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## African American Mothers' Experience in the Neonatal Intensive Care Unit

Lauren Magruder  
*Walden University*

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# Walden University

College of Counselor Education & Supervision

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Lauren Magruder

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Walden University  
2021

Abstract

African American Mothers' Experience in the Neonatal Intensive Care Unit

by

Lauren Magruder

MA, James Madison University, 2015

BS, James Madison University, 2013

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Counselor Education and Supervision

Walden University

March 2021

## Abstract

Black/African American (B/AA) mothers struggle disproportionately with problems related to childbirth. B/AA mothers have higher rates of premature births, infant death prior to age one, and death during childbirth. The purpose of this research was to add to present knowledge regarding B/AA mothers who have had a baby in the Neonatal Intensive Care Unit (NICU). Womanist theory was selected as a framework for the study because it focuses on the intersection of gender and race in relation to B/AA women. The experience of B/AA women in U.S. society is unique, in that it involves several pervasive stereotypes and controlling images. The research question for this study focused on the lived experiences of B/AA mothers who had a baby in the NICU within the past 5 years. The study consisted of 8 B/AA mothers and data was collected through semistructured interviews. Hermeneutic phenomenology was used to address the meaning within participants' experience. Themes that emerged from the data included protector, support, restrictive institutions, and trauma. This study may promote positive social change as counselor educators and supervisors may apply the findings to improve their training of counselors to ensure that they are equipped to engage with this population effectively. These include ensuring that counselors are culturally competent and knowledgeable regarding the unique experience of B/AA mothers. Counselors may thus be better able to engage in interventions that decrease mental health symptoms and provide support for B/AA mothers.

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## Dedication

This is dedicated to my husband, Eric, and daughter, Logan. You both continue to motivate me to be the best version of me. Eric, I cannot thank you enough for your support during this process. I know it has been difficult at times, but I could not have done this without you. Logan, I love you more than I can put into words. Thank you for being my motivation to hopefully inspire change that began with you. I hope that I make the both of you proud.

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## Chapter 1: Introduction to the Study

### **Introduction**

According to the Centers for Disease Control and Prevention (CDC), one in 10 births in the United States in 2018 was a preterm infant. There are physical and mental health risks for infants who are not fully developed at birth. When babies are born prematurely, they are taken to the neonatal intensive care unit (NICU), in which staff focus on assisting babies in growing and developing outside of their mother's womb. The NICU environment, along with the experience of having a preterm baby, may be impactful for mothers as well as their children, with the potential for negative physical and mental health implications.

Fourteen percent of all births to African American mothers are preterm, in comparison to 9% of births to Caucasian women (CDC, 2019). The exact causes of this racial disparity are unknown. A disproportionately high preterm birth rate continues to have an impact on the African American community. There is a need to investigate this issue, as Black/African American (B/AA) mothers give birth to preterm babies at higher rates than other races. There seems to be a lack of knowledge regarding this phenomenon, as I will demonstrate in the next chapter; support regarding this unique experience with B/AA mothers is limited.

There are many potential social implications of this study. First, this information adds to the limited body of literature on this specific topic. Next, with information from this study, counselor educators and supervisors will be better equipped to train counselors

who may provide counseling to clients. Finally, this study may provide the foundation for research for training programs at hospitals that contain NICUs.

The following sections of this chapter focus on the necessity of the study. In the background section, I briefly summarize the current literature as well as identify gaps. The problem statement and purpose of the study are identified, along with the research questions, followed by the theoretical framework.

### **Background**

The birth of a child is not always a pleasant, happy experience for a mother. A CDC study estimated as many as one in eight women experience postpartum depression in the United States (CDC, 2020). Outcomes of the study further demonstrated that these numbers vary per state, from one in 10 to one in five. Rates of postpartum disorders are higher for mothers who give birth preterm. Preterm birth rates in the United States are higher than in other western developed countries (Nutor et al., 2018). According to Bouras et al. (2015), mothers of preterm infants experience higher levels of psychological distress and have an increased chance of suffering from postpartum disorders. Bouras et al. also identified that one of the risk factors for preterm birth was African American ethnicity. B/AA mothers have the highest rates of preterm births at 13.8% in comparison to mothers with other racial identities (Nutor et al., 2018). Nutor et al. (2018) cited various reasons for this disparity, including low socioeconomic status (SES).

There is a gap in the literature regarding the actual experience of B/AA mothers in the NICU. There is limited literature regarding maternal mental health in general. Rates of postpartum depression continue to increase, and there are limited programs to assist

mothers with this. Research focusing on B/AA mothers in the NICU is limited. Studies in the counseling, nursing, and psychology fields have been conducted on depression, anxiety, social support, and so forth. However, within my literature review, I could not find a study in the United States that focused on the NICU experience in the past 5 years.

This study was necessary to determine how to better assist mental health providers in supporting mothers through the traumatic experience of preterm birth. If these women are not properly supported through mental health services, then the risk of adverse health consequences increases. There may be an increase in postpartum disorders such as depression and anxiety. Mothers may not attach well with their children, and this can lead to problems later in adulthood. This study may assist in training and providing direct care support to mothers who have a preterm infant in the NICU.

### **Problem Statement**

Mothers who give birth to preterm babies often face unexpected and stressful events (Lomotey et al., 2020). For such mothers, stress can be linked to the infant's medical condition, the interruption of normal parental responsibilities, being physically separated from the baby at the hospital, and the NICU environment (Lundqvist et al., 2007). Optimal parent–infant interaction and potential attachment may be negatively impacted by these stressors (Lundqvist et al., 2007). The NICU experience may have deleterious effects on the mother's well-being. Pregnancy and birth are incredibly stressful for mothers; the resulting stress can be associated with major mental health conditions such as major depressive disorder, generalized anxiety disorder, and posttraumatic stress disorder. As such, it is imperative that healthcare workers, mental

health care practitioners, and researchers truly understand the implications of pregnancy and birth (Kimmel, 2020).

In 2011, mothers gave birth to a half million babies (11.7%) who were premature (Giurgescu, 2013). *Preterm babies* are defined as babies born before 37 full weeks' gestation (Lomotey et al., 2020). Giurgescu stated that 65% to 70% of preterm births are due to spontaneous preterm labor or preterm rupture of membranes. Medical interventions have not decreased the number of preterm births; therefore, mental health interventions are necessary to assist mothers who give birth to preterm babies. Babies who were born preterm have higher rates of health concerns, including higher rates of infant mortality, neurodevelopmental delays, and chronic illness (Bouras et al., 2015). Immediately after babies are born preterm, they are taken away from their mother and enter the NICU (Lomotey et al., 2020). The situations in which these births occur cause stress to the mothers. Immediately following the birth of a preterm baby, there are stressors, such as being separated from the baby, that may lead to anxiety and depression.

B/AA mothers have higher preterm birth rates (16.8%) when compared to non-Hispanic White women (10.5%) in the United States (Giurgescu, 2013). Researchers and scientists speculate that stress and racism are some factors that may contribute to this disparity; however, they do not know what causes this disparity (Mirsa et al., 2017). There are experiences of psychological stress that are unique to members of minority groups. These minority stressors include perceived stress, psychological stress, anxiety, and depression (Giurgescu, 2013). According to Giurgescu (2013), chronic stressors such as living in areas that have high rates of crime and racial discrimination may be related to



preterm labor. This stress may lead to psychological conditions within mothers that can cause preterm labor. Mental health disparities affecting the B/AA community may contribute to the amount of preterm births and mothers' ability to engage in treatment if necessary.

Though the literature does indicate such negative experiences, through an exhaustive literature search, I was unable to locate information that directly addressed the lived experiences of B/AA mothers who had preterm births that necessitated NICU treatment. As a result, counselor educators are ill equipped to train counselors to meet the needs of this constituency; counselors are thus not able to provide adequate mental health support to these mothers.

### **Purpose of the Study**

The purpose of this hermeneutic phenomenological (HP) research was to bridge the gap in the literature related to the meaning of the lived experience of African American mothers who have had a preterm infant in the NICU.

### **Research Questions**

The research question was as follows: What is the meaning of the lived experiences of B/AA mothers who have had a preterm infant in the NICU within the past 5 years?

### **Theoretical Framework**

Qualitative HP researchers aim to explore the lived experiences of participants and the interpretive nature of phenomena while excluding judgment (van Manen, 2014). Heidegger and Gadamer were important figures in the shift toward focusing on the

meaning versus descriptive nature of research (van Manen, 2014). HP includes how experiences may impact the way in which a human will view a specific event or phenomenon (van Manen, 2014).

I used a feminist lens with HP, as this allowed me to encompass the experience of mothers as women. The feminist lens focuses on the interpretation of experience while including how power may be a factor (Gardiner, 2018). Using this framework allowed me to identify factors that might be different due to gender as well as how gender impacted mothers' experience.

More specifically, I used a womanist lens. Womanism is a specific type of feminism. This lens (also referred to as "Black feminism"), founded by Alice Walker, focuses on the intersectionality of race and gender (Lindsay-Dennis, 2015). B/AA women's experiences are qualitatively different from those of women of other ethnicities due, in part, to lasting institutionalized, societal prejudice extending from slavery. Patricia Hill Collins (1996) expounded upon this idea in response to the second wave of feminism, which did not address racial differences. This framework allowed me to focus on the factors related to race and gender that might impact women's experience in the NICU. The lens of a Black woman involves a unique experience. The combination of HP with a feminist lens and womanist theory allowed me to view and interpret the data while including specific components that may have impacted the experience. It was important for me to highlight the participants' experience in the NICU as B/AA mothers, and that could not be effectively examined without including the intersectionality of their identities as B/AA and women.

## **Nature of the Study**

I used a qualitative HP approach in this study. One of the key components in qualitative research as well as the goal is to gain insight and meaning (Patton, 2015; Ravitch & Carl, 2016). This design worked best for my study based on my research question (What are the lived experiences of African American mothers who have had a preterm infant in the NICU within the past 5 years?). I was seeking to understand the lived experiences of subjects; therefore, an HP approach was used (Rudestam & Newton, 2015). Specifically, the HP approach involves looking at the interpretive nature of the lived experience as humans interpret the world and experiences based on their own background (Laverty, 2003).

I wanted to investigate the meanings of the experiences of mothers who encountered this specific phenomenon. I did this using a semistructured interview. The participants were identified through social media posts. The posts occurred on various platforms such as Facebook, Instagram, and Twitter. I also posted in specific groups that were related to identify potential participants. I later analyzed the data using a qualitative HP approach to identify themes.

## **Definitions**

*Black/African American (B/AA)*: Those who identify as Black and/or African American. This term does not encompass those of Hispanic or Caucasian ethnicity.

*Controlling images*: Images and thoughts that the majority group (particularly White men) have of African American women that perpetuate their place or status in the world as subordinate (Collins, 2004; Dow, 2015).

*Intersectionality*: This term was coined by Kimberle' Crenshaw. It refers to the two identities that Black women have as “Black” and “women,” with the understanding that these aspects of their experience cannot be understood separately (Crenshaw, 1989).

*Metastereotype*: A stereotype that reflects the belief of individuals from a marginalized group in the beliefs that others from another group hold about them (Jerald et al., 2017).

*Microaggression*: “Racial microaggressions are the everyday slights, insults, putdowns, invalidations, and offensive behaviors that people of color experience in daily interactions with generally well-intentioned White Americans who may be unaware that they have engaged in racially demeaning ways toward target groups” (Sue et al., 2007, p. 183).

*Minority stress*: A concept originally used to explain how members of sexual minority groups endure societal stress based on their identity (Hatzenbuehler, 2009).

*Neonatal intensive care unit (NICU)*: A hospital section for sick or premature newborns (Kynoe et al., 2020).

*Preterm birth*: Any birth at less than 37 weeks of gestation (Nutor et al., 2018).

*Postpartum depression*: A form of depression that occurs at least 4 weeks after delivery (American Psychiatric Association, 2013).

*Stereotypes*: Cultural beliefs about a specific group (Burnett et al., 2020).

*Womanist theory (womanism)*: Term coined by Alice Walker and expanded on by Patricia Collins. This theory focuses on the unique perspective on the world that develops

through the intersectionality of gender and race for African American or Black women (Collins, 1996).

### **Assumptions**

A fundamental assumption of HP is that there are multiple perspectives or interpretations. Van Manen (2014) stated that HP is focused on multiple perspectives of the participants or research subjects. Therefore, I assumed that those who have vastly different backgrounds (including cultural backgrounds) will have varying experiences.

I assumed that participants would be easy to locate and willing to participate. This assumption was directly related to obtaining data for the study. Another assumption was that the participants responded truthfully and honestly. Honest and truthful responses increased the trustworthiness of the study.

### **Scope and Delimitations**

This study was focused on B/AA mothers. Therefore, fathers, grandmothers, grandfathers, aunts, uncles, and cousins were excluded. Those who did not identify as Black or African American were also excluded due to the purpose of the study.

The research study focused on mothers who had a baby in the NICU within the past 5 years. Due to constant change in the field of mental health and evolving practices, I sought to provide the most up-to-date information possible. Researchers in future studies could adjust the number of years since participants' NICU experience based on their focus.

The study included thick descriptions and rich data based on interviews. The themes may be transferable to other geographic locations. Another delimitation was that I

did not include mothers who had a baby during the COVID-19 pandemic. This factor could have impacted the data, as facilities had different restrictions affecting prenatal, delivery, and postpartum care.

### **Limitations**

I anticipated potential barriers involving the recruitment of participants from the specific population of interest. The participants had all experienced the event of interest and might not have been willing to share specific details. I believe that overall, participants were open in communicating, but there may have been details that were difficult for them to talk about due to traumatic experiences. The willingness of the participants to provide meaningful data was a potential barrier, in that they may have experienced a traumatic event. An approach that I used to address any limitations regarding honest communication was sharing parts of my experience to make participants feel more understood and less judged.

In qualitative research, causality cannot be determined (Schonfeld & Mazzola, 2012). Therefore, themes are used to inform regarding a specific phenomenon. I identified themes, and future researchers can determine more specific details and linking of events. The way in which I conducted my interviews might also have been a limitation. Interviews were based on self-report (Schonfeld & Mazzola, 2012). The use of self-report data involved an assumption that the participants were being truthful.

### **Significance**

The results from this research may improve the knowledge of both counselors and counselor educators. Counselor educators may identify ways to best support these

mothers and train counselors to effectively provide support to them. Events within the NICU may impact mothers' experience, and mothers may require professional support to cope with stressors. Counselors working with B/AA mothers who have had babies in the NICU may provide them with support that enhances the development of their babies. The results may provide information that helps in mitigating the relational impact of the NICU experience on families, as well as the impact of this experience on attachment.

My goal is that this study will not only aid in the provision of training for counselor educators and supervisors, but also inform the efforts of counselors with their clients during sessions. Counselors may become more knowledgeable about the experiences of their clients and ways that they can assist their clients more effectively. Long-term impacts of the study may include a decrease in the risk of psychopathology for the mother and the child. The totality of these impacts may advance positive social change.

### **Summary**

In the United States, mothers are at higher risk of preterm birth than in other Western developed nations. For B/AA mothers, the rate of preterm birth is nearly double that of the overall U.S. population. The NICU experience is unique and may be filled with varying emotions. The maternal mental health crisis must be investigated specifically in relation to B/AA mothers with babies in the NICU.

The following chapter will provide an in-depth literature review. The literature review will provide information regarding mental health as well the chosen theoretical frameworks. Chapter 3 will include information related to the methodology of the study.

Chapter 4 will focus on the results of the research while Chapter 5 will include conclusions and implications of the research.



## Chapter 2: Literature Review

### **Introduction**

Mental health continues to be a problem in the United States, where one in five adults are diagnosed with a mental illness (National Institute of Mental Health, 2019). Mothers experience additional stressors when faced with the birth of a child. Some mothers give birth to premature babies that must remain in the NICU after delivery. There are racial differences in the incidence of premature birth between B/AA and White women. The experience of preterm birth impacts the mental health of the mother. Little is known about how to prevent this phenomenon and effectively provide care and support to mothers while in the NICU and postpartum. As a result, counselor educators are ill equipped to train counselors to meet the needs of this constituency; counselors are thus not able to provide adequate mental health support to these mothers. The purpose of this HP research was to bridge the gap in the literature related to the lived experience of African American mothers who have had a preterm infant in the NICU.

The following sections in this chapter will provide a foundation for my research. I will identify the theoretical framework that will be integrated throughout the review of literature. Sections will focus on the mental health of women generally, as well as Black women specifically. The experience of being a mother and a Black mother will also be highlighted. Finally, I will focus on resources that Black mothers may use during this traumatic time. Throughout this exhaustive review, I will identify gaps in the literature regarding the overall support and mental health services provided to Black mothers with preterm infants in the NICU.

### **Literature Search Strategy**

To ensure that I conducted an exhaustive literature review, I began by using the Walden Library databases. The Walden Library offers access to multiple search engines, including PsycINFO and Sage Publications. I used Google Scholar to identify articles as well. I searched for articles dated between 2015 and 2020 to ensure that the most current data and information were included in this literature review. To ensure the accuracy of the information, I used peer-reviewed articles.

Search terms included *womanism, Black feminist thought, feminism, hermeneutic, phenomenology, qualitative, African American mothers, Black mothers, babies, birth, prenatal, perinatal, preterm birth, premature birth, NICU, neonatal intensive care unit, mothers, delivery, insurance, low SES, social support, spirituality, family stress, birth rates, health disparities, mental health support, depression and mothers, depression and Black mothers, PTSD, PTSD and childbirth, anxiety and motherhood, anxiety in women, lack of support mothers, and social support mothers.*

In the subsequent sections, I will focus on women and mental health. Next, I will elucidate the experience of B/AA mothers. In my exhaustive search, I found limited information regarding Black mothers with babies in the NICU and their overall care. Gaps in the literature are present.

### **Theoretical Foundation**

Theoretical foundations set the basis for the review of literature as well as the study. The importance of this foundation was that the study was informed by assumptions from the two chosen lenses. The following sections will highlight two lenses that were

used within the study. HP was used as it focuses on the interpretive nature of the experience or the meaning that the participant derives from the phenomenon (van Manen, 2014). I also used womanism as a lens. Womanism focuses the unique experience of B/AA women and how historical context and stereotypes have shaped their experiences (Collins, 2000). This lens allowed me to address the interpretive nature of data while including the unique experience of African American women.

### **Hermeneutic Phenomenology**

HP is a qualitative methodological approach in which the focus is not just on describing lived experience; interpretation is the central focus (van Manen, 2014). According to van Manen (2014), the goal of HP is to focus on others' experiences to understand the deeper meaning of a specific phenomenon as well as the context of the human experience. Martin Heidegger, a 20th century philosopher, wanted to view objects within the context of human life, which is dynamic. It is important in HP that researchers "acknowledge their own past experiences and existing knowledge as embedded in and essential to the interpretive process" (Bynum & Varia, 2018, p. 253). HP is focused exclusively on the interpretive nature of experience (van Manen, 2014). This important distinguishing feature was essential to this study.

In exploring the experience of African American mothers with babies in the NICU, I focused not solely on their experience, but also on the meaning related to their experience. The meaning of their experiences may be related to forms of discrimination and racism. The Black experience is identified as unique to the race, and the Black woman's experience is unique to women of other races. The differences in this

experience and the meaning that participants place on their experience are important to investigate.

