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Preventing Kernicterus:
Racial Equity for Neonatal Jaundice

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Abstract

Neonatal jaundice is a common phenomenon among infants worldwide but the condition may progress to severe hyperbilirubinemia and if this progression is left unchecked, kernicterus may result. Kernicterus is the result of bilirubin toxicity that has reached the brain. It may result in irreversible hearing loss, brain damage, and death. Black and African American infants represent twenty five percent of reported kernicterus cases in the United States. This racial health disparity represents a practice gap that this project aims to highlight and address through provider education. Midwives and paraprofessionals at a midwifery organization in the Pacific Northwest were invited to participate in a story completion process as a means to inform an educational module for providers of neonatal jaundice care. Results of the story completion process were consistent with what we know about health equity and adequate care: listening and trust are foundational to the patient-provider relationship. Empowering families to be literate in the care of neonatal jaundice is imperative. The concepts formed the basis for a provider module that is included in this study. The content of the module has been tailored to the care of neonatal jaundice in Black and African American infants and includes an educational handout for the families and caregivers of this population.

Racial Equity for Neonatal Jaundice

Imagine yourself with a brand-new baby of your own. This is your first child, a completely life-changing experience; how exhilarating and scary those first weeks of new life! Imagine you have been awake for more than thirty hours, supporting your partner as she labors through childbirth. The two of you are exhausted and ecstatic, and your family is being discharged home because the baby is medically stable. Nurses come and go, providing supplies, blankets, and endless paperwork. At home, you dump the papers on the kitchen table. Maybe you sift through them later, saving the breastfeeding handout and newborn feeding log. One page that pictures an infant with yellow skin is shuffled to the bottom of the pile. Nobody at the hospital mentioned that your African American baby might turn yellow.

There is a misperception among healthcare providers in the United States that Black and African American (AA) infants are at less risk of developing hazardous hyperbilirubinemia and kernicterus. Recent research, including an important clinical review by Okolie, et al. (2020), has illuminated the racial health disparity among infants who present with kernicterus in the United States twenty-five percent of neonates with kernicterus are Black or AA, in a country where that demographic makes up fourteen percent of live births. This documented racial disparity is rooted in a healthcare system with a history of marginalizing the unique lived experiences of people who identify as Black and AA (CDC, 2021; Williams, Lawrence, & Davis, 2019; Bailey et al., 2017). Patients and providers within this system continue to grapple with flawed health outcomes research (Vyas et al., 2020), a mutual lack of trust (Gravlee, 2021), and substandard discharge education for Black and AA families (Muvuka et al., 2021).

In response to this systemic racism, healthcare providers and organizations are working for justice in new ways. Organizations that are led by women of color with missions to serve families of color, immigrants, and otherwise marginalized populations are growing and have much knowledge to share. This paper aims to highlight the experiences of trusted providers and paraprofessionals at one midwifery organization in the Pacific Northwest (PNW) and investigate the experiences, attitudes, and assumptions that providers have regarding care for neonates and families identified as Black and AA.

In addition to American Psychological Association (2020) guidelines regarding racial identity in academic writing, the terminology in this paper adheres to the Center for the Study of Social Policy (CSSP) recommendations (Nguyen & Pendeleton, 2020). Whenever possible, "people first" language has been used. The terms Black and AA will be used interchangeably to refer to persons of African descent living in the United States. As recommended by the CSSP, the terms Black and White will be capitalized. White will be used in reference to people who are racialized as White in the United States. This includes those who identify with ethnicities and nationalities that can be traced back to Europe. The CSSP notes, “To not name “White” as a race is, in fact, an anti-Black act which frames Whiteness as both neutral and the standard” (Nguyen & Pendleton, posted March 23, 2020).

This Doctor of Nursing Practice (DNP) project has been designed to improve organizational and provider literacy regarding neonatal jaundice for Black and AA infants and families. This project aims to create a neonatal jaundice module for providers tailored to the needs of Black and AA infants and families. The creation of this module is rooted within an emancipatory nursing praxis framework (Chinn & Kramer, 2013; Walter, 2017), and principles of design justice (Costanza-Chock, S., 2018.) This project is an intentional partnership with a local healthcare organization whose mission is to serve families of color, immigrants, and marginalized populations. Midwives and paraprofessionals from the organization were invited to participate in a story completion process to investigate their experiences in caring for Black and AA infants and families. Meanings and themes that came out of this process were then incorporated into a neonatal jaundice module, complete with a handout for families to take home. The next section provides an examination of evidence that supports this project, followed by a discussion of the design within the framework of emancipatory nursing praxis.

