quality of care. Lack of compassion under dehumanization & devaluation alluded more to showing joy for new baby and celebrating Black women's pregnancy or empathizing with mothers' trauma of the loss of their baby, whereas compassion in quality of care looked more at not making compassionate or responsive choice to ensure more favorable outcomes. The theme Dehumanization and Devaluation was eliminated as the data relayed the lack of compassion, empathy, and insensitivity of providers made Black women not feel seen or valued as a woman and was collapsed under the overarching theme of "Not feeling seen" as a sub-theme.

The overarching theme of "Not feeling seen: When I am disregarded and not cared for as a unique individual" noted how Black woman felt that providers level of care was jaded by bias and discrimination and often resulted in women not feeling seen as a unique individual with unique needs as assumptions are often made upon meeting them without getting to know them. The theme also includes two additional subthemes "When my privacy is not valued" as woman didn't feel seen as valuable when their body and space are not dignified and respected, and "When my care is based on the insurance I have" as women reported judgements made about them based on the type of insurance they caried and receiving substandard care as provider often didn't explore treatment options. And lastly, as noted above, the third sub-theme is "When I am shown a lack of compassion" as women expressed providers showing a lack of empathy, specifically in terms of not validating their pregnancies, neglecting their emotional needs (whole person approach) as well as showing no compassion for the trauma experienced with either losing a child, or experiencing a near death experience.

The re-occurring code/theme of not feeling heard, not listened to, or feeling dismissed was eventually coded as the Theme "Not feeling heard: When I experience poor outcomes due to not being listened to" as the data showed because of not feeling heard often resulted in women

feeling that they received neglectful care, delay in diagnosis, handled carelessly, inadequate treatment, and lack of follow-up care which resulted in women experiencing poor outcomes or severe maternal complications which resulted in them experiencing a maternal near miss. Women being dismissed for concerns related to pain and other issues, tended to be ignored or not listened to base on the covert or overt assumption that Black women had a higher pain tolerance. Further, the theme, Loss of Self-Advocacy was included as a subtheme under "Not Feeling Heard" and was retitled "When I (or a loved one) try to advocate for my care" as women often spoke up and advocated for themselves, along with family members advocating for them, however, indicating it was often met with opposition, as providers either challenged or ignored their concerns. In this phase, the researcher collapsed "internalized racism" under this sub-theme and removed it from the racial bias theme, as this had the propensity to impact a woman's ability to advocate for themselves or not, out of fear of embodying assumptions about Black women and being labeled or judged based on stereotypes.

Lastly, the third theme emerged "Not feeling communicated: When I'm not given the opportunity to engage with my provider to make decisions" as women expressed a lack of dialogue/ discussion with their providers about medical decisions whether it was having birth plans honored, or forced c-sections, and receiving delayed communication. Women felt a bias from providers noting that they perceive that their providers perceived them as being less educated or not smart enough to have intelligent conversations with to understand medical conditions and terms. This theme includes two subthemes "When there is a lack of transparency in information shared" and "When there is a lack of education provided" which both are more related to women not being provided transparent information and rationale given for medical interventions and lack of education around their symptoms or medical conditions as providers often didn't speak in plain language/or oversimplified information, which led to women feeling disrespected for not being included in their healthcare and receiving biased care based on provider assumption that they were uneducated and didn't understand medical terminology.

Interestingly, the one code that undergirds all three themes and six subthemes is "Biased and discriminatory care based on preconceived ideas of Black women/stereotypes." In every aspect of a Black woman not feeling seen, heard, or communicated with is based on assumptions made about them regarding their skin color, socioeconomic status, educational levels, insurance coverage, pain tolerance, compliance, marital status, and being labeled as angry or difficult, which ultimately impacted their experiences with healthcare providers in maternity care settings and led to perceived disrespectful encounters and poor outcomes.

Appendix F

Matrices Marker Quotes

Tables F1-3

Table F1. Theme 1. Not feeling seen: "When I am disregarded and not cared for as a unique individual."