Husserl is referred to as the father of phenomenology (van Manen, 2014). He focused on what is referred to as transcendental (or descriptive) phenomenology. Transcendental phenomenology focuses on the object or phenomenon itself without the meaning or context being included (van Manen, 2014). This form of phenomenology also focuses on the phenomenon itself void of individuals' interpretations. Transcendental phenomenology was not appropriate for this study because the experience of the NICU from the perspective of African American mothers cannot be effectively explored void of meaning. The study was aligned in such a way as to provide the participants with space to describe and interpret their experiences.

Feminist research focuses on gender inequality, empowering women, social change, and how gender impacts women's lives (McHugh, 2014). According to McHugh (2014), feminist researchers have identified sexual bias in traditional theories. Feminist researchers often use qualitative research, as it allows marginalized groups to be involved in the research process (McHugh, 2014). McHugh also stated that feminists in phenomenology focus on creating a space to hear women's stories while focusing on listening to others. As researchers listen and create this space, women's experiences are then articulated into meaning (McHugh, 2014). I sought to use a feminist lens to focus on the women's experience. Using the feminist lens assisted in highlighting unique struggles and gender inequities related to Black women's interpretations.

## Womanist Theory

Womanism (coined by Alice Walker, 1983) or “Black feminism,” as it is sometimes called, is a derivative of feminism. Alice Walker’s womanism includes the intersectionality of race, class, and gender (Collins, 1996). Womanism is focused on the unique experience of African American women in the United States (Collins, 2000). Black women in the United States have shared experiences that are unlike those of people who are not Black and female. Womanism encompasses Black feminism and involves love and appreciation for Black women’s culture and strength (Snider, 2018). In this study, the terms *womanism* and *Black feminism* are used interchangeably.

Collins (2000) discussed how the intersectionality of race, gender, and class can be traced back to the slavery period in the United States. The unique experiences and culture of African American women began in slavery as they were treated differently from White women. Stereotypes are integral to this theory. Stereotypes about Black women originated in historical phenomena such as slavery and have continued to permeate through culture, affecting how others interpret Black women’s behavior. This interpretation has also become embedded into how Black/AA women view themselves and thus how they view their experiences or create meaning.

Multiple female stereotypes arose during slavery and continue to permeate Black culture today. The *mammie* stereotype was born in the slavery era as Black women were viewed as providers; they were used to take care of their own children as well as the White children of the families they worked for (Collins, 2000). Their provider role included feeding and raising children. This asexual, subordinate role maintained the

oppression of gender and sexuality in Black females. The mammie was not able to be viewed as a sexual being or female. The mammie stereotype continued after slavery ended, when Black women could only obtain low-paying domestic jobs.

The next stereotype of Black women that arose was that of the *matriarch* (Collins, 2000). According to Collins (2000), the matriarch was perceived as a bad mother as she focused on her career and therefore could not focus on her children or family. The matriarch stereotype involves intersectionality with class, gender, and race. The matriarch was perceived as asexual and as emasculating her male partners. This emasculation occurred due to her perceived strength and control, which were traditionally male attributes (Collins, 2000).

Two additional modern stereotypes for Black mothers are the *welfare queen* and *Black lady*. These two seemingly contradictory images represent two extremes. According to Collins (2000), the welfare queen stereotype emerged as Black women gained access to federal government assistance that previously was not provided to them. This term first appeared in a presidential campaign by Ronald Reagan in 1976 (Dow, 2015). The “welfare queen” mother is lazy and does not work hard, as she is dependent on others to take care of her. She not only is materialistic, but also does not prioritize her children or instill values in them that are in alignment with U.S. capitalist thought, such as hard work and success. The “Black lady” comprises characteristics of both the mammie and the matriarch. This female is often perceived as strident, as working too much, and as having no time for romantic relationships and therefore being asexual. All of these stereotypes provide negative views of Black females and mothers. They continue

throughout today's culture and impact perceptions held by the majority culture and by Black mothers themselves.

For Black mothers, the stereotype of the *super strong Black mother* or *strong Black woman (SBW)* is a complex controlling image (Collins, 1996; Davis & Afifi, 2019). *Controlling images* are defined as “gender-specific depiction(s) of people of African descent within Western scholarship and popular culture” (Collins, 2004, p. 350). Dow (2015) defined controlling images as “elite white male interpretations of African American womanhood [that] serve as powerful rationalizations for African American women's subordinate place in society and their continued oppression” (p. 40).

The SBW stereotype was formed as a response to the “Black matriarch” with a focus on strength and resilience (Dow, 2015). In theory, it was supposed to be a positive stereotype, but it became another negative stereotype and unrealistic ideal. Black mothers are strong in Black culture; however, this “strength” often adds a subtle pressure. The standard that the SBW must live up to daily is unobtainable (Davis & Afifi, 2019). These women are expected to put the needs of others first, therefore giving up on their own hopes and dreams. Other expectations include suppressing emotions and resisting asking for or receiving help (Jerald et al., 2017). Images of the SBW are seen in literature, magazines, television shows, and music (Dow, 2015).

As stated by Collins (2000), “Emotional strength is essential but not at the cost of physical survival” (p. 184). A Black woman must succeed in the home as a wife or mother, at work, and in any other role she fulfills. This controlling image leads to continued oppression, as the image is unobtainable and unhealthy (Davis & Afifi, 2019).

Consequences of the SBW stereotype include increased stress, anxiety, depression, emotion avoidance, binge eating, irregular sleep, and smoking (Jerald et al., 2017).

Women who identify with the SBW stereotype are less likely to express themselves to others for fear of weakness, thus leading to a lack of emotional support from others. This internalization negatively impacts physical and mental health (Dow, 2015).

Although the terms are sometimes used interchangeably, controlling images and stereotypes may differ. A *stereotype* is a “psychological construct related to attitudes and cognitions,” and a *controlling image* is a “sociological construct relevant to ideology and structural inequality” (Jerald et al., 2017, p. 488). Some common controlling images in Black culture are the mammie, angry Black woman, strong Black woman, tragic mulatto, Jezebel, and Sapphire; these began in slavery and continue to permeate mainstream culture (Snider, 2018). These controlling images are a form of gendered racism and impact “how mothers understand their choices and the meaning attached to their experiences” (Dow, 2015, p. 50).

*Self-defining* is a response to controlling images as a form of resistance (Snider, 2018). It is thought to be critical to the survival of Black women and creates the ability to thrive (Snider, 2018). Controlling images may lead to internalization and cause psychological harm to Black women, which is why self-definition is crucial (Snider, 2018). Black women are expected to wear a mask, and self-defining encourages empowerment through authentic and realistic self-representation (Snider, 2018). The stereotypes are an integral part of this lens. These stereotypes, which began in slavery, are passed down throughout generations and therefore are often intentionally or



unintentionally engrained in Black women (Collins, 2000). Thus, the stereotypes are impactful on their own interpretation of their experiences.

In the African American community, there is a focus on relative and nonrelative kin, as well as extended family networks. According to Collins (2000), this began in the slavery era, as slaves helped to care for children who were not biologically theirs, following a practice that continues today. *Bloodmothers* are defined as those who gave birth to their children. *Othermothers* include individuals who assist in raising children who are not biologically theirs, such as grandmothers, sisters, aunts, cousins, family friends, and so forth.

Womanism, unlike feminism, is focused on the advancement of Black culture, including Black males (Collins, 1996). Womanism was an appropriate theory to use within this research because it helped to highlight the unique experiences that African American mothers face with a baby in the NICU and the postpartum period. Womanism was used in the formulation of interview questions as I sought to understand how the intersectionality of race and gender impacted participants' experience. Once the data had been collected, the results were interpreted using a womanist lens, as the experience of being a Black woman could not be ignored within this phenomenon.

Womanist theory was part of the theoretical foundation that was used in this research. Womanism assisted in analyzing literature, in developing research questions, as well as in coding and analyzing the results of the research. According to this theory, there are fundamental differences in the lived experiences of B/AA women in comparison to other groups. This theory was applied to elucidate this notion. The goal was to identify

how being a Black mother impacted participants' NICU experience with their infant and the postpartum period.

Both theories were used within this study to accurately explore and answer the research question. A HP lens allowed the participants to interpret their experience in the NICU. The participant questions were created in alignment with this theory, so that they could express their own perception and make meaning of their experience. The data were also analyzed through this lens to create meaning based on the experience and assist in finding solutions. The HP lens does not encompass the intersectionality of race and gender. Womanist theory highlighted the experience of these women as B/AA mothers. This lens alone would not have left room for interpretation or exploration of the meaning of the experience. Therefore, both lenses were required to adequately interpret the data and provide recommendations.

### **Women's Mental Health Concerns**

The CDC reported that one in 10 women in the United States identified having a depressive episode within the past year (Zhou, 2019). The Substance Abuse and Mental Health Services Administration (2018) stated that one in five women experienced an affective disorder (depression or anxiety) within the past year. The CDC (2020) provided a list of risk factors for depression in women that included the following:

stressful life events; low social support; previous history of depression; family history of depression; difficulty getting pregnant; being a mom to multiples, like twins, or triplets; being a teen mom; preterm (before 37 weeks) labor and

delivery; pregnancy and birth complications; and having a baby who has been hospitalized

Mental health disparities affect women in relation to anxiety, in that women have higher anxiety prevalence rates than men, exhibit more symptoms, experience greater distress, and are more service seeking (Panayiotou et al., 2017).

Women are at increased risk for PTSD in comparison to men (Michopoulos, 2015). Approximately 25% of women experience childhood trauma (Bosch et al. 2020). Childhood trauma is associated with increased risk of anxiety, depression, and PTSD. Multiple traumas increase the risk of depression and PTSD. Women are more likely to experience trauma related to sexual assault, domestic violence, and childhood sexual assault than men (Wamser-Nanney & Cherry, 2018). This trauma places women at a higher risk for internalizing disorders such as depression or anxiety (Wamser-Nanney & Cherry, 2018). Men often report externalizing disorders such as conduct and substance abuse. According to Wamser-Nanney and Cherry (2018), women exhibit symptoms of trauma to include intrusive thoughts, hyperarousal, sexual anxiety, and an overall perception that the world is dangerous in relation to men. These authors have also suggested that women and men at a young age are socialized in a way that impacts their mental health. For example, women may be taught to seek out help and express their emotions whereas men are not.

There are varying treatment methods for some mental health disorders. Treatment involves a decrease in symptoms related to the mental health illness. Some treatments include psychotropic medications and mental health counseling in various forms such as

group, individual, and/or couples/family (National Institute of Mental Health, 2021).

There are varying approaches that focus on relaxation or calming techniques such as mindfulness and meditation (Jennings & Apsche, 2014). These treatments will hopefully mitigate the symptoms and improve overall quality of life for these women and their families. Continued difficulty managing symptoms may lead to other adverse consequences and continued poor mental health for women.

Research regarding gender disparities continues to be conducted to add to the knowledge base. Although Caucasian women experience disparities due to gender, there are additional barriers for minority women especially African American women (Watson & Hunter, 2015). The disparities caused by the intersectionality of race and gender are consistent with womanism. The unique intersection and experience lead to an increase in mental health illness and resistance to treatment (Watson & Hunter, 2016). The lack of treatment and continued mental health stigma permeate throughout generations. There are significant gaps in the research focusing on minority mental health specifically in the Black community. Potential future directions in research can include focusing on how to decrease the stigma related to mental health in the Black community.

### **Black and/or African American Women's Mental Health Concerns**

According to Woods et al. (2016), African Americans are more likely than Whites to report major depression and to experience psychological distress. African Americans also experience more chronic morbidity related to depressive symptoms in comparison to their White counterparts. African Americans have large unmet mental health needs. Approximately 13.6% of the general population sought treatment for depression while

only 7.5% of African Americans. When treatment is sought, African Americans are less likely to continue after their initial visit. If they engage in treatment the course of treatment is shorter. African Americans are also less likely to be prescribed antidepressants.

Data shows that African American women are more likely than White women to report feelings of sadness, hopelessness, worthlessness, or that everything is an effort all the time (CDC, 2012). Approximately 41% of African American women reported seeking care for depression in comparison to 60% of White women in the past 12 months. Per Woods et al., (2016), this disparity is often attributed to lower income, educational attainment, and environments that include trauma, violence, and discrimination. Other factors attributed to this disparity are a mistrust of healthcare providers, self-reliance, cultural differences, stigma, and lack of awareness of available resources. African American women most frequently mistrust providers and believe they will not care for them appropriately.

According to Woods et al. (2016), African American women are over-diagnosed with psychotic disorders and underdiagnosed with affective disorders. These women are often not provided with new comprehensive treatments. African American women often refuse to immediately be placed on medication and feel their provider is not understanding their concerns. There is a stigma in the Black community regarding mental health and this brings shame and embarrassment to the individual and their family (Woods, 2016). The authors related this to self-concealment which occurs when the individual turns the stigma onto themselves. Self-reliance is also important to Black

culture. This is defined as “notion that a person should not look to others for support but rather deal with the stress, hardship, or emotional pain independently instead of reaching to others for informal or formal assistance” (Harris et al., 2020, p. 3). Woods et al., (2016) identified these concepts as reasons these women do not seek mental health treatment “perceived obligations to appear strong, to suppress emotions, and to care for others, resistance to dependence/vulnerability, and determination to succeed despite a lack of resources” (p. 1138). According to womanism, the SBW is in direct conflict with mental health services as that it is contradictory to self-reliance (Watson & Hunter, 2016).

African American women are at higher risk of experiencing trauma and developing PTSD or other trauma disorders (Johnson, Williams, Pickard, 2016). In the United States, African American women rates of PTSD are 7.8 to 8.7% compared to 6.9% to 7.4% of Whites. These women often are exposed to more traumatic events than Whites to include violence and witnessing violence (Johnson, Williams, Pickard, 2016). African American women also have higher rates of interpersonal violence than other groups (Blakely & Grocher, 2017). Interpersonal violence is defined as “intentional acts of harm or abuse by one human being to another human being” (p.2). Some examples of interpersonal violence include rape, domestic violence, and stalking. African Americans experience high incidence of childhood trauma that may later lead to psychiatric disorders in adulthood such as depression, anxiety, and PTSD. (Myers et al., 2015).

Racism is the primary driver in creating health disparities. Racism is defined as “a system of oppression that structures opportunity and assigns value for interpersonal

exchange based on someone's perceived race and occurs in multiple levels to include institutional, interpersonal, internalized, and cultural” (Slaughter-Acey, et al., 2016, p. 11). Interpersonal racism is “defined as prejudiced assumptions about an individual's abilities, motives, and intentions due to the individual's race and discrimination, defined as unfair treatment of an individual due to his or her race” (Slaughter-Acey, et al., 2016, p. 11). Racism significantly impacts Black women’s lives physically and mentally (Slaughter-Acey, et al, 2016). Microaggressions also occur in various settings to include hospitals.

Those at lower risk of preterm birth may be negatively impacted by race. Black women were 2.5% more likely to go into labor prematurely due to interpersonal racism. According to Alcala and Cook (2018), racial discrimination impacts health services. Those who experience racism are less likely to engage in optimal healthcare. Experiencing racism leads to a lack of trust in healthcare system and providers. Minorities as well as those with federally funded insurance report higher rates of discrimination.

According to Coley et al. (2018) there are continued health disparities between Black and White mothers. African American mothers do not receive adequate prenatal care in comparison to White mothers in the United States. Black mothers are 2-3 times more likely to begin prenatal care late in their pregnancy or decline it. Inadequate prenatal care leads to adverse outcomes to include preterm births.

## **Maternal Mental Health**

During the perinatal period, emotional distress usually causes complications to childbearing (Sockol, Epperson, & Barber, 2014). The perinatal period is defined as time from pregnancy until the end of an infant's first year (Lever, Cavanaugh, and Strauss, 2016). Perinatal mood and anxiety disorders (PMAD) are the most common conditions for women during pregnancy and postpartum (McKee et al., 2020). According to the Sockol, Epperson, and Barber (2014), 10-15% of women experience a depressive episode either during pregnancy or the first year postpartum. The prevalence rates for women with minor episodes of anxiety and depression is 25-50% (Kimmel, 2020). The transitional period after birth is demanding and includes lifestyle changes as well as new responsibilities; this period increases the risk of psychological problems (Monteiro et al., 2018).

Depression and anxiety predict negative outcomes for both the child and the mother during the perinatal period. Depression increases the risk of preterm birth, low birth weight, and preeclampsia in the infant (Sockol, Epperson, & Barber, 2014). The authors also stated that postpartum depression may lead to undesirable child outcomes to include difficulties managing behaviors and cognitive development. Suicide rates may be increased during the perinatal period (Kimmel, 2020). Perinatal anxiety is a risk factor for poor birth outcomes as well as behavioral and emotional difficulties in children (Sockol, Epperson, & Barber, 2014). The prevalence of postpartum anxiety is approximately 9.9% in the US (Monteiro, 2018). Mothers may struggle to get their child to necessary medical appointments to include vaccinations, wellness checks, as well as struggle to breastfeed



or use safety measures such as proper car seats (Stepanikova & Kukla, 2017; Young et al., 2019).

Postpartum depression is defined as depression within one year of childbirth and it currently affects 12% of all mothers (Young et al., 2019). Screening is required by the American Academy of Pediatrics up to six months postpartum specifically at one, two, four, and six-month appointments (Ko & Haight, 2020; Young et al., 2019). Screening and assessment will thus lead to an increased number of people receiving treatment/and or support for their mental health concerns during this critical time. Results from research also report that symptoms may decrease after birth and then increase closer to a year postpartum (Holditch-Davis et al., 2015). Treatment varies based on geographic location and resources available (Ko & Haight, 2020).

Postpartum depression includes symptoms such as low mood, anhedonia (difficulty enjoying activities), lethargy, tearfulness, changes in appetite and sleep patterns, difficulty concentrating, irritability, and suicidal ideation (Stepanikova & Kukla, 2017). Postpartum depression increases the likelihood of maternal suicide and harming the infant. Child maltreatment is defined by the World Health Organization as “*all forms of physical and emotional ill-treatment, sexual abuse, neglect, and exploitation that results in actual or potential harm to the child’s health, development or dignity*” (para. 1). Child maltreatment can include “physical abuse; sexual abuse; neglect and negligent treatment; emotional abuse; and exploitation” (World Health Organization, 2016, para. 1). Childhood maltreatment is related to poor mental health and negative outcomes in adulthood (Ayers et al., 2019). There is not only a relationship between prenatal

depression but, also PTSD in child maltreatment. These mental health concerns also lead to higher incidence of Adverse Childhood Experiences which are related to severe physical and mental health disorders later in life (Atzl et al., 2019).

According to Stepanikova and Kukla (2017), there are several risk factors for postpartum depression such as

pre-pregnancy depression, depression and anxiety during pregnancy, stressful life events during the perinatal period, low social support, childcare stress, difficult infant temperament, low self-esteem, neuroticism, poor relationship with a partner, medical complications during pregnancy and delivery, and low socio-economic status (1670).

Perceived discrimination in pregnant women was also seen as a risk factor for depression (Stepanikova & Kukla, 2017). This perceived discrimination is unique to minorities specifically, African American woman who are at a disadvantage in this country regarding mental health.

Other mood symptoms to include mania and hypomania can be triggered by childbirth (Kimmel, 2020). According to Kimmel (2020), some women are diagnosed with Bipolar disorder for the first time during the postpartum period. Postpartum psychosis is defined as women who have mania or psychotic symptoms with the presence of depressive and/or anxiety symptoms (Kimmel, 2020). The prevalence of postpartum psychosis is 1-2 per 1000 births and is seen within the first few weeks (Perry et al., 2019).

Women of low socioeconomic status, ethnic/racial minorities, and single women are at higher risk for PMAD (Sockol, Epperson, & Barber, 2014). Women who were

diagnosed with PMAD or had a serious mental illness (SMI) had greater incidence of preterm labor (McKee, 2020). SMI includes disorders that impact functioning and include bipolar and psychotic disorders (McKee, 2020). Experiencing trauma during childbirth increases the risk of developing postpartum PTSD (Ayers, 2017). Another factor that increases risk of PMAD during pregnancy is the previous loss of a baby (Farren et al., 2020). Lastly, there are increased rates of postpartum depression when the mother has a baby admitted into the NICU (Bansal et al., 2018). Diagnosis and treatment of mental illness is even lower in minority women as there are barriers present (Young et al., 2019).

Parents of young children report higher levels of stress than those who are childless (Mitchell, Wister, & Zdaniuk, 2019). Parenting stress is defined as psychological and physical burdens related to parenting responsibilities (Nam, Wikoff, & Sherraden, 2015). There are long term effects for parents and children. The parental stress it leads to “low self-esteem, low self-efficacy, low satisfaction in the parental role, and heightened risk of depression and anxiety” (p. 278). Parenting stress varies between races and is higher in African American culture due to systematic racism and other race-related issues. Through the womanist lens, it was important to focus on the unique experience of B/AA women.

### **Black and/or African American Mothers’ Mental Health**

The mental health disparity with B/AA women continues to permeate to mothers. There are several factors which are and will be highlighted to support why their levels of PMAD are higher. Unfortunately, researchers still believe the rates are higher due to the

lack of reporting or inability of healthcare professionals to accurately diagnose the disorders in this population (McKee, 2020). Black mothers often endure compounded stress during pregnancy that includes healthcare discrimination, lack of access to resources, and financial burdens that impact their mental health. During the postpartum period, this stress may become a mental health concern. The lack of mental health support and identification of symptoms may lead to continued distress.

Per Nam, Wikoff, and Sherraden, (2015), racial and ethnic minorities experience higher levels of parenting stress. Black mothers report higher levels of overall depression than Whites. The difference in minority stress is attributed to economic hardship, maternal and child characteristics, and environmental factors. According to the family stress model of economic hardship, material hardship and a lack of resources leads to potential anxiety and depression. For example, a mother may not have resources and therefore, will face material hardship as she will not be able to provide for her family. This inability to provide can lead to psychological stress. The depression and anxiety that may be an outcome will impact the mother's functioning. The mother may not interact with her family or support system as much leading to further isolation. Another source of stress can be that mortality rates of Black infants are 2.2 times higher within the first month of life than White infants (Mathews et al., 2015). Therefore, the mothers could experience higher rates of anxiety.

Results from research have indicated that Black mothers often feel as failures if they ask for help or report feeling overwhelmed as they have internalized the SBW controlling image (Dow, 2015). Black women in the United States are more likely than

other women to suffer from chronic mental (generalized anxiety and somatization) health (Jerald et al., 2017). Racism and sexism are thought to play a role in this disparity. These symptoms may become chronic due to the lack of ability to reach out for help and mistrust of the system.

Perceived racial discrimination is the “belief that one has experienced differential unfair treatment based on racial group membership” (Jerald et al., 2017, p. 488). Racial discrimination is a chronic social stressor that increases allostatic load that increases negative health outcomes and decreases engagement in healthy behaviors (Jerald et al., 2017). Allostatic load is defined as the “cumulative wear and tear on the body that occurs over time when the activation of stress responsive systems is repeated or prolonged, causing multisystemic dysregulation” (Ross et al., 2020, p. 719). Allostasis is referred to as the body’s physiological process of maintaining stability during change. As the first year after birth is marked with many changes and increased stress the allostatic load is greater (Ross et al., 2020). The greater the allostatic load the more negative health outcomes mentally and physically. Higher perceived support is related to a lower allostatic load (Ross et al., 2020). Minorities are believed to be impacted by social stressors and more vulnerable to a higher allostatic load (Ross, et al., 2020).

A metastereotype is when an individual from a marginalized group believes others from another group believe about them (Jerald et al., 2017). Metastereotypes indirectly and directly associated with poor health outcomes. Black women reported increased stress and reduced well-being being focused on others’ beliefs about them (Jerald et al., 2017). Black women often experience a mistrust in their providers

especially if they are White. Black women are more likely to have unfavorable outcomes during pregnancy and delivery (Adams & Thomas, 2018). Discrimination occurs during prenatal care and has been identified with hospital/doctor visits. may not experience (Adams & Thomas, 2018).

According to Assari (2018), health disparities are poor for those who identify as African American or Black. These disparities begin in the prenatal period as evidenced by preterm birth rates, chronic disease, and mortality rates. Health disparities are caused by structural racism and systematic injustice towards Blacks/African Americans. Social inequalities such as poverty, unemployment, and a lack of education often lead to health problems. There is little information on the disparity of mental health with B/AA mothers. This disparity has some causes, but limited studies have provided in depth information.

Treatment rates are low for minority women diagnosed with postpartum depression (Bodnar-Deren et al., 2017). Mental health stigma is higher among Black women than White women (Bodnar-Deren et al., 2017). Bodnar-Deren et al. also discussed how Black women are more likely to seek spiritual counseling than mental health counseling or psychotropic medications (2017). Culturally there is a stigma, potentially from the SBW controlling image that Black women can and should be able to handle their responsibilities regardless of how intense their mental health symptoms. These women internalize these stressors and are less likely to identify there is an issue that needs to be addressed or their health is important enough to focus on.

According to Taylor and Kuo (2019), Black Americans use mental health treatment less than any other racial/ethnic groups. A barrier to treatment includes a small number of Black therapists (Kawaii-Bogue, Williams, & MacNear, 2017). Most African Americans prefer a therapist with the same race. Black Americans have reported negative experiences with mainstream therapy and mental health services. This continues to be a difficulty as there are a large percentage of White providers in the United States (Coley et al., 2018). There are multiple barriers to access treatment to include stigmas, cost, transportation, and childcare. With the added responsibility of another child the mother may not be able to afford treatment. Mothers may also not be able to attend treatment due to a lack of transportation. Immediately after birth, mothers are unable to drive and must depend on others for transportation. Some mothers may not be able to attend treatment due to an inability to find childcare. Other barriers for effective therapy include misdiagnosis, lack of social support, and disempowerment (Kawaii-Bogue, Williams, & MacNear, 2017).

Treatment rates for PMAD is low in minority women. There are often many responsibilities for these mothers especially if they work or have other children and their own treatment is not a priority. Women may not have the economic means to obtain treatment with the increased financial obligations from the new baby. These mothers may also be focused on their new baby and minimize the necessity to focus on their own health. Finally, culturally due to the reluctance to share emotional vulnerabilities these women may not understand postpartum mental health and its potential impact. The SBW controlling image may make Black woman believe they do not need to seek treatment

and can overcome this difficulty on their own. They may struggle with the negative connotations regarding treatment such as being weak. Mental health is not seen in the Black community as a necessity or a high priority (Fripp & Carlson, 2017). This may be due to all the other important responsibilities such as other children, working, and education.

I have illustrated the gaps through this literature search. There is limited information related to the mental health of mothers with newborns through the various stages beginning at prenatal until parenting. A potential reason for the lack of information is the lack of engagement in services. The lack of information also leads to a lack of treatment and thus growing disparities. Future research should focus on decreasing the stress and increased coping methods to potentially prevent the development of disorders. The next section will focus on the NICU.

### **Mental Health of Mothers With Babies in the Neonatal Intensive Care Unit**

Approximately 7% of all births result in some level of NICU care (Hynan et al., 2015). It has been estimated that 20-30% or more of NICU mothers experience a diagnosable mental health disorder during the first year postpartum (Hynan et al., 2015). There are an additional portion of those who meet subclinical criteria; this means they meet some but not full criteria for a mental health diagnosis.

Having a baby in the NICU impacts the mental health of the mother as well as the parent child relationship (Turner, 2015). The authors also stated, mothers may experience increased rates of stress as well as anxiety and depression. Mothers have reported a lack of confidence in their ability to care for their baby and overall physical distance from



them consistently as they are in the hospital. This experience strongly differs from those who have a full-term healthy baby. There are feelings of powerlessness and intimidation as parents are often uninformed about the NICU experience (Hall et al., 2015). According to Turner (2015), mothers reported increased guilt and self-blame for not being able to care for the newborn full term. There is also anxiety around infant death as their newborns are in the hospital for severe medical concerns. Being in the NICU forced mothers to hold their babies and then leave them there. While taking the baby home, mothers were concerned about the ability to provide adequate care for them.

According to Madalynn (2020), NICUs were introduced in the 1960s to prevent infant mortality and focused on physical health and care. In 1992, NICUs began to focus on family centered care (FCC). The FCC focused on the parent child relationship. Visitation was increased as parents were able to interact with their child more. Kangaroo care (skin to skin) was used as it promoted development in the babies. The relationship between mothers and nurses was also important as it leads to less anxiety in mothers and increased confidence in competence. Parents are assisted with feeding where lactation specialists are available. Benefits of this approach included “shortened length of infant hospitalization, reduced hospital readmissions, better neurodevelopmental outcomes and infant weight gain, less maternal anxiety, and higher-quality maternal caregiving” (p. 68).

According to Lotterman (2019), mothers who gave birth preterm were more likely to suffer from postpartum depression, anxiety, and PTSD than mothers of full-term babies. Moderate to late preterm babies (between 32-36 weeks gestation) are closer to full term babies (Lotterman, 2019). These mothers are often overlooked as medical

professions assume; they are less distressed due to the higher chances of survival. These psychological symptoms did not end after hospitalization but continued up to 6 months postpartum. This finding shows that mental health care during postpartum is important to overall health.

There are increased amounts of stress by mothers due to the NICU environment itself to include the lights, sounds, and machines (Gonya et al., 2019). The results of the study by Gonya et al., (2019) indicated that nursing shifts can be a source of maternal stress. There are new people around the infant and a lack of security with the variability in nursing shifts. The stress may impact the parent child interactions and overall well-being. Following a NICU stay, parents experience large amounts of stress. Stress can be both financial and emotional (Purdy, Craig, & Zeanah, 2015). Financially, parents may have strains at their job, increased income with a new baby, and medical bills. Emotionally, the mothers experience stress from being a new mother and a mother of a child with high needs (Purdy, Craig, & Zeanah, 2015). The emotional stress of a preterm baby and hospitalization can impact the family unit. Social isolation is a related factor to parent stress and has a large impact on the family (Lakshmanan et al., 2015). Social isolation can cause the mother to increase her own depressive symptoms and put a strain on her relationships with others.

During the transition home and while the infant is in the NICU, mothers may blame themselves for the preterm birth (Adama, Bayes, & Sundin, 2016). They may also prioritize the baby due to guilt from being preterm and wanting to provide them with everything. This will cause them to not only neglect themselves physically but mentally

as well. The lack of self-care may impact her mother's relationship with her spouse and/or other children.

Although, the NICU experience is higher in the United States than other Western developed countries. There is still limited information regarding why the rates are higher and how to decrease them. Hospitals and other medical settings continue to be ill-equipped to manage the mental health concerns of these mothers. As stated previously, there continue to be disparities in B/AA mothers and preterm births.

### **Mental Health of Black/African American Mothers with Babies in the Neonatal Intensive Care Unit**

Preterm birth is defined as giving birth prior to 37 weeks gestation and is a public health issue (Bouras et al., 2015; Sealy-Jefferson et al., 2016). In 2020, 12% of births were preterm in the United States (Bouras et al., 2015). Various factors are thought to cause preterm birth to include maternal age, Afro-American ethnicity, previous induced abortion, and a prior preterm birth (Bouras et al., 2015). According to Bouras et al., other factors such as maternal smoking and prenatal depression and anxiety may also increase the chances of preterm birth.

In 2016, the rate of preterm births for African American mothers was 13.8% compared to 8.8% of non-Hispanic White women in the United States. Black mothers and fathers are twice as likely to have a preterm birth than white mothers and fathers (Giurgescu, 2018). According to Giurgescu, preterm births are the leading cause of infant mortality in Black families (2018). These racial disparities are difficult to account for aside from medical conditions and social determinants of health. Therefore, it is

necessary to decrease the disparity through increased support for mother during the perinatal period. According to Braveman et al., (2015), there is a significant disparity in race and preterm birth (PTB).

PTB predicts infant mortality, as well as other developmental delays in childhood (Braveman et al., 2015). These childhood difficulties may lead to adulthood chronic disease, disability, and premature mortality. According to Braveman et al., (2015) there are several factors that lead to potential PTB that account for the racial disparity to include socioeconomic status that can impact health. These include lack of healthcare, poor nutrition, limited resources, and education. Neighborhoods that have high poverty levels, unemployment, segregation, and high incidence of crime may also have an impact on PTB (Braveman et al., 2015). Social factors related include social isolation and overall stress. In a study completed by Braveman et al. (2015), SES was controlled for and the disparity was analyzed. When SES was equal both White and Black women were equal with PTB. When the higher socioeconomic levels emerged, Whites improved however, Black women continued to have high rates of PTB which leads researchers to believe there are other factors that contribute to the disparity. These factors are related to chronic stress.

Depression is thought to play a role in this disparity. Although the variance in depression rates between pregnant women is large, some speculate it may be due to pregnant Black women not seeking or receiving mental health care (Nutor, 2018). Low socioeconomic status also impacts PTB. Low SES is related to financial problems, interpersonal conflict, unemployment, and a lack of social support (Nutor, 2018).

Pregnant Black women are more likely to live in disadvantaged neighborhoods than pregnant White women (Giurgescu, 2018). The neighborhood conditions and discrimination may increase the risk of psychological stress and depressive symptoms in pregnant Black women. Low SES is often related to overall poor health and risky behavior (Ncube et al., 2017). Social support and inconsistent or absent relationships increase the probability of PTB. Black women do engage in kin networks where they have support but may not allow themselves to communicate or experience emotions that may be perceived as weak from others and do not want to ask others for help.

Other psychosocial factors such as maladaptive coping skills to include avoidance and an internal locus of control increased the chances of preterm labor (Giurgescu, 2018). The SBW is expected to manage all her roles and responsibilities. This subtle stress may largely impact the women and lead to preterm labor. The SBW may experience a higher baseline allostatic load and the stress of a new baby and pregnancy may lead to other conditions that lead to preterm labor.

There are substantial impacts to the mother following a PTB due to the emotional distress (Bouras et al., 2015). According to Bouras et al., (2015), mothers of a preterm baby experience higher levels of psychological distress to include anxiety and depression than mothers of full-term babies. Feelings of disappointment, fear of infant death, and altered parental experiences such as not spending time with the baby impact these mothers. Other impacts of the traumatic event include self-blame, guilt, and shame (Bouras et al., 2015). A loss of the expected mother roles during the babies' NICU stay

contributes to psychological distress. PTSD related to preterm birth is also possible (Holditch-Davis, et al., 2015).

The mother's responsiveness and sensitivity to her infant is impacted. The mothers of babies in the NICU reported higher levels of stress, anxiety, and depression (Bouras et al., 2015). According to Pineda et al., (2018) there are increased demands to care for the infant in the NICU and balance other responsibilities. Increased parent participation while the infant is in NICU leads to improved outcomes both short and long term. In one study, increased parent participation was more common for Caucasian women.

Researchers have identified differences in care for infants in the NICU based on race (Profit et al., 2017). A systematic review was completed on racial/ethnic disparities in the NICU by Sigurdson et al., (2019). According to the Sigurdson et al., (2019) the outcomes included neonatal mortality rates being higher in hospitals with more Black infants, infants received less breast milk and mothers received less breastfeeding support, nurse understaffing, and early intervention referrals were lower for Black infants. These disparities in the treatment of the infants may be related to the treatment of their mothers.

There are barriers to Black mothers visiting the NICU if they have other kids and responsibilities in the home. According to Brown et al., (2016) there was less social support while with the baby in the NICU. Visiting the baby depending on the length of time in NICU can create financial burdens (Brown et al., 2016). A lack of knowledge and trust with medical providers may impact the mother's confidence in making decisions for their child's care. The transition home with the baby is often difficult for B/AA mothers

(Brown et al., 2016). According to Brown et al. (2016) this included stress and anxiety regarding the ability to adequately care for their baby who will require special attention.

### **Resources**

There are limited resources available for B/AA mothers. There are some community resources to include support groups for women that can be connected to the hospital or separate (Hall et al., 2015). Family and friends are also considered a source of support. There is limited information regarding what resources are available for the mother while in the hospital. There are mental health counselors in these areas that can provide services. These counselors are often not aware of the need for their services and the barriers to mothers receiving this information. The following information provides more details regarding support and barriers.

### **Support**

Some women lack support during the perinatal period. Negative attitudes are associated with depression during these times (Sockol, Epperson, & Barber, 2014). Psychosocial support is identified as a mitigating factor for the development of mental health difficulties related to PTB (Hall et al., 2015). Mothers may not want formal support from a professional during this time. Hall et al. (2015) also stated that mothers often receive less support from their family and friends as they are also unaware of the NICU experience. Support may be provided through peer support groups which occur in the hospital or community. The purpose of peer support groups are to increase a sense of comfort among parents where they can share their vulnerabilities, receive validation, gain perspective, as well as encouragement in order to advocate for themselves and the baby

(Hall et al., 2015). Benefits of support groups include obtaining psychoeducation as the mothers did not feel prepared to be a mother. Another benefit is the shared experience between other mothers with babies in the NICU (Turner, 2015). Mothers benefit from improved mental health. First, rates of anxiety and depression rates are lower. Second, increased well-being through confidence, increased coping mechanisms, self-esteem, and acceptance. Their overall ability to better care for their infant's needs in the NICU led to a shorter hospital stay (Hall et al., 2015).

According to Hall et al., (2015) there are several types of support groups. First, in person peer support groups are when a parent mentor is assigned to the mother. This support group is there to assist the parent in whatever they need during this transitional period. The mentors are matched as closely as possible with culture, language, etc. Hall et al., (2015) stated the advantage is the parents will reduce feelings of isolation that may lead to depression. A disadvantage to this form of group is that if parents are not matched well this may not be a productive relationship. Peer support groups can also be done via telephone. The telephone allows greater flexibility (Hall et al., 2015). A disadvantage is mothers may not have the time to meet via telephone. According to the authors, the second form of support is the parent support group which is led by a parent, NICU professional, and/or mental health provider. The goal of this group is to provide education to the mother. The mothers will be able to hear from professionals and obtain information that may not be available to them otherwise. A benefit to this is the access to professionals and developing relationships with them (Hall et al., 2015). A disadvantage is that some may not feel comfortable discussing their concerns around other parents for



fear of judgment. The final form of support group occurs via the internet. Hall et al., (2015) reported internet support groups are growing in popularity and are often run by a veteran parent and/or mental health professional. An advantage to this form of group is the anonymity as others may be inclined to participate. Mothers can access the information at any time no matter where they are. A drawback for this is that there may be a lack of oversight and misinformation may be passed along to NICU mothers.

Per Hall et al. (2015), support groups are not offered in all NICUs or hospitals. There may be several barriers to using support groups during this time for African American woman. The SBW image would explain why African American woman will not reach out to other parents for assistance. Culturally, there may not be many parent mentors or peers that are “matched” appropriately. Cultural differences may impede the relationship and lead to overall distrust. There may be a lack of resources to attend these meetings via internet, phone, or in person (Edmonds, Mogul, & Shea, 2015). As resources are getting more spread out, mothers may not be able to transport themselves to meetings in the community. They may not have the resources to take care of their child in the NICU, family at home, and attend groups (Edmonds, Mogul, & Shea, 2015).