Perceived Disrespect	Theme	Sub-Themes	Marker Quote(s)
	Not feeling seen: When I am disregarded and not cared for as a unique individual. (Race Discrimination/Unfair/unequal treatment based on race/bias)		"Just drop the preconceptions, drop the racial bias. Your personal bias hurts your patients and makes you miss signs. The person in front of you is a person, they're a human body that has biological, psychological, and emotional needs, honestly, I think the treatment was due to my race."
			"Maybe if I was a White woman, they would have had a lot more respect for me and a lot more-- Like all the other two women were. You can tell they had some type of prejudice in their mind."
		Perceived idea of a Black women (biased and discriminatory care based on assumptions/stereotypes)	"I think there's a preconceived idea of women of color, like how we all are or how we act, or just painted in a bad light instead of just saying this is a woman giving birth like any other woman, I'm going to respect her."
			"When we go to certain clinics and certain hospitals, we're looked at just because we are just- there's another black chick walking in here pregnant.

		I think a lot of them were just expected just to be pregnant and on housing, and being on food stamps and all the other stuff."
	When my privacy is not valued (leave exposed on table/multiple people in birthing space-students, residents)	"Yeah. So I thought that was just a huge disrespect to my body and as a pregnant person to leave someone exposed and vulnerable on a table just poor treatment overall.' but I think, you know, definitely she just had **itty customer service, you know, and just overall disrespect of my body and privacy."
	Perceived idea of a Black women (biased and discriminatory care based on assumptions/stereotypes) Black women less sensitive. Experimental. Hyper sexualization/media portrayals.	When I got there, I noticed they were sending me students instead of my regular physician or even an attending. I was like, Nope, if you don't need to be in the room, you got to go. I hate to say, I knew I was an experiment, and I was a teachable moment, and I didn't want to be a teachable moment in labor and delivery."
	When I am shown a lack of compassion. (Lack of empathy, Not feeling seen or valued/Lack of validation of pregnancy/devalue of Black body and needs/neglected emotional, physical, and mental needs/trauma, loss of child)	"It didn't really feel caring. I would've liked someone to come in and say, it's going to be okay. Pat me on my shoulder. To show me a little bit of concern, some kind of love, and I didn't get any of that. I just felt like I was alone the whole time."
		"I felt like I was a number in a line. That was the worst care I've ever had. It was like nobody was taking what was happening to me. It was

		like they didn't care. I know they don't really care. I know I really am a number but to put it out there in my face where I felt it, it was horrible."
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Assumption that Black women are inherently strong and need little support. "Strong black woman" Neglect of emotional needs.	"The way that we're viewed by the medical field, like this idea of she's going to be all right. You got this. It's always this idea that all of the loads that we're carrying are loads of our own, number one, loads that we deserve and that you're going to be fine. Like, you're going to get through this. You're going to be just fine. You're going to overcome. It's this idea that we're always good when, honestly, 9 out of 10 times we actually are not, especially mentally. Physically, we know that like Black people, we have all the things. We have the high blood pressure. We have the heart disease. We're obese. We have all the things, we're not okay. We are not okay."
		"Still think there's very much stigma. When it's a woman of color coming in- not even a woman of color, a Black woman coming in giving birth, there's almost that look of "How many other children do you have already?" It's not a, you know, a delighted kind-of, "Are you having any more?", it's like, "Are you having any more? Gonna keep doing this?" kind of feeling. And it definitely feels- it's definitely there. It feels like a,

		"You shouldn't be having any more kids."
	When my care is based on the insurance I have. (Lack of continuity of care/seeing multiple providers/sub-par care/lack of treatment options)	"Because I'm low class, I have Medicaid. We're still human, and if I was in the health field, which I have, but if I was a doctor and I'm coming in and even though I know this person has Medicaid and I know I'm paid to only do a certain amount of things, I still would take that extra mile just because I'm human."
		"You got Medicaid, you're treated like a bum. If you've got private insurance, you're treated like royalty…you got to have the best insurance for the best care. You're treated like trash, you're threatened, you're looked at and despised. "You get whatever we give you and whatever outcome is, pray that God is with you."
		"The nurse there asked me did I take my medicine. I was like, No, I went to the doctor instead. I was like, Do I need to take my medicine? She was like, No, you're here now. You done waited too late to take any kind of medicine. She's like, You should have listened to your doctor beforehand. That's what y'all do, y'all don't listen. Okay. I definitely reported her, and she was a White nurse, and it was like, What do you mean, y'all?