There are recommendations for mental health workers in the NICU (Hall et al., 2015). First, each NICU with at last 20 beds should have mental health professionals designated to this department. These mental health workers should have a designated space for individual and group time. Mental health workers as part of the team should meet with the mothers regularly and provide resources when necessary. Next, these workers may act as a liaison between other medical professionals to advocate for the

mothers (Hall et al., 2015). Mental health workers should be able to accurately assess, diagnose, and provide therapy to the NICU mothers while the child is in the hospital.

### **Friends/Family**

According to the World Health Organization (WHO) social support networks are a determinant of health (Holt-Lunstad, Robles, & Sbarra, 2017). Overall, Americans are engaging in less social interaction. The absence of social connectedness and interaction is related to early death. Social interaction is viewed as a public health issue and can impact health negatively. Therefore, mothers especially those who experienced a PTB need to have social networks in order to promote their physical and mental health. These support networks can be informal or formal to include family or friends.

According to Atkins (2017), approximately 70% of Black single mothers endorse symptoms of depression that warrant a diagnosis; this is nine times the rate of the general population. Depressive cognitions often lead to depressive symptoms and a lack of perceived social support (Atkins, 2017). Depressive cognitions are “specific maladaptive cognitive distortions” that include “feelings of powerlessness, helplessness, purposelessness, worthlessness, loneliness, hopelessness, emptiness, and meaninglessness” (Atkins, 2017, p. 465). Depression includes withdrawal and social isolation. Perceived social support is defined as “relational provisions of attachment, social integration, opportunity for nurturance, sense of reliable alliance, and guidance” (Atkins, 2017, p. 466). Therefore, it is important that these women receive social support from friends/family. These mothers who are experiencing depression are less likely to

engage in positive health practices such as relaxation, exercise, safety, and preventative health measures which could include mental health support (Atkins, 2017).

According to Atkins (2017), low income African American mothers have the highest rate of PTB. Preterm babies without significant complications have three times more cost than a full-term baby. The discharge from the hospital often causes high parental stress and anxiety which may lead to acute care visits (Atkins, 2017). The transition home is often difficult as mothers are unaware if the newborn is able to manage their health in the home without being monitored by health professionals. According to Atkins (2017), during the transition, support from family and friends is important. Support from a community of NICU parents as well as other community resources were reported. These networks will provide additional emotional support to the mother when necessary. Within the womanism framework, if there is a perceived low number of African American women who are experiencing this the new mothers may not reach out for support. There also continues to be the SBW controlling image that mothers will not seek support as they do not want to be perceived as inadequate mothers. There may already be guilt/shame regarding not being able to care for their child initially and this may only exacerbate it.

Social support will increase parent competence as low social support is related to low parent competence. Support both emotional and physical can improve maternal well-being and mother-child relationship (Brown et al., 2016). Support from family and friends as well as nurses is important (Adams, Bayes, & Sundin, 2016). These mothers are experiencing low confidence in their ability to care for their child due to their NICU

stay and health concerns. Mothers may have mixed feelings some may include joy, fear, sadness upon discharge from the NICU. The constant state of fear these mothers have for their preterm baby may last over a year. These feelings warrant support from others.

In the 1990s, Sharon Hayes coined the term intensive mothering. It is defined as “the increasingly common belief that good mothers should first and foremost be caregivers and should invest great swaths of time, money, energy, and emotional labor in intensively raising children” (Elliott, Powell, & Brenton, 2015, p. 351). Being Black and poor are not seen as good mothers. In 2009, 50.4% of Black children were being raised by a single mother in comparison to 18.5% of Whites. Black women are three times more likely than White women to balance motherhood and employment; however, they are raising children in poverty. Support from their partner was a necessity during this time (Adama, Bayes, Sundin, 2016). Higher satisfaction with the father’s involvement and role with the new baby leads to a reduction in depressive symptoms (Mayers et al., 2020). As a single mother, there are added stressors and a void in support. This void in support leads to a lack of ability for the B/AA mothers to care for themselves in relation to adequate sleep and diet among others that impacts mental health. There are also added stressors to raising children due to the controlling images placed on kids and the need for their Black mothers to protect them. These women are self-reliant and sacrifice for their kids. This is related to the SBW stereotype and having to have it all together. These women focus on their family and child often ignoring their own needs which include their mental health.

## **Spirituality**

Spirituality is defined as “private, individual-level concept that is characterized by perceptions, beliefs, and feelings about a sacred or divine higher power, universal spirit, or ultimate purpose” or “as a sense of existential well-being which has been referred to as an understanding or belief in the meaningfulness of one’s own life” (Staton-Tindall, et al., 2013, p. 1246). Spirituality was identified as a way for parents to manage the stress of their child being in the NICU (Heidari, 2017). Most parents feel as though there is a lack of religious or spiritual involvement while experiencing this traumatic event.

Brelsford and Doheny (2016) wrote that when using spirituality, there are positive and negative coping strategies. Some mothers chose to focus on God’s love and using faith to combat anxiety feelings. Negative coping included focusing on feelings such as anger and doubt, as well as feeling abandoned by God. In the study by Brelsford and Doheny (2016), mothers who had strong religious beliefs remained strong. Those who had minimal attachment to religion/spirituality remained the same. Higher levels of spirituality are associated with better mental health to include higher “levels of optimism, self-esteem, social support, and life satisfaction” (Kaufman, 2019, p. 3).

Spirituality is embedded in Black culture and churches are core to many communities (Staton-Tindall, et al., 2013). In a study completed by Coughlin et al. (2017), maternal child staff were surveyed; higher levels of spirituality were from African Americans. Approximately 80% of African Americans in comparison to 50% of the general population identify religion as important. Most African Americans identify as Christian and attend church weekly (Avent & Cashwell, 2015). The Black church began

during the slavery era. Slaves were not allowed to worship with their white owners, so they began meeting together in secret places. Eventually these places became more visible. The Black church is seen as a source of strength and support. It focuses on the individual as a whole and is a substitute for professional mental health treatment.

According to Staton-Tindall, et al., (2013), African Americans view religion as important and are often associated with religions. Due to the high level of importance placed on religion/spirituality, it is used to cope with mental health difficulties such as depression, anxiety, and PTSD. Attendance and connection with the church has led to positive outcomes within overall wellness of African American women. According to Woods et al., (2016) most African American women do not believe in depression as an illness and view it as a normal reaction to life stressors. They more often engage in culturally appropriate services such as religion instead of therapy.

## **Barriers**

### ***Low Socioeconomic Status Impact***

There are numerous barriers involved with low SES status and pregnancy (Edmonds, Mogul, & Shea, 2015). Barriers to prenatal treatment included insurance/economic factors, transportation, and ambivalence to care (Edmonds, Mogul, & Shea, 2015). These women do not have access to the same resources and may not be in their area. Low SES relates to other factors to include a lack of transportation. Transportation barriers may impact the mothers from receiving the support that they need as they cannot access it. Another important factor is ambivalence to care. Often those in low SES are thought to be “surviving” and being surrounded with environments that are

conducive to trauma/neglect. The environments may not have adequate food/water. There are often areas where violence is also prevalent. If these women are focused on surviving, then mental health support is not a priority or necessity.

### ***Insurance***

Uninsured women face discrimination in the hospital twice as high as others (Gadson, Akpovi, & Mehta, 2017). A barrier also includes Medicaid processes as mothers may not be knowledgeable about enrollment periods and eligibility. There are often certain providers that accept Medicaid and these providers may carry implicit barriers towards B/AA women. Also, difficulties with insurance coverage may determine the amount and type of mental health services the mothers can obtain. These women may not be knowledgeable about providers in their area that are able to provide services to them with their insurance or financial situation. Often financial responsibilities are a source of stress and many cannot afford services without insurance. Specific rates of NICU stays range based on the hospital and state. The average rates can be around 3000 per day not including provider bills and additional fees.

### ***Prenatal Care***

Prenatal care is vital to maternal and baby health. Without early prenatal care there is an increase for the “risk for unintended high-risk pregnancies, cesarean deliveries, or prematurity” (Danilack, 2015, p. 806). The goal of prenatal care is to improve pregnancy outcomes. This time is also used to assess risk as well as provide support (psychosocial, cultural, and educational) There are barriers to prenatal care some include difficulties with insurance, financial issues, inability to identify pregnancy, lack

of appointment, lack transportation, and undesired pregnancy (Shah, Revere & Toy, 2018). A major barrier to prenatal care during the appropriate time is consideration of abortions. Those women who are considering abortion are hesitant to obtain treatment (Johnson, 2003). Prenatal visits normally last approximately 10 minutes and occur every four weeks until 28 weeks, two weeks until 36, and weekly after (Carter et al., 2016). Due to the time constraints, there is often limited time to discuss issues with pregnancy, breastfeeding, or newborn care among others (Carter et al., 2016). This is another barrier as the mother's may not believe that their concerns are important enough to discuss with their provider.

African Americans (11.7%) are less likely to obtain prenatal care than Whites (5%; Nypaver & Shambley-Ebron, 2016). Black women are less likely to get timely and affordable care (Gadson, Akpovi, & Mehta, 2017). The travel involved may be a barrier to getting to appointments. When the mothers receive care, they are more likely to report adverse experiences and do not receive adequate care (Coley et al., 2018; Gadson, Akpovi, & Mehta, 2017). Participants in a study by Gadson, Akpovi, and Mehta (2017), reported being discriminated against while in the hospital for delivery. One of the causes of this discrimination was communication barriers. According to Attanasio and Hardeman (2019), Black women are more likely to report poor provider-patient interactions during medical care than Whites. In a 2017 study, 32% of Black women reported experiencing discrimination due to their race in healthcare (Gadson, Akpovi, & Mehta, 2017). One potential explanation for the disparity are implicit biases that White providers may hold. An implicit bias is unconscious and automatic. These implicit biases



will impact how the level of medical care they provide to Black patients. Implicit biases such as Black women being angry or aggressive may have the clinician view them as defiant and noncompliant. These Black patients often report feeling unheard and disrespected. Due to these feelings, middle class Black women have focused on self-preservation and improving their image in the eyes of their White provider to eliminate the biases (Attanasio & Hardeman, 2019). This decision has resulted in the inability to effectively communicate their needs or concerns with the provider.

### **Summary and Conclusion**

Mental Health is a current focus as the rates continue to increase of PMAD. There are maternal mental health concerns for women in the United States. Women in the United States struggle with postpartum depression and other illnesses at high rates. Women have mental health difficulties and experience affective disorders and other disorders specific to being a female. Women are more often diagnosed with affective disorders than men (Substance Abuse and Mental Health Services Administration, 2018). In my literature review, I have identified disparities related to race and gender. Being Black adds additional stress due to the intersectionality of race and gender. B/AA women often experience high levels of misdiagnosis. B/AA women also seek treatment at low rates and therefore, their mental health symptoms continue or worsen (Watson & Hunter, 2016). Specifically, B/AA women in the United States have babies prematurely at a disproportionate rate compared to White Women. These women have risk factors that contribute to these high rates. B/AA mothers with premature babies in the NICU have unique characteristics that lead to the necessity of mental health care. Due to the gaps in

the literature regarding the meaning of their experience it would be beneficial to gather this information through semistructured interviews. Chapter 3 will provide more information regarding how I determined the meaning of this phenomenon within this population.

## Chapter 3: Research Method

### **Introduction**

The purpose of this HP research was to bridge the gap in the literature related to the meaning of the lived experience of B/AA mothers who have had a preterm infant in the NICU. The first two chapters of this study included information that related to mental health for women and mothers. Specifically, the information provided focused on racial differences affecting B/AA mothers with preterm babies in the NICU. I identified gaps in the literature that became the focus of the study. The current chapter will highlight the research design, my role as the researcher, methodology, and issues of trustworthiness.

### **Research Design and Rationale**

I focused on the experiences of B/AA mothers who have had a child in the NICU. The main research question was the following: What is the meaning of the lived experiences of B/AA mothers who have had a preterm infant in the NICU within the past 5 years?

Qualitative research design was used because the focus of this research was on taking a deeper look into a concept or phenomenon. This research design used words instead of numbers. HP focuses on the meaning derived from a phenomenon within a group. This design was most appropriate for the research question. The question itself focused on an interpretation or perception of an experience or phenomenon that cannot be measured and must be described in words. HP focuses on the human experience as it is lived (Lavery, 2003). Heidegger used the term *dasein*, which refers to the meaning of a human in the world (Lavery, 2003, p. 24). According to this theoretical framework, a

person creates meaning based on life experiences, and this becomes the person's reality or truth. The current study explored how the participants' own life experiences had impacted their perception of the phenomenon.

Quantitative design was not used for this study and was not appropriate for the research question. Quantitative research focuses on numerical data, and the goal is to focus on the relationship between variables. This research did not involve looking at a relationship or two unique variables. Mixed methods research design was also not appropriate for this study. A mixed methods design requires an element of quantitative research (Sahin & Ozturk, 2019), which was not included in this study. Mixed methods design includes elements of both quantitative and qualitative research to answer a research question (Sahin & Ozturk, 2019).

### **Role of the Researcher**

My role as the researcher was that of an observer and second instrument in qualitative research. I served as an observer through interviewing and data collection. Within phenomenological qualitative research, it is believed that it is very difficult to completely remove inherent biases, as they may be unknown to the researcher. These biases are necessary and important if the researcher is aware of them and their potential impacts, according to Gadamer (van Manen, 2014). When adopting a foundation of HP, researchers cannot remove themselves from their research and eliminate all biases (Neubauer et al., 2019). Researchers must be aware of biases and can include them in their analysis of data.

Because I had characteristics in common with the research group, I had to be careful to ensure that my study was trustworthy. Like the participants, I identified as a B/AA woman who had a baby in the NICU within the past 5 years. With the similarities in our characteristics, I had shared experiences with the participants. Being like the group that I was studying had costs and benefits. I sought to connect with these mothers and hoped that they might be willing to not only participate, but also share their authentic experience with me. This honesty provided rich data and results that are meaningful. I anticipated that my identity as a member of a minority group might assist in others feeling comfortable sharing with me. It would have been naïve of me, however, to believe that my identity as a B/AA mother would automatically ensure that others trusted me.

As a researcher working within the womanist framework, I showed my level of commitment to the topic, my ethic of caring, as well as my personal responsibility to this topic (Lindsay-Dennis, 2015). This occurred through *participatory witnessing*, which is defined as actively engaging the self in all aspects of research (Lindsay-Dennis, 2015). I sought to demonstrate my level of commitment through explaining to participants the purpose of the research to me. Additionally, I showed an ethic of caring through being invested in not just data collection, but also the goal of impacting change for the population. Personal responsibility and investment were also important. I engaged in reciprocal dialogues with the participants and assisted in the participants telling their stories, which is critical for this population (Lindsay-Dennis, 2015). My personal

responsibility and investment were also displayed through my engagement in the interviews.

One of the potential costs was that I could have overidentified and assumed certain details about participants' experience that they did not explicitly state. I used my dissertation team in cases that required further interpretation. I used clarifying questions to ensure that I understood what participants were communicating. Given the characteristics that I had in common with the participants, it was important for me as a researcher to take care of myself and address potential emotional impacts. One way that I managed this was through journaling following each interview. Another way that I monitored my own emotional state was through spacing out interviews and giving myself time to debrief between them if necessary with a colleague or member of my dissertation team. I also had oversight by experts in the field (my dissertation committee).

Due to my current work setting and the potential for conflict of interest, I did not recruit participants from my workplace. There were no prior relationships in which power was an issue. In my area, there might have been participants whom I knew personally or professionally. Reflexivity was used throughout the process to identify potential biases. Reflexivity is defined as researchers engaging an inner dialogue or self-critical aspect to identify how they may impact their research through their positionality (Berger, 2015). I used reflexivity throughout the research process to increase the trustworthiness of the study (Berger, 2015). A journal was helpful for field notes so that I could ensure that I was documenting additional information that enhanced the richness of the study (Phillippe & Lauderdale, 2018).

## **Methodology**

My role as a researcher was clearly outlined to include how I managed the subjectivity within the study. In the previous section, I explained why I chose the specific research method for this study and its appropriateness for the research question. The current section will focus on the methodology. Specifically, I will explore participant selection, the instrument used, and data collection methods. Finally, I will explore how I ensured that the study was trustworthy.

### **Participant Selection Logic**

The population of interest was B/AA mothers. I used purposive sampling in the study. This is also referred to as *judgment sampling* (Etikan et. al., 2016). In this form of sampling, participants are chosen based on them meeting specific criteria. The inclusion criteria for this study were identified as being Black or African American and having a baby in the NICU within the past 5 years. Purposive sampling is common in qualitative studies, in which researchers attempt to find cases that will provide the most information and rich data for their research question (Etikan et. al., 2016). The participants self-reported their race and having a baby in the NICU within the past 5 years.

I anticipated that I would need eight to 10 participants for this research study in order to reach saturation (Creswell, 1998). If saturation had not been reached, I would identify and interview additional participants. Within this study, rich data were collected that provided overarching themes that led to implications in practice for the counseling field. The population that was studied was very specific; therefore, a relatively small

number of interviews was required to reach saturation. Sample size within HP is often small. At least six interviews are common within phenomenology (Mason, 2010).

Recruitment of participants occurred in multiple ways. First, I posted approved content onto various social media platforms and groups to obtain participants. If I had been unable to identify an adequate number of participants, I would have used participants to identify others who might qualify for the study. Flyers were not used due to COVID-19 safety precautions.

### **Instrumentation**

The data for the study were collected through semistructured interviews that were audio recorded. The interviews began with reviewing informed consent and the purpose of the study. The interview questions were used to answer the research question. The interview questions can be found in the Appendix. When necessary, I asked probing questions. I maintained a log of follow-up questions for potential use for future participants. As a qualitative researcher, I was also an instrument. According to Pezalla et al. (2012), an interview is an active exchange of information by at least two parties. The way in which I interviewed the participants to include my style and the interpretation of communication impacted the exchange of information.

### **Researcher-Developed Instruments**

Currently, there is a gap in literature regarding the experience of B/AA mothers with preterm babies in the NICU. Therefore, there were no pre-existing interview questions for this topic; I created the interview questions. The interview questions were in alignment with womanist and HP theory. I asked questions that clarified meaning derived



from participants' unique experiences as Black women. Other questions related to controlling images and activism were included as they that are important tenets to the womanist theory.

### **Procedures for Recruitment, Participation, and Data Collection**

Data were collected through individual interviews that I conducted. The interviews lasted approximately 60-90 minutes and were conducted virtually via Zoom. I audio recorded the interviews to transcribe the data. The data were stored on a password-protected computer. If during recruitment there had been too few participants, I would have continued to investigate until saturation was reached. Saturation was reached once participants no longer included new information regarding their experience. I discussed saturation with my dissertation committee prior to moving forward. I provided a debriefing after each interview in which I discussed the next steps in the research study, reviewed any questions or concerns, provided participants with resources, and thanked them for their time and participation.

### **Data Analysis Plan**

I interpreted the meaning from the interview responses to answer my research question. I transcribed the data by hand. Transcribing the data by hand allowed me to become more intimate with the data and focus on what participants were saying and how they were saying it. There are three approaches used for thematic analysis of phenomena: (a) holistic or sententious, (b) selective or highlighting, and (c) detailed or line by line (Magrini, 2012). I chose the selective or highlighting approach by van Manen. The first stage included reading and re-reading the transcripts of the interviews (Parsons, 1997).

After careful examination of the interviews, I highlighted initial themes that emerged from the participant responses. I wrote the highlighted initial themes on index cards and put them on a board. Once this was completed for all participant interviews, I used this information to review any similarities and differences among the participants. Essential themes were identified and recorded. Both individual and composite textural as well as structural descriptions were included. Individual textural descriptions include the “what” of the phenomenon with the participant (Eddles-Hirsch, 2015). Composite textural descriptions include themes across the group or universal of the “what.” Then I identified the structural descriptions, which include the “how” of the phenomenon (Eddles-Hirsch, 2015), first within the individual and then in the composite descriptions.

The next steps included identifying subthemes from the themes and data responses that I collected. A trifold board was used to organize responses into themes, subthemes, and broader categories depending on the responses provided. I consulted with my dissertation committee throughout data analysis to ensure that I was interpreting the correct themes, categories, and subthemes. Discrepant cases were included in the research. If an interview appeared to provide a unique perspective, I asked follow-up questions to gather further data related to the unique experience. This information was important to the study and the overall implications.

### **Issues of Trustworthiness**

Trustworthiness is necessary for a high-quality research study that provides conclusions that will enhance the respective field (Peterson, 2019). There are counterparts in quantitative data that might be more familiar such as validity, reliability,

rigor, and objectivity. In qualitative data, researchers focus on credibility, transferability, dependability, and confirmability. In the next sections, I will define and illustrate how these were included in the study.

Credibility (internal validity) determines if the results or participants' responses are valid or "fit in" with the researcher's perspective or the study's purpose (Nowell et al., 2017). I enhanced credibility in multiple ways. First, I had my committee members review my data to decrease researcher bias through triangulation. I let the participants have access to their interviews to clarify any discrepancies once data were transcribed through transcript checking. If they saw any mistakes, participants could provide clarity on their intentions. The interviews were also audio recorded. Digital recordings assisted in transcribing the interviews and conducting data analysis. I included direct quotes from the participant interviews to accurately analyze the data (Peterson, 2019). Finally, my dissertation committee had access to my data and determined if there were inaccuracies in data collection.

Transferability refers to the ability to transfer results in similar settings, situations, and so forth (Nowell, 2017). The burden of determining if results are transferable is determined by the person who wants to transfer them (Peterson, 2019). I used thick descriptions within the research to enhance this element of trustworthiness (Peterson, 2019). Van Manen (2014) warned against generalizing phenomenological studies as the goal should be to identify what is unique or essential about the phenomenon and what makes it singular and unique. A goal in this study was to provide themes that allowed the

basic tenets of the phenomenon to be universal to all B/AA women while highlighting the uniqueness and importance of their experience.

Dependability focuses on whether a study can be replicated—specifically, if someone else could follow the study in a logical manner (Nowell, 2017). To enhance dependability, I practiced reflexivity through journaling. This self-reflective journal included field notes from the interviews (Nowell, 2017). All of the interviews were recorded and transcribed. The research project was traced through an audit trail that my dissertation committee used. Experts within the field (dissertation committee) were used throughout the process.

Confirmability is established when each of the prior elements of trustworthiness have been achieved (Nowell, 2017). This element relates to whether the findings and conclusions from a study are derived from the data (Nowell, 2017). Bias from the researcher can be included in qualitative data as well as subjective experiences. Confirmability was also established through my explicit inclusion of procedures. My procedures and methodology included in-depth detail to enhance confirmability. I also used my dissertation committee to discuss whether and how my bias impacted my interpretation of the results. Field notes were used to document my experience during the data collection period.

### **Ethical Procedures**

The Institutional Review Board (IRB) provided oversight of all research studies. Walden University has its own IRB. The IRB ensured that all research is ethical and follows U.S. guidelines. IRB approval was sought after the oral presentation of the

research project to the dissertation committee members. Approval was required prior to participant recruitment and data collection. The IRB identified potential risks or ethical concerns and ensured these are mitigated. Once the study was approved participant recruitment began. Informed consent was provided to the participants. Informed consent is a process that was followed throughout the study. I also included language regarding the potential sensitive nature of the information and provide mental health resources in the event there is psychological distress because of the interviews. Participants had the right at any time to withdraw from the study. Both “Black” and “African American” was used in the recruitment of participants. The terms were used to ensure that the appropriate criteria were met for the participants and it was in alignment with the research study.

All recordings and interview transcripts were kept in locked cabinets and password secured computers. No names or other identifying information were used in the data analysis. Pseudonyms were used for the participants.

### **Summary**

This chapter focused on the research method. I provided information on the HP study that used. A specific focus was on my role as a researcher as well as methodology and trustworthiness of the study. The following chapter will focus on the results of the study. Specifics that will be included in Chapter 4 are demographics of the participants, setting, data collection, data analysis, results, and trustworthiness.

## Chapter 4: Results

### **Introduction**

The purpose of this HP research was to bridge the gap in the literature related to the meaning of the lived experience of B/AA mothers who have had a preterm infant in the NICU and to provide information that will support counselor educators and supervisors. Therefore, the main research question was as follows: What is the meaning of the lived experiences of B/AA mothers who have had a preterm infant in the NICU within the past 5 years? I developed semistructured interview questions to answer the research question above. The current chapter will include information regarding the setting and demographics of the participants, followed by data collection techniques, data analysis, and evidence of trustworthiness. Finally, I will provide results derived from data analysis.

### **Setting**

In this section, I will review the setting and any identifiable changes that occurred. There were no identified deviations that negatively influenced the interpretation of the findings. All interviews were conducted via Zoom. Due to COVID-19 and related safety protocols, this option proved to be the safest. At the time of data collection, safety protocols from the state of Virginia as well as the CDC recommended being 6 feet apart from others while wearing a mask as necessary for social distancing. The online platform was sufficient to conduct the interviews due to the impacts of COVID-19. The interviews were conducted as planned according to what was described in the IRB documents approved by Walden on November 20, 2020.

## Demographics

All participants met the inclusionary criteria for the study. These included identifying as a B/AA woman who had a baby in the NICU within the past 5 years. I used purposive sampling to obtain participants. The research sample consisted of eight women from the United States. Participant ages ranged from 22-33 years at the time of their babies' birth. As per the requirements, all participants had an infant in the NICU within the past 5 years. Time spent in the NICU ranged from 7 to 100 days. Six of the participants were married. There were 6 participants who could not participate due to having a baby during the COVID-19 pandemic.

**Table 1**

### *Participant Demographics*

	Age at birth	Baby age at birth	Time spent in NICU	Significant relationship
Kristina	30	31 weeks, 6 days	1 month	Yes
Grace	25	Between 34 and 37 weeks	1 week	Yes
Ashley	30	32 weeks	1 month	Yes
Dream	27	26 weeks, 5 days	80 days	Yes
Denise	22	26 weeks, 3 days	82 days	No
Terri	28	33 weeks	1.5 months	Yes
Corrine	29	32 weeks, 1 day	100 days	Yes
	33	25 weeks, 2 days		
Erica	29	34 weeks, a few days	1 week	Yes

## Participants

The participants were eight B/AA women who had a premature baby in the NICU. The women volunteered to participate in the study based on an invitation posted on social media sites including Facebook, Instagram, and Twitter. These women all

wanted to provide information that would be helpful in improving the conditions of future B/AA mothers who have preterm babies in the NICU. The women varied in age from 22-33 years when they gave birth to their babies. The participants varied in their occupations, which included nurse, teacher, and mental health counselor. Women varied in their relationship status at the time of the birth from single to married. The time spent in the NICU by these mothers and their babies varied from 1 week to approximately 100 days. The participants, their babies, and partners were provided pseudonyms to protect confidentiality.

### *Kristina*

Kristina was 30 years old when she delivered her baby at 31 weeks and 6 days gestation. She struggled to manage her blood pressure throughout her pregnancy. Kristina had been ignored by providers, and as a nurse she purchased her own blood pressure monitor. Two days prior to giving birth, her blood pressure went to 160 over 110, and she called her doctor to inform her to come in that night. After receiving the results of her urinalysis, she was told that she would have to have an emergency C-section. Her son spent 1 month in the NICU.

Kristina is married and has an older son who was not born prematurely. She is a NICU nurse herself who gave birth in the same hospital where she worked and provided care for her son. This experience proved to be unique, as she was very knowledgeable about the NICU process as well as the medical terminology that was used by doctors and other providers. "I had a little advantage because I knew kinda what to expect," she explained. Kristina struggled at times with the separation of being a NICU nurse and a



mother. She reported verbalizing her boundaries with the two roles to her husband. Kristina reported that she received limited support from family as her mother had died unexpectedly a few months prior. “It was very overwhelming. My mom had died what 4 months prior.” She struggled with the grief and loss from losing her mom and then shortly after having a traumatic birth with her second son.

Kristina’s overall experience included a great deal of positive support from the NICU nurses, who were also her coworkers. She described their support as “unmatched.” Although her coworkers provided excellent support, she still struggled to manage her mental health. Kristina did not seek additional support and instead dealt with most of her grief/loss and trauma on her own. She leaned on her husband for most of her support.

Kristina continues to be passionate about NICU mothers and babies, especially those who are B/AA. She tries to provide them with extra support and care as she knows this experience firsthand. There were often times in the interview when we laughed at certain aspects of our shared experiences, such as talking about babies’ developmental milestones with others who have not had this experience. I felt as though we connected during this interview and were able to talk about her own insecurities as a mother and how difficult having a baby in the NICU really is.

### *Grace*

Grace was 25 years old when she gave birth to her daughter. To this day, it is unclear at what gestational age her child was born at, but the assumption is that it was somewhere between 34 and 37 weeks. The lack of clarity on the gestational age was in alignment with the questions and concerns throughout not only her pregnancy, but also

her NICU stay. Her daughter stayed in the NICU for a week. She was engaged to her child's father at the time of her birth. Grace was a first-time mother.

She described her delivery as “really bad” and a “terrible experience.” Grace went in for a checkup, and her blood pressure was high and she had a mild case of preeclampsia. She was told to go the hospital to run additional tests, where the doctors would attempt to lower her blood pressure via medication. After some time, her doctor arrived, and her blood pressure did not go down and she had to deliver the baby. Grace waited to get an epidural and was not progressing in labor. She reported a very painful experience and ended up having an emergency C-section that she was not prepared for. During her NICU stay, her daughter went back and forth between the NICU and Grace's room. Grace was never provided clarity on what the exact issue was outside of her blood sugar. She stated that there were “a lot of tears” during this time and that it was very stressful.

During the interview, Grace provided information about her experience. She often appeared to use relatively mild words in her descriptions such as “not great” but later identified the same experience as “terrible.” This might have been due to the rapport and trust built with me throughout the interview. I validated her experience and provided her a safe space to discuss the ways in which this experience might not have been positive and had impacted her. Grace thanked me for studying this specific demographic because she had become passionate due to the impact that her experience had on her and her family.

*Ashley*

Ashley was 30 years old when she gave birth. She gave birth at 32 weeks, and her daughter stayed in the NICU for 1 month. Ashley was married to her husband at the time and had four other children in the home. This was her second NICU stay, as her fourth child was also premature. Ashley was admitted to the hospital for cramping. She was having contractions that were difficult for the doctors to stop, and after an ultrasound they found out that her placenta was abrupting. After this, she was advised that she would have to have a C-section, and she ended up having a blood transfusion as well.

During the interview, Ashley presented as very relaxed. This could have been a result of having a preterm baby previously. She often discussed the differences in her two experiences and ways that she had changed to better her experience. Ashley looked up doctors who specialized in high-risk pregnancies (placenta abruption, to be exact) because that was what she had experienced previously. She reported struggling with her first NICU baby, recalling, "I would cry all the time." Ashley described stronger emotions and a difficult experience with her first premature baby due to being uninformed and unprepared. Like Kristina, Ashley had additional support from her in-laws with her older kids. Ashley described being in a difficult situation with balancing the needs of her other kids while her baby was in the NICU, as she wanted to make sure that she was there for everyone. She also reported that her older kids provided support when she returned home with the baby, which was helpful.

*Dream*

Dream was 27 years old when she gave birth to her daughter. She was married at the time and had recently moved to California. She gave birth with very limited support as her mother was thousands of miles away in Virginia. This was Dream's first child. Her daughter was born at 26 weeks and 5 days. She stayed in the NICU for 80 days. Dream reported that she was a stay-at-home parent for her daughter's first year and that she had recently gone back to work as a teacher. She had no desire to have another child, and this decision had been impacted by her NICU experience with her daughter.

Dream was informed by her doctor during one of her checkups that she would not make it past 34 weeks; at that time, she was only at 26 weeks. The doctor reported that it was "not a matter of if preeclampsia would occur or not but when." That night, she went home and woke up with a "terrible" headache. When she arrived at the hospital, her blood pressure was 192 over 98. She was admitted and stayed in the hospital for 3 days, and then she was informed that she would have to have an emergency C-section to prevent waiting on something "bad to happen to both you and the baby." Her memory was foggy regarding the next steps. After birth, she remembered her daughter being wrapped in plastic and intubated immediately. Dream was not able to see her daughter until the next day.

Dream reported having a good overall experience with the nurses; however, there were instances that stuck out to her where the level of care was not appropriate. For example, she had noticed that her daughter had thrown up, and "her nurse that was watching her that was doing her cares was on Zillow looking at houses." This experience

infuriated me as I began to think about what could have happened if Dream had not noticed or brought it to the nurses' attention. It was interesting hearing about the procedural differences between the hospitals in California in comparison to experiences I had heard about in Virginia. Dream's child is very close in age to my daughter; this shared experience of having a B/AA daughter who is now a toddler was a connection between us. There was an unspoken acknowledgement of the difficulty of the experience and the impact that it still has on us.

### *Denise*

Denise was 22 years old when she gave birth to her daughter at 26 weeks and 3 days gestation. Her daughter remained in the NICU for 82 days. Denise had a hemorrhage and was diagnosed with gestational diabetes. Around 22 weeks gestation, she began to experience pain. She also struggled with a condition that involved severe morning sickness and thus dehydration. One night, she ended up going to the hospital thinking that she was experiencing dehydration; she thought, "I just need to go get an IV." She found out that she had a placenta abruption and was told, "If we don't take her now, you're both gonna bleed out." Denise struggled with the initial transition to the NICU. Her baby did not cry when she was born because she was too little, and she wasn't able to hold her for 4 days.

Denise recalled that the experience was "horrible." There were times that I could hear the emotion in her voice and I really felt awful. I had to ensure that I focused on the interview and remembered my role as a researcher. She went on to say, "it took 26 days to even just hear her cry." Denise went on to describe the impacts of her NICU stay,

including surgeries and appointments that she still attends years later due to her baby being premature. She carries an immense amount of guilt as well. Denise had minimal support during this time, as her mother was helping with her other child. While her daughter was in the NICU, the relationship with her daughter's father discontinued, she connected with other NICU moms, and they communicate regularly and have "reunions."

### *Terri*

Terri was 28 years old, and her son was born at 33 weeks gestation. He stayed in the NICU for a month and a half. Terri is married. She is currently a mental health counselor who focuses on maternal mental health as well as a parent coach. Terri began advocating for herself during prenatal care, when she felt as though "I really started to receive poor care" from a provider. At 23 weeks, Terri had a cerclage (stitch) put in her cervix to assist the baby in staying in longer. Terri then felt as though she needed to switch doctors and went to a teaching hospital in the area. She reported more positive experiences at the new hospital. At 31 weeks, after a doctor's appointment, her water broke, and she went into labor. She described her delivery as "good."

Terri was very vocal about the positive experience that she had with Black doctors and nurses at the second hospital. "My nurses were really phenomenal, and maybe that's because majority my nurses were Black," she explained. When she was in the NICU, she identified that the more attentive doctors were those who were Black. She reported that the "social worker was really terrible" and "there was a total lack of mental health." Terri struggled during the transition and described it as "emotionally difficult." There were times of intense anxiety, sadness, and loneliness. During this time, Terri did

not have appropriate resources. Terri went to stay with her parents for a month to get additional support and stabilize her mental health.

### *Corrine*

Corrine had two premature babies: one at age 29 and one at age 33. Her son was born at 32 weeks 1 day and her daughter at 25 weeks 2 days. Corrine immediately began talking about the trauma experienced during her children's NICU stays. She first mentioned not seeing her son for 48 hours after his birth. She went into the hospital, and after her urinalysis, she found out that she would have a C-section. Corrine described the differences between her son's and her daughter's experience in the NICU. Interestingly, she felt unprepared for her son and attempted to prepare herself for her daughter but was unable to due to the severity of her daughter's needs. Her daughter's birth was difficult as she went into the hospital at 24 weeks and 1 day and was told that she would need to stay on bedrest for the next 10 weeks to prevent a premature labor. Approximately a week later, she gave birth to her daughter. Her daughter was in plastic when she was laid on her chest and was immediately taken to the NICU. Prior to completing the delivery process, she was providing permission for potential medical procedures for her daughter. Her daughter remained in the NICU for about 100 days. Corrine described dropping her son off at school and then going to the NICU all day and returning to pick her son up daily. Twice per week, she would go back to the hospital in the evenings to be with her daughter. Corrine is self-employed and was able to be flexible with work during this time.

Corrine identified times that she experienced discrimination. Although she thoroughly described these situations the word discrimination was never used. An example includes a white nurse that told her little black girls do the best in the NICU and said it made me “feel like she would be the first to be neglected... because you guys feel like little black girl babies are fighters.” This instantly reminded me of the SBW image and how this is placed on babies as young as newborns. During another instance she stated she didn’t want to believe that this occurred, but the nurses would speak to other NICU moms differently. Corrine as the others reported not receiving mental health support during this time.

### ***Erica***

Erica was 29 years old when she gave birth to her daughter at 34 weeks gestation. Her daughter stayed in the NICU for one week. Erica reported her prenatal care was “great.” She was visiting her family for the holidays and ended up going into labor spontaneously. Erica reported being unprepared not only with being away from her but also with the delivery as she had no indication of health conditions. She felt pressured into medical interventions during her delivery without feeling like she had adequate information to decide. Erica struggled with the lack of information provided to her in the NICU. She described feeling like she was looking through the glass and not that she was her parent and involved in the process.

Erica’s NICU experience although not extensive was very impactful for postpartum anxiety for almost a year. She described not taking her baby outside from January until April as she was scared that she was going to get RSV. Erica was taking her



baby's temperature multiple times a day and she would "freak out" if she sneezed or coughed for fear, she was getting sick. Erica never received support and it was not until she became pregnant with her second child that she was informed she had postpartum anxiety. She was determined to prevent another NICU stay with her other children and found providers who could support her effectively. Erica is a stay at home mom and discussed once her children are older, she would like to volunteer at NICUs based on her own experiences to support families.

### **Data Collection**

Upon IRB approval, I posted the approved language on social media sites. I was able to identify participants rather quickly as my social media posts shared quickly. After I was contacted based on their interest, their email address was obtained, and the consent form was sent to them. Once they consented to the interview, I scheduled a time for us to meet that was convenient for both parties through email. Data collection began on November 28, 2020. Data collection lasted about 2 weeks until saturation was reached. I collected data from 8 participants.

Data collection occurred via Zoom. The 8 interviews varied in duration from 30-75 minutes. Data was recorded via audio recording on a password protected computer. I used the Zoom platform and participants were instructed to not use the video feature. The same protocol was used for each participant as well as the semistructured interview questions for consistency. Interviews varied between days and times due to coordinating availability with the participants. Some interviews did not require 60-90 minutes to

conduct. There were no other identifiable variations or unusual circumstances in the data collection techniques.