		Because, by one, I'm not slow, I'm not dumb. Just because I go to this doctor doesn't mean I don't have any morals about myself, because with both pregnancies, I did go to the doctors who accept Medicaid."
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Assumptions made about insurance type and financial stability/Black women having inadequate health coverage/substandard care provided as provider doesn't explore treatment options.	"I constantly got the question do you have Medicaid? She stated that a provider said 'Oh, we can't do the 3D ultrasound because your insurance won't cover it.' I'd be like, Why? 'She's like, Medicaid doesn't cover those things.' I don't have Medicaid, it literally got so frustrating."

Table F2. Theme 2. Not feeling heard: "When I experience poor outcomes due to not being listened to."

Perceived Disrespect	Theme	Sub-Themes	Marker Quote(s)
	Not Feeling Heard: When I experience poor outcomes due to not being listened to. Not feeling heard/dismissal of pain, medical complaints. Delayed care resulting in negligence/poor outcomes/ lack of attentiveness/not referred for care/delay in scheduling appts or f/up's, feeling like they were handled carelessly)		"If they would've just maybe listened more, maybe my baby could have made it, or maybe my tube. Both times no one listens. [sniffles] If I wouldn't have listened to my body, I would've been dead. I would've died of internal bleeding because I'm over here being told, "No everything's fine." "They ended up jumping on my chest and they broke my rib down here and they broke the other one here. I can remember them saying, She's going, she's going, she's going. All I could think about was my mom. The last thing that I said that they heard me say was, Take care of my mom, take care of my mom. Then by the time I had gotten up, I was two days off the vent... people don't really get to talk about how traumatic it is to not be heard by your physician or to get put in a position to where you have to be put on a vent because of medical negligence all

		the way round, and it's because people didn't listen to you." "I don't know, but I wish that when I was telling him that something was wrong, he would've listened to me because then maybe I didn't need that emergency C-section. Maybe you could have caught it. Maybe I didn't need a blood transfusion. Maybe right now I wouldn't have incontinence." 'I was in significant pain, and the pain was dismissed. Not only was it dismissed, it was misinterpreted as if, you know, this is the third baby, so I know if I'm having pain, I can clearly say this isn't a contraction. Right. I can clearly say that what the pain is feeling like.'
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Perception that Black women have a higher pain tolerance. (Undertreatment of pain and dismissal of complaints about discomfort or pain)	"As a black woman, I feel pain just like everybody else, so if I tell you that something is wrong believe me the first time…we're just regular people just like everybody else. We're regular people. We feel the same things as other people, and our healthcare is not something that you know we can ignore."

		"No, my pain is the same as a White person's. Just as they would listen to a White person, they need to listen to us as well because we all bleed the same and some people's tolerance might be higher, but when you're screaming or when you're crying or when you're in pain or when you're struggling to move, help that person, listen to that person."
	Loss of self-advocacy (Don't speak up, assert preferences, ask questions, or challenge medical decisions made by healthcare provider for fear of being judged/labeled/receiving poorer care)	"I did advocate for myself, but there are many instances where I stayed quiet cause I just felt like, oh, you know, I ran across my mind like oh I'm this black woman doctor who's over here *itching at people and complaining and now people are gonna see me as X, Y, Z. And I know what that means. That means that people stop coming in the room. People stop engaging with you. People stop--you know, people don't give as good care just cause they're like I don't wanna deal with this person."
		"You don't know what you're talking about. I explained that I was having contractions that were close apart and that I was in active labor. I don't remember the exact verbiage. They said something to

		the extent of, Well, we don't know if you're in active labor, we need to wait and see. We need to see if you are really in labor. It was kind of this passive-aggressive way of saying, You don't know what you're talking about." "She was like, Okay, all right. I'm going to start calling people." He was, No. My mother-in-law says, Send her to Grady, send her somewhere else. He was like, I'm not sending her anywhere. She told him, she was like, Okay, you don't have to send her anywhere. She called every doctor, every specialist that she knew in the Metro Atlanta area." "I tried calling for a nurse the first time I was experiencing those symptoms. Then, my fiancé insisted that they come back and things like that. I would say that he tried to be like a barrier, or someone in between to try to advocate for my health and things like that."
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Assumption	"It's how the medical community sees me as a woman of color, I'm dark skinned. I'm a full set woman, heavy, you know, and I don't

	that Black women are naturally more aggressive or angry/internalized Racism.	consider myself to be like pushy or aggressive that a lot of people who generally associate as a negative idea around dark black skinned women…And so I often find that I'm not given full information about things or sometimes when I ask questions I'm not being answered to." "I really dislike just I felt like when I actually thought I knew my body, I would bring that up, and then a doctor or [White] midwife would just dismiss it and that felt really defeating. That was probably the worst mentally. It made you doubt yourself."