### **Data Analysis**

A HP design was used to analyze the data. I focused on the interpretation and context of the information (Lavery, 2003). A premise of HP is that people cannot be removed from any situation in fact they are engaged and interpreting their environment consistently (Horrigan-Kelly et al., 2016). The first part of data analysis was reviewing my own field notes. In completing my field notes, I used this to identify emotionality that was being conveyed during this interview based not only on word choice but the way in which they communicated this information which included particular inflection in tone, long pauses, etc. My experience as a B/AA mother was a tool to use as a part of the data collection. I assumed that others would be truthful in communicating with me if they knew I shared that experience.

All participants were engaged in the interviews. I was surprised by their willingness to share very intimate details with me regarding this experience. I found myself very intrigued by their stories. During the interviews, I was intrigued by their stories. I had to ensure that I remained a researcher and not a therapist. There were times I had to remind myself that I was not their therapist. Many participants mentioned others not knowing how it feels and the uniqueness of the experience. I think I benefitted from it as I was not asking them questions about every detail as I know some of the common terminology used in the NICU. Some of their stories brought up different emotions both

positive and negative. Participants thanked me for researching and assisting with this population.

Recordings from Zoom were transcribed by hand. I printed out each transcription and then read them multiple times. I engaged in the initial data analysis level of immersion. Immersion allowed me to better understand the participant responses and engage in deeper analysis. Each time I read the interviews, I highlighted specific parts or phrases that stood out to me such as strong emotional words or unique situations. In this step, I also made notes in the margins of the transcriptions. After this, I highlighted items that stood out to me or were common experiences for the participants. I used the highlighted sections and notes and put them on large sticky pads that were color coordinated for each participant and separated by questions. Once brief statements were identified on the sticky notes, I put them on a tri-fold board and transposed them there. These key words or phrases were placed in different sections of the board. I put check marks next to phrases or items that were similar across participants. I completed this for all 8 participants. Next, I reviewed brief notes that I made during the interviews with my personal experience during the interview. I wrote down the observations that I noted.

Then, I began to develop themes and subthemes based on the information on the board and the sticky notes. I used the hermeneutic loop during this time. Essential themes were those that all or at least seven participants endorsed. Subthemes were identified within each essential theme based on less common experiences or emotional responses. This allowed me to simplify the themes to adequately analyze the data. I developed larger categories initially to include experiences related to prenatal care, delivery/transition,

nurses, future, need to advocate, and support to name a few. These categories were narrowed down to advocacy, trauma, lack of information/preparedness, support, passion, future impact, and culture. From this method the following themes emerged protector, support, restrictive institutions, and trauma. Also, sub themes were included for protector: self, babies, and sisters; trauma: feelings, hypervigilance, and future planning; support: nurses, personal, and mental health.

Within HP, one of the most important features is the researcher as a second instrument. My experience as a B/AA mother who has had a premature baby in the NICU cannot be separated from the data analysis. The lens that I use to interpret the world is the womanist theory. I attempted to separate myself from the research to remain objective originally. Later I went back through on analysis and included ways that I interpreted their responses and how as a second instrument I was able to analyze the data. I have learned to navigate the world as B/AA that has its own tragedies and triumphs. During data analysis, it was important for me to push myself to challenge my own thoughts and go beneath the surface to really examine what the participants were communicating based on their experience particularly as a B/AA mother.

Data analysis included identifying if there were discrepant cases and how to interpret that data. I identified data that seemed to be anomalies such as unique responses or experiences. I included this data in the analysis. One of the discrepant cases was using a participant who currently lived in California. Her experience had a vast amount of similarities with other mothers. There were some differences in her experience due to potential differences between states regarding NICU care.

### **Evidence of Trustworthiness**

Credibility was enhanced through being consistent during the interview. The same procedures were used for each participant. All interviews were audio recorded to assist in data analysis. There were no identifiable discrepancies. I asked clarifying questions during the interview when necessary. Direct quotes were included in the data analysis. My committee had access to my interviews. Participants were sent their transcripts for transcript checking of any errors or misinterpretations of their responses.

Transferability is likely due to providing thick descriptions. Although, themes and subthemes were identified. Unique experiences of the researchers were also documented by participants. The results of this study are in alignment with participants who are like the population and not generalizable to the population.

Dependability was achieved as all interviews were recorded and transcribed. An audit trail was left for dissertation committee members to use. The audit trail will ensure others are able to follow the procedures of the study. Also, consultation was sought regarding questions with data collection. I compiled field notes during this process as well. The field notes included notes regarding participants and my reactions to the interviews. These were taken after each interview as I wanted to be present during the interviews and not be focused on taking notes.

Confirmability includes seeking data to confirm research. I recorded field notes for the study. I included detailed information regarding procedures of the study. This shows how I derived themes from the data. My committee was there if I had questions or felt bias during data collection.

## Results

The interview responses results of the data were used to assess this question “What is the meaning of the lived experiences of B/AA mothers who have had a preterm infant in the Neonatal Intensive Care Unit (NICU) within the past 5 years?” There were four themes that were derived from the data: protector, support, restrictive institutions, and trauma.

Below are the four main themes identified along with sub-themes. Direct quotes are also included to provide more details.

**Table 2**

*Essential Themes and Subthemes*

Essential themes	Subthemes
Protector and the angry Black woman	Self, baby, sisters
Support and the strong Black woman	Nurses, personal, mental health
Restrictive institutions and ignorance	Communication & knowledge
Trauma and the strong Black woman	Negative feelings, hypervigilance, future planning

### **Protector and the Angry Black Woman**

Protector was a word I used to categorize part of the participants’ experiences. Protector is related to advocacy which I identified as a common experience. Protector also embodied their experience as they often felt as if they had to be protective over themselves, their babies, and future mothers with similar experiences. Who they were protective of framed the sub themes of self, babies, and sisters. All the mothers described ways in which they engaged in this. Their advocacy efforts were present in different ways. I chose this specific theme as the mothers described their experience needing to not

only advocate for themselves in life or death situations but also with their children to ensure they were getting adequate care from providers. Finally, these mothers also described ways in which they are advocating for other or future B/AA NICU mothers based on their experiences. I will describe the relation to the *Angry Black Woman* at the conclusion of this section. The *Angry Black Woman* is like the *Black Lady* controlling image that was discussed in Chapter 2.

### *Self*

Several mothers identified having to protect for themselves with medical professionals. There were times that these mothers were in jeopardy of losing their lives due to medical complications. The mothers reported that they felt “ignored” or “dismissed”. Kristina who is a NICU nurse shared her experience with professionals and taking matters into her own hands regarding her health. She shared:

I kinda had a concern about my blood pressure before the actual preeclampsia came in full force. Um and it was kinda blown off. Um so that was a little bit bothersome for me I’m not gonna lie. But the night that I was admitted into the hospital I did call my doctor I let her know it’s even higher than before and I was admitted right away. And she took the steps necessary to make sure I was screened for everything which ultimately led to my baby being born early.

Kristina had to advocate for her own physical health to ensure that she was safe, and her baby was safe after her doctor didn’t take her seriously. Kristina included details that “I invested in my own monitor and started watching myself.. I had to hold her accountable.” As a medical professional she was knowledgeable about ways to ensure her

own health but was unable to depend on the doctors to be proactive and thus had to advocate for herself.

Terri had to go to a maternal fetal medicine doctor. Her experience with this doctor was negative. She shared,

I was referred to somebody at the hospital where the practice I was at had privileges. And that's when I really started to receive poor care. And I really felt like my MFM, she was short with me. She didn't answer my questions thoroughly she. I mean it was literally like you could visibly see she was just trying to get out the door, all the time. When I was advocating for myself. She would become physically frustrated with me.

Terri was in pain and was told these were normal “when in fact it turned out that my son’s foot, I was feeling the pain because his foot was getting ready to rupture the membrane.” This ultimately led Terri to switching doctors to a teaching hospital where she felt as though she would receive better care.

Denise, too, reported not having doctors take her claims seriously. She reported having an increase in pain “I’m telling my doctor and they kept telling me it was just growing pains.” Denise had a baby 18 months prior and stated these pains were different. Her experience is as follows:

And I remember telling my mother and I told my boyfriend at the time, the girls’ father. I just said, something's not right. I just don't feel right in....It was Saturday night, and I went in and I said he had gone out so I told my mom I was like I just need you to watch Makayla. And I just need to go get an IV they told me that it's



probably just the fact that I'm dehydrated I just need to go get some fluids I'll be back in a couple hours I should be fine after that. And I drove up to the hospital thinking that it was just gonna be normal. They're just gonna tell me I was dehydrated, just because I was so sick from my morning sickness, and I will just be home in a few hours, and I went into the ER. And I remember the lady asking me She's like, are you, um is you gonna give birth.

She later found out had she not checked herself in that night she and her baby would have died as her "placenta was starting to detach." Denise added "I don't feel like nobody listens when we're like no something's wrong and I feel like a lot of people do say something's wrong when something's truly wrong. They don't want to listen." This experience was common with the mothers reporting symptoms and being ignored by professionals until it became an immediate concern.

Ashley who had two babies in the NICU described advocating for herself after her first NICU experience.

Once I found out I was expecting I look up, but high risk, different high risk doctors in the field because I had a placenta abruption so I wanted someone who was maybe experienced with that... she knew other high risk doctor who could monitor me

Ashley's experience with her first premature baby caused her to engage in preventative measures to ensure a different outcome. Although she still gave birth prematurely, she reported being less stressed and a less severe situation than her older child who had to have surgery.

***Babies***

The participants also identified times they felt as though they had to advocate for their child in different circumstances. There were times they did not believe the care for their child was adequate. Denise shared a story regarding her daughter needing surgery when she got older after a condition preemie babies can develop. She brought her daughter to the doctor and reported something was wrong. “I felt relieved and I felt horrible sort of feeling relieved because you know. I’m like oh my god there’s something wrong with my kid, but then I am like I knew there was something wrong.”

Dream shared an experience where she noticed her daughter was uncomfortable and nothing was being done. “When you after a certain amount of time you start to learn your baby even when they are in the NICU.” One experience where she had to protect and advocate for her child was an instance when she arrived at the hospital to visit her.

I came in and Mya. She was visibly fussy like you could see her crying, which was not very loud, but the nurses are close enough to hear when a baby's upset. And when I walk over, I could see throw up like all down her neck. And when I looked over that her nurse that was watching her that was doing her cares was on Zillow looking at houses.

Unfortunately, Grace shared that she should have advocated but she did not know what to do and everything was overwhelming. Corrine reported attending meetings and talking to others to ensure her daughter was receiving adequate care.

### *Sisters*

Sisters is a unique term that I used to categorize this section. This term is used often in the B/AA community and can also be spelled “sistas”. Within the B/AA community kinship is still important or the focus on family and the sense of community even if they are not blood related. Participants welcomed me into this “sisterhood” as a researcher but also as a B/AA mom. Participants were very eager to share their experiences with me. Most of them thanked me for being involved in the research with this topic. Corrine reported “I’m really stoked that you’re doing this it’s awesome” and “I think is going to be so monumental.” Grace stated it is just “so important the topic you are looking at.” For some of them this has become a passion for them, and they are involved in various ways.

Dream reported “I love the hospital where I gave birth and I actually donate to them now.” She has also started her own YouTube channel that is geared towards her NICU experiences.

I’ve met so many women on social media, because I started sharing my journey with Mila the day she was born. And I’ve gotten to meet so many women from all over the world. Sharing their stories with me asking for advice and things like that and then I even have one mom. She randomly messaged me, and she asked me to go live on Instagram for her so she could tell her story and I’m like, that’s not something I do like. It’s not but I had to sit back and think about because she had an NICU baby, and I had to sit back and think about what she was really asking me and say like this isn’t about me, like she wants to tell her story just like I’m

telling my story and for whatever reason she chose me but I'm gonna ask that and take her up on our offer and I actually started a YouTube channel. And I have a series called after birth.

Dream's description of the ways in which she is connecting with others was inspiring. Although she went through a traumatic experience, she felt compelled to assist others in their journey of healing. This story of a random person wanting to share her story was a chance for both Dream and the mother to find spaces to support each other and advocate.

Terri has become a therapist that focuses on maternal mental health. She also has support groups at her local hospital for NICU moms. Terri stated:

where was a conversation about support groups, you know I mean just at the very basic. So now I provide some support for NICU support groups at a local hospital where I live. And that hospital the support group is housed within that hospital. So, it's like so different, talking to the moms who've had the support from the beginning in hospital versus like how I felt.

Terri has turned her experience into a niche in her career. She discussed wanting to provide services to others that she had not received. Terri did not receive mental health support until her son was 10 months old; yet, she reported assistance in the beginning would have been beneficial through this process.

Erica's experience led her to want to assist others in her shoes. Erica described being in the hospital for the holidays was difficult and not spending time home with

family. New Year's Eve and Day were spent in the hospital. This led her to wanting to assist others.

I want to volunteer a little bit more I really would love to volunteer and like help families who are in the NICU for the holidays. I am obsessed with talking about this now and like sharing my experience with other moms.

Kristina is a NICU nurse and uses her platform to assist other moms. She stated, "I have a real passion about this." Kristina's unique experience as a NICU nurse and a B/AA NICU mom allows her to see multiple perspectives. She stated in response to what she would like improved.

I think that could be done more and I think that just you know people like us putting that awareness out there. Don't be afraid to ask questions don't ever assume that a doctor knows more than you. I know that that I am not trying to discredit physicians because they are smart, they work hard, we need them, but understand that they are a person first. If you have a true concern and if you feel something is not right click into that black girl magic and let them know because yea and if they don't want to listen find another OB because it's unfortunate that we are losing black women because of this.

Kristina's protective nature with other moms is apparent in this section although she is a provider as well. She reported multiple ways to advocate for self, but one way is to speak up and ask questions no matter what. There is an assumption that the doctors are always right and to listen to them. The mortality rates for Black women in labor are astonishing

and there is a possibility that as B/AA mothers we should speak up and ensure others are listening to our concerns and intervening.

The angry Black woman or Black lady is seen as strident and working too much. The angry Black woman may be harsh and aggressive. This is a stereotype that many of these women described in their experiences being a protector. They walked a fine line between protecting their own health and that of their premature baby's health. Since women are seen in this negative life, there are times that the approach must be modified to ensure that others are hearing what is wrong and not perceiving you as the "*angry black woman*". This perception is one that women who are vocal regarding concerns. Where white women may be advocating for themselves and their immediate concerns are addressed, these women had to be in severe situations to get support. This experience of needing to protect them and their babies influenced the participants to protect their "sisters" to hopefully prevent them from dealing with the same stressors.

### **Support and the Strong Black Woman**

Support as stated in Chapter 2 is important to NICU mothers. It is also a component of managing traumatic events. The following theme highlights how the mothers viewed support from varying entities to include nurses, personal, and mental health. Throughout these subthemes, I will illustrate how the participants viewed the support and if it was beneficial for them through this process. The final sub theme includes detail regarding the significant lack of mental health care that was received by these mothers and is representative of the B/AA culture. The SBW was discussed in detail in Chapter 2. The SBW in this context is related to how these mothers forced

themselves to ensure that they were fulfilling their multiple roles and not really dealing with their own reactions to the traumatic event. Consistently, mothers were discussing how they ignored their own mental health needs to ensure their babies were healthy and functioning appropriately. At the conclusion of this theme, I will discuss how this is viewed through the womanist lens.

### *Nurses*

There were varying cases related to nurse support. The support was on a spectrum of indifferent to very helpful. Kristina who gave birth at the hospital she worked in reported that the nurses “they answered all my questions, wiped my tears, they hugged me... nurses were literally a bulk of my support system.”

In Dream’s hospital the nurses led support groups for the mothers for peer support. The group was for scrapbooking. This seemed to have connected Dream to her nurses more closely. Dream even made goodie bags for her nurses with a note to show her appreciation for all their hard work and dedication to her and her daughter’s care. Terri worked with B/AA nurses and providers and reported the NICU was diverse. Terri stated,

The nurses were really like my people you know you find your nurses, and you get really familiar with them over the course of the time. And I found, so I would say this in general my nurses were really phenomenal. And maybe that's because majority my nurses were black especially the daytime nurses, and my nighttime nurses were a little bit more often, white women.

She attributed her positive relationship with them to the fact that they were a similar race. She went on to describe a situation that occurred with a white NICU nurse.

One notable nurse, and she was an older white woman... I did not enjoy her being my nurse, my son's nurse because she didn't. She didn't show up with the same level of compassion and warmth that the other nurses did. So, she was like, her answers were always really short. Like she didn't explain things as thoroughly. She wasn't as in tune with my parental worries as the black nurses were.

Grace had an experience that she classified as indifferent with the nurses in the NICU. She reported being emotionally overwhelmed throughout the process. Her experience with the nurses did not provide additional support to her. Grace's experience is as follows:

The nurses weren't a bad, like, um, I just always, I think that my experience was like, I don't know if like the word is indifferent they just. It wasn't that they didn't care, but like, it's like they just, I guess it's because they're there. It's their job.

Grace did not feel the same level of compassion or support as some other mothers did with her nurses. Erica reported a similar experience to Grace. Erica stated that there were times that "very much like we were just connected we were just like looking, it was we might as well been looking through the window versus like being involved with her care". Her care for her daughter felt passive and she was following along to ensure her daughter was taken care of but not an active member or her parent.



*Personal*

Along with medical support staff such as nurses. The participants that I interviewed had help in various ways from different people to include family, friends, and religious support. Ashley had multiple family members to support her through this process. Her husband, parents, and other children provided her support during various times to include being in the NICU until the transition home. She described her support as

Yeah, I have my husband, mom. My mom and my dad are great because I have other children that were at home so they would come to the house... they would take me out my dad would take me first because I had a C section so I couldn't drive for two weeks. So he would take me and pick me up, or he would take me into my husband would pick me up. Anything I needed, they, my parents or my husband would be there.

Terri fortunately had individuals in her family who were knowledgeable about what was going on and provided support as they could. Terri shared the following story regarding her familial support,

And then I called my god sister who's the OB and she said, you need to go upstairs and tell Chris that he can't go to work today. And he must stay home with your baby. And you need to get out of the house. And if you come back home after a day out and you still feel the same. Now we need to talk about postpartum depression and we need to call your provider, but if you come back home and you feel relief, then we know that it's exhaustion, and that you just need to like get

some more breaks and get more sleep... and that did help. And then my dad came, and he took me home and I stayed for a month. And that really helped.

The support that Terri received during this time was impactful for her own mental health as she was significantly struggling to manage her emotions while taking care of her son who had recently discharged from the NICU. Kristina also stated, “of course my family my in laws they came into town and were a huge help especially caring for my oldest son”. Grace’s mother came to stay with her post-discharge.

Additional support aside from family included friends and religious support. Denise’s best friend was there right after the baby was born to support her. Her best friend assisted her in naming her baby as she did not want her to remain nameless in case something catastrophic occurred. According to Denise,

I refused to get down there until I had like finally confirmed her name, just because I was worried that she wouldn't have a name just in case something happened. I had decided on her name. But, um, I wasn't too sure and then. So, my best friend and I were bouncing off ideas and I actually found out her name means God is my strength. Um, so I ended up keeping that as her name.

Some participants reported religion as a source of support. Corrine reported having her family and friends pray for her. The nurse that asked if she had been able to hold her baby was someone who attended her church and had recognized her. Dream also reported that the Chaplain at the hospital was supportive while in the NICU.

### *Survival or Mental Health*

Every mother identified significant impacts to their mental health because of having a premature baby in the NICU. Most of the participants reported some type of postpartum mental health disorders or symptoms that they experienced but were never fully diagnosed. These mothers were not diagnosed as there was no support provided to them during this time. The participants described social workers who were not attentive to their needs, not being provided resources as they were not prepared to be in the NICU, as well as not having the time to focus on this. These mothers had to choose between surviving and their own mental health.

Amanda reported “postpartum depression and anxiety” with her first NICU baby. Grace stated she struggled with depression and anxiety. Erica reported Terri reported there was “a total lack of mental health support... the social worker was terrible.” Terri also stated, “I never thought about mental health because I'm like trying to survive so like thinking about mental health, but I've been thinking about something that wasn't already in my plan or on my radar.”

Although, Grace's baby did not have a typical NICU stay she struggled with perinatal mood disorders related to her daughter. Grace reported that she struggled with depression and anxiety.

I have now. Like, um still some anxiety like some postpartum anxiety in relation to just like her, just like having to leave her and I think that I also like in the first few months home struggle with like depression that I didn't see. I feel like the

people around me saw it, but nobody really like said anything to me, everybody's kind of like tiptoeing around me.

Grace explained not realizing she was struggling with depression until her mother discussed what she was noticing with Grace to her fiancé. Subsequently, her anxiety was not taken seriously, and her doctor related it to COVID not her actual postpartum experience.

The mothers included recommendations of what would have been beneficial to them or for future mothers. A common recommendation was postpartum support groups for mothers. Terri reported, “pre prepared resources for as a parent and a list of local support groups virtually and in person.” Another recommendation from Terri was requiring a mental health professional to do an “exit interview” to better assess mental health. Corrine added there was a support group she is a part of in her area that she found out about after the NICU stay but was told she should have been provided the information while in the hospital.

I found out about a group, after being discharged from the NICU the NICU project which is a NICU support group by a couple of moms who are out of the hospital or who had kids at the hospital. But none of those things were available to me while I was there, supposedly from what I was told by the lady who runs it because I was supposed to be told about this, so that I could do those calls while I was in the NICU. But I wasn't told about them.

This group would have been beneficial for her to seek additional support from others who are experiencing the NICU as well. The group would have been a place where

she felt as if her experience was normalized and there were others struggling with something similar. Although she had her oldest son in the NICU these experiences differed significantly. She also shared that this group is predominantly White and therefore it is something that is missed by not having others who have that similar cultural identity. The participants also included their experiences with mental health in the B/AA community and how that may have impacted the lack of support. Kristina who was not in a predominantly B/AA hospital shared her experience regarding mental health. She stated,

I think that there's this idea that as an African American woman you're strong and you just deal, and you just do it. So, I noticed that yes, a lot of the attention was on Niko and not too many people outside of my husband asked, how are you? You know and so I think it's just assumed. Well you got it you're doing fine. How is the baby?

She went on to say, "I literally felt like I was losing my mind and like no one really knew". She also struggled with speaking to her social worker regarding how she was feeling. There were also other times that were related to her experience as an African American. Kristina also shared,

The hospital where I was at the social worker gave me a sheet basically postpartum like screen depression screen kind of thing, Brian knew how emotional I had been and like distressed I had been, and he said be honest. Kristina be honest when you fill it out and I remember like I was pretty honest like my feelings, depression, and I remember I know the social worker. I worked

with her closely she works in the NICU. I remember her coming and saying Kristina your screening is a little concerning and I want to talk to you and are you ok. It was very again it was very generic please tell me you're ok so I can walk away because I have too much on my plate. That's kind of how I felt.

Erica's statement is also in alignment with Kristina's as she stated,

I think is specific to African American women I don't think that we talk enough about postpartum depression and we definitely don't talk enough about postpartum anxiety, I didn't even know what that was, at the time, nobody ever told me about that.

She went on to say,

When I went back to my midwife, she didn't ask me about that. She they asked you the typical like, are you feeling sad. Are you having depressing thoughts, but nobody ever asked me about the anxiety part? And I think a lot of times people think that that's normal. And I think black people in general we just when it comes to like mental health stuff we're like, oh, you're fine, like, you know, especially like our parents' generation I just feel like they don't really take those things seriously, so nobody ever asked me if that's what it was or ever said hey you take her temperature a lot like maybe you have postpartum anxiety like maybe you're anxious about her getting sick. And so it wasn't until I was pregnant with my second daughter and I hired a doula for her birth, and she asked me to we're doing like our like get to know you interview and she said, Did you have postpartum depression or anxiety with your last baby and I was like, No, and then

I started describing some of the stuff that I did with her, and I was like, but that's normal and she was like, No, you had postpartum anxiety.

These experiences all illustrate the lack of mental health support for B/AA mothers who have babies in the NICU. These experiences are common and professional supports were not in place for these women. Corrine made a powerful statement regarding being a B/AA mother in this situation that summarizes the tone of the other participants. She stated,

Black women... we tend to as women kind of put on our superhero cape and we want to save everyone... I would want to say it is okay. In that time to be vulnerable... you feel the responsibility to be strong for everyone around you.

Support is fundamental for managing your emotional reactions to traumatic events. It comes in many forms with the participants some include friends, family, or church members. The support unfortunately at times appeared more practical as they needed someone to assist with transportation, other kids, or buying items to name a few. The mothers were missing professional support to manage the experience of being a B/AA mother in the NICU. Again, the SBW controlling image was apparent in their descriptions. The women felt as though they had to be able to do and manage everything without having a place to release their emotions or work through what they were going through as they had to be “strong” for their children and others around them. The SBW was used to cope and survive through this traumatic event and maintain after the transition home. There was no time in many of these mothers’ minds to focus on themselves or their mental health when their babies were fighting for their lives.

## **Restrictive Institutions and Ignorance**

I decided to use restrictive institutions and ignorance as the title for this theme. Restrictive institutions here include healthcare and educational systems that often perpetuate racism. According to Evans-Winters (2014), systems such as education and society perpetuate racism especially in relation to B/AA women. Womanism and critical race theory overlap in that both theories focus is on ways society has interacted differently due to race which impacts the individual. These mothers engaged in systems that continued to discriminate against them. Regardless of if there were first-time mothers or mothers with multiple children there was consistent reports of an overall lack of knowledge and communication from providers. The providers did not provide them with adequate information to make informed decisions about their babies care or provide them with beneficial communication. The healthcare and educational systems that these mothers are a part of may not have equipped or afforded them the same opportunities to engage in the same dialogue that a White Woman may have been welcomed into. A controlling image in the B/AA community is one of ignorance as well. Others see B/AA people as less intelligent and thus may not think that they can engage or can understand certain aspects. The following information will focus on two subthemes of communication and knowledge.

### ***Communication***

Communication overall was poor according to the mothers. Communication lacked with the families and from provider to provider. Grace had two different due dates that were provided by two different providers and neither party discussed this to clarify



the date. After discharge, when Grace went to the follow up pediatrician appointment the hospital records had not been sent. Grace described why she would have wanted better communication.

You know just better communication between the hospital and pediatrician.

Because like I am a new mom my mind is everywhere like I barely made it out the door for that first appointment. So you know like checking the blood sugar was the last thing on my mind.

Grace was overwhelmed with the responsibilities of being a new mom, her traumatic birth, and then transitioning home with her daughter. In retrospect she talked about wishing they would have ensured her blood sugar levels were ok as that is why she was in the NICU. Erica reported that there was a struggle for everyone to work as a team to communicate. Per her report,

Okay, first of all, I didn't feel like there was enough communication amongst the whole team like now of course I know that nurses change shifts and the doctors changed shifts and everything but it never felt like there was like one chain of communication. When we came in I felt like I had no idea what had happened to her and the time that I hadn't been there, like had she eaten had she like had any procedures like there was no like when you come in, there was no like rundown of okay this is what has happened

Erica stated the lack of communication that occurred with her and her family.

Although rounds occurred with the medical team, "I really wanted more information."

She was not initially made aware of rounds or that it was possible for her to attend them.

Corrine stated that there was a lack of communication between providers, “to have to explain her medical history, really bothers me.” She also stated:

There was not a lot of communication because I felt like in every appointment like when I’m at the eye doctor I’m telling them about cardiology when I am at the cardiologist, I am telling the about pulmonology. When I am at the pediatrician, I am telling them about all the things.

This experience for Corinne was directly related to her trauma. She continued on to say, “and so it's just like I wish there was some kind of level of communication because I think what they fail to realize is, every time you repeat it a little bit you're reliving the trauma, you know.” Here are instances that have caused this mom significant distress due to having to relive the trauma. This trauma is something that can be prevented as well. Corinne did not discuss talking to the providers about their lapses in communication. Therefore, this behavior continued and will continue to future moms.

### ***Knowledge***

Most of these mothers were not prepared to give birth to a preterm baby. During prenatal care, there was a significant lack in information regarding complications or what consequences could occur. To begin with, most reported a lack of knowledge regarding delivery and the initial transition to the NICU. Terri, who was in the hospital, said, “I would have liked maybe like somebody to come talk to me about it again and see if I had more questions.” Grace stated, “I delivery I guess it wasn’t like what I expected it to be” and “I guess I just didn’t prepare myself enough.” Her doctors did not provide her information ahead of time on what to expect if there were complications. Grace also

reported while in the NICU “no one ever explained to me what was going on.” She was unclear regarding exactly why her child was in the NICU and what would need to occur for her to come home. Grace reported the baby was in and out of the NICU into her room.

Erica was a first-time mom who was having her baby with doctors she did not work with and a hospital she had not planned on giving birth in. She began unprepared as she was visiting family when she spontaneously went into labor over the holidays. She stated, “I never felt like anybody was really explaining to me what was really going on. And there was a lot of fear, everything was like we would come in and they would be like, well, well.” Erica was not educated about the NICU or provided necessary information.

Dream was a first-time mother with her child Mya. She was not prepared to give birth when she did and was ill prepared for the NICU. Dream stated that

It was good to see that she was okay, but scary at the same time because NICU life was completely new to me and I didn't really know what to expect. There were babies everywhere. There was lots of machines lots of noise. Nurses everywhere.

Ashley had two babies in the NICU and reported feeling better prepared the second time she gave birth. She reported with her oldest “I really didn’t understand it all.” Corrine had two babies in the NICU as well. She reported with her first baby she was not prepared, “it’s shocking... they kind of just point you in the direction of the incubator.” With her second baby, she explained,

I made it a point to everyday be at the NICU by 9 o'clock when the doctor made his rounds. Because had I not been there every day at 9am when the doctor made his rounds. I really would not have known the status of most things that were going on and except for the big-ticket items

Corrine reported was not able to hold her baby for two weeks and "no one ever explained to me the why behind the what." She was asked by a nurse that worked at her church if she wanted to hold her. She was unsure why no one had ever offered this to her and was grateful that this nurse knew her and asked. Corrine explained not knowing how long she would have gone without holding her child had this nurse not asked her. Corrine experienced an overall lack of information that she believed was related to her race. Her account is as follows,

But I think they were very surprised when they realized, like, how much I knew or. Okay, or like I wasn't what I looked like, if that made sense. So when I went into labor with Cammy, I had crochet braids in like I just looked like, you know, whatever they would think like typical black girl looks like not educated college graduate, you know like that kind of thing. So, I think in the beginning, I was treated almost as an afterthought. If that kind of makes sense. It wasn't really until I started spending a significant amount of time there. When nurses like started asking questions about me and my background that I felt like I started the level of care was elevating, if that makes sense. So, it was like when they found out that I had gone to college, or when they found out that I was actually married and like I

didn't have on my rings because my hands were swollen, or when they found out that my husband had a master's degree.

Denise had anxiety about asking questions although she should have been informed about the process and what would occur with her baby. According to Denise, You just feel like you're a new mom and then you feel like is this question a stupid question Am I asking, like, you know, these are the people like I have to be cleared to bring my baby home so am I gonna ask them the right question.

There was pressure for Denise to not only gather the information that she needed for her daughter's care but also to manage the anxiety of wanting to feel competent in caring for her upon discharge. Denise explained that she felt she had to try extra hard to seem capable as a newly single mother with a NICU baby.

Every participant reported lack of knowledge and poor communication at various stages from prenatal care to transitioning home. Unfortunately, a lack of knowledge and communication can be improved by providers during prenatal care and in the actual NICU to assist the mothers. They described previously instances where they were not aware of what was going on or times that communication lacked. There were times that the participants identified feeling like they were discriminated against because they were B/AA. Providers seemed to not have assumed that the mothers were able to handle this information or that they would not understand it. The participants were forced to trust a system and providers who they have not been supported by without being able to have an adequate say as their mother. These women struggled with trying to navigate an experience that they were ill-prepared for and not provided valuable information

throughout the process that may have eased their experience. I too, experienced this unfortunately. I was not clearly told why my child remained in the NICU and had to ask during every shift at the hospital what her progress was towards each goal.

### **Trauma and the Strong Black Woman**

Participants reported the delivery and the NICU experience as having a significant impact on them and a form of trauma. Below I will illustrate how this experience is traumatic and ways that it manifested after discharge from the NICU with these participants. Everyone reported crying often during this process. Often their tone changed when discussing this emotional experience for them and the trauma that they endured. The tone became more somber and lower tones were used. As a NICU mom, I resonated with these feelings as well. There were times when they told their stories that I had flashbacks to the emotional intensity of the situation and at times became tearful knowing the pain that we all endured. I will identify the negative feelings described by these participants, hypervigilance that occurred, as well as the impact on future family planning. Finally, the womanist lens will be used to further elucidate this experience as the SBW.

Corinne was articulate in identifying her own trauma in her NICU experience. She identified various traumatic times some include not holding her first baby for 48 hours and the second for two weeks. Regarding her oldest, her son, she stated,

He was immediately whisked away to the NICU and I wasn't able to see him for 48 hours afterwards. So, the trauma for that for me was not only just sitting there 48 hours without my baby. But it was the fact that I felt like everybody around me

was meeting him but me so like at that time, people were allowed to come in. If one of these other parents, was there, or something like that. So, like I remember my mom met him and my sister in law like all these people like I had literally never laid eyes on him at that point. And so that was kind of traumatic.

Corrine shared that this experience was difficult especially due to the unknown of being in the NICU as a first-time mom. She then went on to explain that her transition with her daughter was difficult. She reported her daughter was in “complete isolation within isolation” with a lot of machines and equipment and “the transition was hard just because of the trauma.” Corinne also explained instances where she relives the trauma through explaining medical information to doctors or the disappointment that occurs when the nurse comes in with the “three-month growth chart and she is still negative 5 days old.” This trigger for her trauma is impactful.

### ***Negative Feelings***

Trauma involves an intense experience of emotions around the event. There are often numerous feelings that are described by those who have endured trauma. Guilt and blame were experienced by some mothers. Others described how horrible their experience was and the intensity of these emotions. I will begin with focusing on the guilt/blame as this theme was identified by multiple mothers. Most participants discussed some form of guilt or blame that they experienced during this process. This guilt/blame occurred in different ways for the mothers. Kristina reported

I was pretty yea I was pretty upset. Um just like that feeling of this is my fault. I, my body did not react well to my own child being in it and now I'm forcing him

out before it's time. So, it's just that overwhelming feeling of guilt honestly. Um and just panic.

Kristina struggled with negative feelings towards her body regarding how her delivery occurred and the implications which meant time in the NICU. Corrine similarly experienced negative feelings towards her physical body regarding the birth of two preterm babies. Corinne reported guilt/blame, "but now, because I've delivered two preterm babies, as much as they tell you that you're not supposed to blame yourself you do, you know." Corinne went into early labor with her baby. Her labor experience also included a large amount of blame with her youngest child who was a micro-preemie and the chances of survival are lower. There was a large amount of blame initially with her youngest child. She explained,

Like again with the whole like blaming yourself. I felt like it was partially my fault because I went to the doctor and they prescribed me Tamiflu Theraflu somebodies flu. But you're allowed to take when you're pregnant and against my better judgment because part of me was like I should just ride this out, you know, I didn't and I took it and it made me feel worse than what it took me to the doctor in the first place. And, like I kept wondering like. Had I not taken that and had I not been throwing up because basically what am I document, telling me was like the amount of pressure that my body was feeling on my cervix as a result of like throwing up, and I only had because of that particular drug made my stomach upset. And then like the coughing and that sort of thing like all of those things coupled together. Basically, signal to my body that it was time to push the baby.



And that wasn't the case, you know, and so I think about those things often, like why not just go with the first mind, especially when I was doing all the things you know to not have this baby early as a result of what I knew from (oldest son)

This guilt that she experienced is like most mothers who gave birth and tried to determine what was the initial trigger for the premature labor. With this traumatic experience, blaming somewhere or putting those negative feelings somewhere seemed to help her try to make sense of everything that was going on. Denise echoed the guilt that she experienced with her baby as well. Denise reported “it’s a horrible feeling because I had to work through a lot of guilt and I still carry it”. She reported the guilt gets stronger dealing with health conditions from her daughter that are more than likely a result of her being a preemie. Denise used the word guilt multiple times in the interview to explain her feelings related to her daughter’s time in the NICU and even current impacts.

There is a plethora of feelings that these mothers experienced. These began when they were notified, they would have a premature birth and lasted well into postpartum. There was no mother that was interviewed that did not identify negative feelings during this time. Here are a few accounts of their emotional experience. Grace stated her delivery was “terrible”. Grace continued to describe it as terrible and horrible. Similarly, Erica reported “I honestly feel that our experience in the NICU really contributed to me having postpartum anxiety a year after she was born.” Another mother Ashley described what it was like for her to sit at the hospital with her child and balance her responsibilities at time.

Of course, it was difficult. Every day was different, having to leave the hospital one with her there was rough, and then having other children at home, so that couldn't, like, stay at the hospital, all the time I had to back and forth, it was kind of rough... overall just going in there every day. It was a struggle, but it was. We just, you know, made due with it.

The transition home was described as “emotionally difficult” by Terri. She also reported feeling “very lonely” and “very unprepared”. Kristina stated the “entire transition home was hard.” Denise explained “it terrified me; I mean it really traumatized me. Um especially when she was born um, she didn't cry. They told me she tried but she was so little that she couldn't.” Denise was not able to hear her daughter cry for 26 days. Most reported having “breakdowns” during this period. Other words to describe this experience are “scared”, “terrified”, and “horrible.” These strong feelings and trauma also led to hypervigilance with some mothers.

### ***Hypervigilance***

Hypervigilance was used as a term due to its relation to trauma. Hypervigilance is defined as “feeling constantly ‘on guard’ or like danger is lurking around every corner” (American Psychiatric Association, 2013). Hypervigilance is a key tenet in the diagnosis of Post-traumatic stress disorder (American Psychiatric Association, 2013). Terri reported anxiety regarding her child. She was nervous and “how do I really know” they are ok.

Kristina who is a NICU nurse engaged in buying a monitor for his son to ensure that he was safe and healthy. She stated

I watched him while he was sleeping. I had his basinet right beside my bed one of those owlets to put on his feet. It's like an oxygen monitor. Yea um my husband thought I was crazy. He said this thing is like \$400 and I'm like I don't care we were getting it because I was sooo scared you know um. And so that was the toughest part of the transition you know. Getting out of my own head and feeling at peace.

She reported that it was "solid 3 months before I was even comfortable enough to let him even take a nap without the owlet. I was super paranoid." She also struggled to leave him with his father and would opt to stay at home even after he invited her to get out of the house and take some time for herself.