Table F3. Theme 3. Not feeling communicated with: "When I'm not given the opportunity to engage with my provider to make decisions."

Perceived Disrespect	Theme	Sub-Themes	Marker Quote(s)
	Not feeling communicated with: When I'm not given the opportunity to engage with my provider to make decisions. (Lack of collaboration/partnership with provider in decision-making/loss of control over birth plans/ Lack of informed consent/Feeling pushed to make a medical decision/Forced/unconsented procedures)		"They need to give us an opportunity. Maybe they need to ask open-ended questions and truly give an opportunity to engage in a real conversation with the pregnant person or postpartum, whatever, to have real conversations." "Well, definitely because like I say I felt like I was rushed to have a baby, and they didn't even give me the chance. And like I said, when I went in there to give them my birth plan, they automatically counted me out from being able to do what I wanted to do because it was my first child, and they didn't think that I would be able to do it." "There's almost this assumption even if you are a woman who has a college education or whatever it may be, you are put into the pile of, Oh, here's this ignorant Black woman. It's how it felt as it relates to explaining things, that I wouldn't be able to understand it

		or that I don't deserve an explanation."
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Bias that Black women are less educated/ not smart enough to have intelligent conversations to understand medical conditions and terms.	"This specific doctor was nowhere to be found, not really communicating. Just the nurse would come in and say, Oh, the doctor wants you to do this, or order this test. I'm like, What's going on? Why are we doing this? Like I said before, people weren't explaining why things had to be done. It was a little bit frustrating as well as confusing and concerning."
	When there is a lack of transparency in information shared. (Lack of information sharing, and rationale given for medical interventions/Unplanned emergency/ unexpected outcomes/or not discuss treatment options)	"They ended up doing a double incision for my C-section. They cut across and up. That part I didn't know until I went to my six-week appointment because having that cut across and up makes it extremely difficult for me to carry again especially the full term because I risk uterine rupture which wasn't even something we talked about during the C-section."
		"And after the second ultrasound at the hospital, they basically left the room, waited maybe ten minutes, came back, and said, "Oh, there's fluid around her heart." Which nobody had ever

		said anything about. The OBGYN, which was the first place I went to with my appointment, never said anything about it when they did an ultrasound. But now suddenly, there's fluid around her heart and, Oh, we need to do a c-section right away."
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Assumption that Black women are non-compliant/or less likely to follow advice or treatment plan/provider put less effort to communicate or provide explanations/information.	"The information provided and communication was sparse. I felt like I didn't know what was going on, and I didn't. I felt exactly how the moment was, I did not know what was going on, because every time I consulted with them, every time I'm thinking, This is what a medical professional is saying, something different happened."
	When there is a lack of education provided. (Lack of education-health education/resources/not being educated about signs/systems of certain disorders/what could go wrong in pregnancy/providers not speaking in plain language/provider oversimplify)	"You can't tell me, Oh, you're bleeding, or "Your pressure is low. Your uterus is contracting. All these different things, you're throwing all this jargon at me but you're not explaining to me why, how, or anything."
		"I didn't really feel like I knew what was going on. Just the one doctor made that very staggering statement saying like, We're going to try to shrink down your uterus to get the bleeding to stop. I still don't really understand what that

		means. They said my uterine scar reopened. In my mind, it's like if you have a scab and the actual scab part rips off and you start bleeding again, that's what I think they meant in my mind.” “I don't know. I feel like I did ask, but the answer was either not sticking because I didn't understand it because they're speaking in medical terms or like-- I don't know. The doctor would come in and give me an update and then my husband would call me and be like, What did the doctor just say? I'd be like, "I don't know.”
	Perceived idea of a Black women. (biased and discriminatory care based on assumptions/stereotypes) Assumption that all Black women come from lower SES and have less health literacy/assume woman wouldn’t understand.	“I also had lots of experiences where they assumed that because I was young and Black, that I wasn't educated. They assumed that my husband wasn't my husband, that he was a baby daddy/guy that got me pregnant. That happened a lot. My husband would say, No, I'm her husband. No, we both have college degrees. No, this is my son.”