Grace reported calling her grandmother to check on the baby who was watching her. "Just for my piece of mind I have to call and make sure she's ok because I'm like thinking of all these things are running through my mind." Erica stated, "I took her temperature, like, constantly, like multiple times a day." This was a result from fear of her getting RSV in the winter. She also reported once she was home the baby was in for the entire Winter to ensure she did not get RSV and must return to the hospital. Erica also reported not letting her cry and would hold her all the time. "I slept in the nursery we had a day bed." She also added she felt "obsessed with the baby" and this impacted her marriage as she "withdrew from him".

The hypervigilance does not just occur while in the hospital as Erica illustrated in her experience. Dream had an incident occur on the way home that she vividly remembered. Dream reported when leaving the hospital,

the ride home was scary because she was sleeping, and she was sleeping, and you couldn't really tell if she was breathing or not. I'm used to having like the machines hooked up to let you know all these things". Overall, the mothers felt more protective of their babies.

The recounts of instances where they were hypervigilant led to them doing anything possible to prevent returning to the NICU or the hospital if they could help it. They engaged in measures to prevent the reoccurrence of the traumatic event. Another way in which some mothers attempted to prevent having to endure this again was through not having additional children following their NICU stay.

### ***Future Planning***

Participants were impacted by the NICU in a multitude of ways. One of the notable impacts is on future kids. Some decided they wanted to be more careful and take certain precautions while others decided against additional children. Due to the NICU experience, Grace reported "the next time around... advocate for myself and what I want and what I don't want like a lot more." Grace did not let this deter her from having other children however it will impact the way in which she engages in prenatal care. Others discussed ways in which they were more involved in their care with subsequent children to prevent another NICU stay. Erica stated, "I always knew I wanted to have multiple kids, so I wasn't afraid of having more but I was hypervigilant about the entire process after that." She went on to say "I found a midwife practice... I went in and I was like this is what happened with my first baby, this cannot happen again. I have to keep this baby until 37 weeks because I do not want to go back to the NICU." The NICU experience did

not deter Ashley either from another baby however she did stat, “In my mind it was like always okay like wait if you know that happens again, but we knew we wanted one more.” She researched doctors who had specialties in high risk pregnancies to ensure that she did not have to endure this again. Ashley ended up having two premature babies.

Dream reported she does not want a baby because of her NICU experience, “I know you get a new placenta every time you get pregnant, but it was just too much”. Corrine also has decided to not have any more children due to this experience.

Like, it comes in waves and I think the biggest wave is I don't trust my body anymore. And because I don't I put the dreams of wanting to have a larger family just completely out of my mind, you know, and so it stinks because it's like, oh, I would have loved to have, you know, two to four children, God willing.

The SBW controlling image is seen throughout this theme. The SBW implies that women must keep it together and continue with their own responsibilities. Sadly, this is another indication of how often these mothers had to endure these traumatic events and expected to not have a response. They described this experience with pain attached to it and continued to be the best mother, wife, etcetera. Most of these women did not receive any crisis intervention services for their trauma. In my own experience, I have often minimized my experience being a NICU mom. These interviews allowed me a space to also see how similar my experience was and solidify that it was in fact traumatic. Often after you have a baby there is an expectation that this is a happy time and that you have nothing to be “upset” about. These mothers too felt as though there were a lot of negative

responses from having preterm babies and being a SBW is functional at times but difficult emotionally.

### **Discrepant Cases**

There were two cases from participants who are not located in Virginia. These participants lived in Texas and California at the time of their babies' birth. There were some differences identified. For example, in California there seem to be varying milestones that must be met to discharge them home from the NICU that are different in Virginia. Also, at the specific hospital in California there were additional activities for the baby and resources that were available to families that included financial support. In Texas, the participant reported living close to the border and the population is largely Hispanic as well as doctors which was different from those who were in Virginia. Overall, there were limited discrepant cases. The cases that may have been more unique were based off on hospital differences to include protocols.

### **Summary**

Chapter 4 included information related to the study setting and demographic information. Next, I provided information related to evidence of trustworthiness to include credibility, transferability, dependability, and confirmability. Results were discussed as well. The results of the study included themes such as advocacy, support, lack of communication/knowledge, and trauma. Sub themes included for advocacy: mother, child, and hypervigilance; trauma: negative feelings, hypervigilance, and future planning; support: nurses, personal, and mental health.

Chapter 5 includes interpretation based on the literature provided in chapter 2. Next, I will identify limitations of the study. Recommendations will be provided for counselor educators and supervisors as well as other stakeholders who may benefit. Finally, I will discuss the potential positive social change and implications related to practice, various levels, and any other necessary recommendations.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this HP research was to bridge the gap in the literature related to the meaning of the lived experience of African American mothers who have had a preterm infant in the NICU. This method was used because it was the best fit for the research question. HP allowed me to include my experience as another tool in the research. My experience was of value to the research and had a potential impact. Key major themes that were identified from the data were support, trauma, lack of communication/knowledge, and advocacy.

Chapter 5 will include information related to the interpretation of the findings. I will identify limitations of the current study. Finally, I will review recommendations and implications for practice. This will provide practical information about how the results of the data will be used.

### **Interpretation of Findings**

Participants discussed their overall experience as B/AA mothers who had a baby in the NICU. Their experiences were described earlier in Chapter 4, with four themes identified. Chapter 5 will focus on comparing this to the literature from Chapter 2. There was limited information in the literature review because this topic has been understudied.

### **Protector**

Protector was synonymous with advocacy in this study. Advocacy was a major theme derived from these results. Mothers advocated not only for themselves, but also for their babies and future mothers or sisters. Mothers reported that they advocated for



themselves prior to delivering their baby. There were situations that could have been fatal for mother and child if the mother had not advocated. One participant reported that had she not gone to the ER, she would have bled out, and she and her baby would not have survived the week. Another participant reported that they had obtained equipment to monitor their own blood pressure to ensure that it did not reach a significant level. This is related to the discussion in Chapter 2 regarding B/AA mothers not receiving adequate prenatal care. Some mothers reported wanting and needing to advocate but not knowing what to advocate for. According to Hall et al. (2015), one of the purposes of peer support groups is to encourage mothers to advocate for themselves and their babies. These mothers were not initially provided information or even made aware of groups to assist in advocating. There were also times when the mothers had to advocate for their babies in the NICU. Dream reported bringing attention to times when her daughter had thrown up and looked uncomfortable so that a nurse would attend to her daughter.

As was evident in their eagerness to be interviewed, these mothers were passionate about this topic. Participants reported ways in which they wanted to give back to this community in differing ways, such as monetary donations, creation of support groups, a career shift, as well as a YouTube channel, to name a few. These participants were able to acknowledge their trauma and struggle and wanting to prevent trauma or make a positive impact on subsequent B/AA NICU mothers. This was also in alignment with my purpose and research passion. Given the traumatic event that I endured, I wanted to ensure that I could make a positive impact on the field and this topic to improve the lives of others in this situation. The Black matriarch stereotype focuses on strength and

resilience. Although some of these women had not received adequate mental health support, they were willing to put that aside to focus on being resilient and creating that experience for others.

### **Support**

Support was a major theme within this study. Support was included as well as a lack thereof within varying topics. Nurses have a significant job in the NICU, as they are the providers who are there most often and interact the most with patients and their families. Their primary responsibility is the care of NICU babies.

Participants reported a range of experiences with nurses. Some reported that nurses were great, describing them as “my people” and a “main source of support.” Some reported, however, that they felt that the nurses were indifferent and that they did not include parents in the process. There were some instances where participants reported experiencing discrimination from nurses. Specifically, Corrine explained that the nurses began to interact with her differently when they were aware of her background, in that she was educated and married. This interpersonal racism was subtle but impactful to some women (Slaughter-Acey et al., 2016). There was another report of doctors making comments about other B/AA mothers that were related to the controlling image of the welfare queen. This participant reported experiencing worry that the doctor would treat patients and their parents according to the controlling image.

Participants also discussed support from their families. Some reported that their parents, in-laws, or other extended family assisted them with transportation, finances, and other children who were in the home. Husbands/fathers were a source of support as well.

Perceived social support is a factor that positively impacts depression and other mental health symptoms (Atkins, 2017). Some reported other support, including religion. This was in alignment with the statement of Staton-Tindall et al. (2013) that religion is important to African Americans and serves as a way to cope.

There was a significant lack of mental health support reported by these mothers. Most reported that no one checked on them regarding their mental health while they were in the NICU. Some reported nurses casually discussing mental health but offering no formal support. There were few identified groups provided by the hospital; they focused on the social aspect such as scrapbooking and were conducted by nurses. Support groups during this time would have been beneficial for these mothers to discuss their shared experience and to receive psychoeducation that was lacking (Turner, 2015). These mothers did not receive mental health diagnoses because they did not receive mental health support during that time.

A pervasive theme related to mental health and support was the SBW controlling image. These women reported feeling like they had to “be all things” for everyone. They had to be wives/partners, mothers, friends, and so on. They had to be strong for their children and not truly deal with what was going on with them. As Davis and Afifi (2019) explained, such a situation is not sustainable. Most of the women had breakdowns and significant times that they had to reach out for help, albeit reluctantly. Consequences of the SBW stereotype include stress, anxiety, depression, and emotion avoidance. These consequences are then exacerbated by the NICU experience and trauma. Sadly, this controlling image is also being placed on NICU babies. Corrine reported how a nurse

discussed how B/AA babies do the best in the NICU. This was something that I experienced as well. The expectation is that the baby is “strong” and can endure things that others may not.

### **Restrictive Institutions**

All of the mothers whom I interviewed reported some form of a lack of communication and knowledge. Most did not know about the NICU and what the experience would entail. Colet et al. (2016) stated that African Americans do not receive adequate prenatal care. Institutions such as those in healthcare and education continue to perpetuate racism. The mothers were not originally provided adequate information or a knowledge base from which to expand regarding their health and the health of their baby during this experience. Participants reported a lack of knowledge concerning the process of delivery and transitioning to the NICU that was sufficient for them. They also reported a lack of knowledge regarding procedures while in the hospital and the transition to home. Participants reported initially not knowing the criteria for discharge or multiple options for their babies’ treatment. At the outset of discharge, some reported a lack of communication between providers.

This information extends knowledge within the field. There has been limited information regarding lack of knowledge and communication in the NICU. Woods et al. (2016) identified mistrust of healthcare providers within the Black community. The lack of knowledge or communication may be related to their mistrust. If mothers do not believe that they are knowledgeable or being communicated with appropriately, this will

impact the trust that they have in the providers or NICU. The providers who took extra time to explain details and answer questions were B/AA.

### **Trauma**

Participants discussed the trauma that they experienced during this time in relation to negative feelings, hypervigilance, and future planning. According to Johnson et al. (2016), African American women are at higher risk of developing PTSD compared to other racial groups. These mothers identified symptoms related to PTSD such as hypervigilance, heightened arousal, and guilt/blame. Self-blame and guilt are common impacts of this traumatic event (Bouras et al., 2015). One of the participants reported, “you’re not supposed to blame yourself, but you do.” There were intense negative feelings regarding the experience from the prenatal stages until the postpartum period. The mothers were rarely provided resources to assist them in managing the trauma. Often, B/AA mothers do not seek mental health treatment because they are determined to succeed despite a lack of resources (Woods et al., 2016). The mothers whom I interviewed were determined to be resilient throughout this process for their babies. Some did not seek treatment because they believed that there was nothing wrong and that their symptoms were normal, whereas others reported that they would seek treatment if the symptoms worsened.

Future family planning was impacted by this experience. Some decided to not have additional children in order to not put themselves in another traumatic experience. One participant passionately reported, “I can’t, I won’t.” There were parents who decided that if they had another child, they would ensure that they received adequate care that

included advocating for their wants and needs, based on their experience with the previous preterm baby. This preparation also stemmed from a lack of trust in the system. Within the context of womanism, these mothers often felt as though they had to ensure that they were taken care of because their doctors had not done this. They often experienced themselves as their own advocates, as stated above.

### **Limitations of the Study**

A limitation to this study was the exclusion of those who were in the NICU during the COVID-19 pandemic. My dissertation committee and I weighed the pros and cons of including such mothers in the study. COVID-19 restrictions varied throughout the state regarding the timeframe in which changes occurred and the actual restrictions. These restrictions might have impacted individuals' experiences and made it more difficult to reach saturation. During the time of the study, there were changes in restrictions that would have proved difficult to overcome. I had to turn down potential participants because they were in the hospital at the time of the pandemic.

Transferability may be a limitation regarding trustworthiness. I used a sample size of eight, which is within the range to reach saturation with HP data. Six of the eight participants were in Virginia during their deliveries. The other two were in Texas and California. Although thick descriptions assist with enhancing transferability, there is still inherent researcher bias. As a second instrument, I have impacted the data and this may lead to more difficulty with transferability as my individual experience cannot be removed.

## **Recommendations**

There are several recommendations based on the results from the study and limitations that have been identified. There are recommendations for future research areas related to this topic. One limitation that could not have been mitigated was COVID-19. The pandemic occurred throughout the study process. There was no national mandate or set of standardized procedures for mental health providers and hospital providers. I decided to exclude mothers who had babies during COVID-19 from my study based on the numerous changes that might have impacted the data. Future studies may include B/AA mothers who were impacted by COVID-19. There may be differences in their experience due to changes in support available in the hospital, specifically in the NICU. There also may be differences in the transition home as some states, such as Virginia, were under special precautions and a stay-at-home order at one point.

Another future direction for research involves looking at the impact of the NICU on B/AA fathers. There were mentions in my interviews of the perceived struggles of participants' husbands or partners. Some participants identified their reliance on their partners emotionally. The current study focused on the mothers' experience. There may be valuable information on fathers. The mental health stigma in the Black community affects males as well as females. There are also differences in fathers' lived experience that were not accounted for. The impact of the NICU on the mother may have impacted the father as well.

The family unit may be impacted by the NICU experience. In the B/AA community, there tends to be reliance on othermothers or extended family. There may be

impacts to those additional supports or household persons. There were significant gaps identified regarding B/AA persons related to the NICU and mental health. There is a need for more focus on this group as rates of mental health disorders continue and rates of NICU babies in the B/AA community remain high. The more research that there is in this area, the more that counselor educators and supervisors will be equipped to train counselors.

### **Implications**

Positive social change implications arose at the conclusion of the study. The initial gap that I identified focused on the meaning of the lived experience of B/AA mothers with babies in the NICU. There were differences in rates of NICU babies born to this population. Through this research, I identified impacts on various levels with the counselor educators and supervisors who train counselors who provide mental health services to clients, schools, and hospitals.

### **Counselor Educators and Supervisors**

Counselor educators and supervisors are the people who are tasked with training counselors to be effective with clients. Based on responses from the participants, it would be beneficial to provide a safe space for mothers to discuss their experience and related feelings. There is a lot of guilt/shame associated with these mothers and their experience in the NICU, whether they believe that they are accountable for what happened or judgments from others on how they should handle being in the NICU.

A large component of this practice is being culturally competent and understanding dynamics that may be unique to this community. Rates of B/AA seeking



and consistently engaging in mental health support are low. Some of the reasons identified for this are lack of support and lack of someone who looks like them or can understand their experience through the lens of a B/AA woman. Therefore, developing rapport is the most important task so that they are comfortable with discussing this experience.

Womanist theory was an important lens to use when working with these mothers. To effectively teach this subject or supervise others in this area, this lens is a necessary one to use. The lens allowed me to understand the experience more intimately, as it is my natural lens. However, the premise of womanist theory is that the intersectionality of the Black female identity is a unique experience. To effectively enter the client's world, the counselor would benefit from understanding it more intensely. One significant aspect is women's relationship with their medical providers. In the B/AA community, there is mistrust of providers (doctors, nurses, etc.). Helping clients to advocate for themselves and find providers whom they trust would be beneficial to them.

Counselor educators and supervisors should ensure that counselors are taught how to recognize trauma symptoms as well as other perinatal disorders. In my research, there seemed to be many mothers who were later diagnosed with a mental health disorder or who recognized that they were struggling with a mental health disorder after discharge from the hospital. There was no official diagnosis, as there was no one there to assist them or diagnose them effectively. The mothers often explained symptoms that were equivalent with being in crisis. Counselor educators and supervisors should be educated on how to manage those in crisis. Crises occur in many different settings and impact

individuals differently. The crisis of having a child in a NICU brings unique challenges, as discussed previously. Immediate support would decrease the significant impact of mothers' mental health over the long term.

### **Training Programs**

Training programs are designed to prepare counselors to see clients. There often are not specialized courses as there is a substantial amount of information that must be retained during the training process. Training programs could add some information within their crisis or multicultural curriculum. Crisis can occur in various settings such as home, hospital, etc. Including information on this topic may make a difference in the ongoing maternal mental health concerns.

### **Hospitals**

One significant theme that I noticed throughout the research and discussed in Chapter 4 is the lack of resources provided for the mothers while their babies were in the NICU. There was limited contact with social workers or other mental health professionals. These mothers were not provided with assistance that would have been beneficial to assist them in managing their mental health. Hospitals could include in their admission paperwork or during their stay mental health resources to include individual provider list, groups offered in the area, as well as other online resources. An individual provider list could be provided for professionals who work with this population or have a relationship with the hospital. Online resources may include virtual support groups, forums, or other services that may be available to the NICU families.

Although I have identified some specific implications for specific groups, my hope is that this study fuels a conversation and deeper look into this phenomenon. Broad social implications include better treatment of B/AA mothers in the NICU that decreases the occurrence of mental health disorders. There are societal and cultural shifts that must occur to do this. In the interim, I would like to ensure that these mothers not only have access to resources but also have options of therapists that they may see to better manage their emotions during this traumatic experience.

### **Conclusion**

This study focused on the meaning related to the lived experience of B/AA mothers who have had a baby in the NICU. During my literature review, there was limited research on B/AA mothers especially in the NICU regarding their experience. I wanted to spotlight the mother's experience to find effective ways to assist them. I chose a womanist HP lens. This allowed me to focus on the unique intersectionality of their gender and race while including the researcher as an instrument. Participants provided me with rich details that better assisted me in understanding their experiences in the NICU. Themes emerged related to the trauma they experience, ways they must become advocates, support they received, as well as an overall lack of communication and knowledge. These themes were in alignment with the research regarding the SBW as well as the mistrust in providers that was confirmed with a lack of communication to them. These mothers found ways to not only care for their babies but survive this experience and be willing to assist others in this process.

This research has become one of my passions. I have had the unique experience of being a B/AA NICU mom. I felt many emotions during this process from excitement to frustration to sadness. I was moved by the amount of interest I had in this study that showed me the significance and potential impact of the research. While in interviews, I found myself identifying with varying portions of their experience. These commonalities were often negative experiences from perinatal to postpartum periods. There were times I felt myself getting physically emotional hearing about events that occurred and ways that they were treated. The NICU has impacted these mothers for life. My hope is that I can create a conversation about this topic that turns into tangible changes such as the training of therapists and the future development of support groups and programs at NICUs.

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## Appendix: Interview Questions

1. Please provide me your age, babies age at birth, and length of time in the NICU.
2. What was your experience as an African American woman with prenatal care?
3. Please provide details regarding your delivery and transition to the NICU?
4. How would you describe your experience in the NICU as an African American mother?
5. How would you describe your experience with providers in the NICU as an African American woman?
6. Please identify and describe your support system while in the NICU?
7. Please identify and describe your experience transitioning from the NICU to home.
8. What was your experience with the preterm baby once home to include follow up with providers?
9. As a result of your experience, is there anything you would like to see improved or continued?
10. Is there anything you think I have missed or would like to add?