Background and Literature Review

Mild hyperbilirubinemia, or neonatal jaundice, is common among neonates worldwide. Infant bodies have difficulty excreting bilirubin, a substance produced when red blood cells break down, which may build up in their tissues, including brain tissue (Marcdante & Kliegman, 2019). Unmonitored, jaundice may progress to significant or severe hyperbilirubinemia. The condition is identifiable, preventable, and treatable if it occurs. Kernicterus, also called acute bilirubin encephalopathy (ABE), is the devastating result of hyperbilirubinemia left unchecked (Maisels, 2006, p. 443). The condition may result in permanent hearing loss, disabling brain damage, and even death. Hazardous hyperbilirubinemia is the precursor to kernicterus and is defined as total serum bilirubin (TSB) greater than 24 mg/dL (Bhutani et al., 2004).

Hyperbilirubinemia is subdivided into two categories. Conjugated bilirubin is often referred to as "direct-acting" bilirubin. Elevated levels of direct bilirubin are defined as greater than 1mg/dL if TSB is less than 5mg/dL, or greater than twenty percent the total level of bilirubin if TSB is greater than 5mg/dL. Elevated levels of direct bilirubin signal cholestasis and need prompt evaluation to discover the underlying cause. Many disorders can present with neonatal cholestasis, including but not limited to biliary atresia, infection, and some rare genetic disorders (Bhutani et al., 2016, Pathogenesis section).

This paper is concerned with the more common cause of neonatal jaundice, called unconjugated or “indirect,” hyperbilirubinemia. Physiologic jaundice refers to a transient and benign increase in total bilirubin levels in almost all infants. Hyperbilirubinemia becomes significant when TSB levels reach 5mg/dL in the first 24 hours of life or at levels greater than 10mg/dL after 24 hours of life (Wong & Bhutani, 2020). Evaluation and monitoring should begin if significant hyperbilirubinemia is noted as TSB may climb to severe or extreme levels.

The most common cause for hyperbilirubinemia is increased bilirubin production due to hemolysis (Wong & Bhutani, 2020 “Causes of,” section). This is generally known as hemolytic disease of the newborn. ABO incompatibility is the most common cause of hemolytic disease of newborn. Infants who sustain trauma in the birthing process (cephalohematoma, for example) are also at risk for hemolytic processes and subsequent hyperbilirubinemia. Jaundice may result if lactation is impeded or latching is difficult. Infants with greater than 10% weight loss in the first week of life should be monitored closely (Marcdante & Kliegman, 2019, p. 250). Infants who are exclusively breastfed are at higher risk for neonatal jaundice, and lactation specialists should be available to mothers who wish to do so but have concerns or difficulty with breastfeeding. Breast milk jaundice is the persistence of neonatal jaundice beyond the first two weeks of life but is generally mild and typically does not require interventions (Wong & Bhutani, 2020).

Other risk factors for hyperbilirubinemia include late preterm gestational age, East Asian race, jaundice observed before discharge, and macrosomic infant of diabetic mothers (AAP, 2004). All of this is to say that there are many considerations in the initial risk assessment for neonatal jaundice. Currently, the American Academy of Pediatrics (AAP) deducts a risk point for Black or AA infants (as maternally self-reported). Three recent papers discuss the error of guiding clinicians to consider Black and AA infants as being at lower risk for hyperbilirubinemia than other races (Wickremasinghe et al., 2013; Bhutani et al., 2016; Okolie et al., 2020). In reference to these reports, Okolie et al. (2020) write, “Hazardous hyperbilirubinemia risk in Black neonates went un-recognized because earlier studies analyzed all infants with severe hyperbilirubinemia as a single group and failed to differentiate risk as a function of less frequent extreme or hazardous hyperbilirubinemia” (p. 1200). That is, while Black and AA infants are at lower overall risk for total serum bilirubin levels greater than 20 mg/dL, they are not at lower overall risk for TSB levels greater than 30 mg/dL.

In the past, kernicterus has been named a “never event,” by the Joint Commission because hyperbilirubinemia can be diagnosed, treated, and is preventable (Levy, 2018). Despite this designation, kernicterus continues to occur. Population-based studies report that the incidence ranges from 1.2 to 2.3 per 100,000 live births per year in Denmark, Sweden, and Canada (Alken, 2019). The incidence is lower in the United States (0.44 per 100,000 live births), but this preventable condition remains a problem (Wong & Bhutani, 2020). Crucially, in the United States, twenty-five percent of babies who develop kernicterus are Black.

Approximately 60% of all newborns will develop jaundice in the first weeks of life (Mishra et al., 2008). Healthcare providers often rely on visual inspection to identify jaundice. However, current literature including AAP practice guidelines cautions that visual inspection for neonatal jaundice is unreliable, particularly in darkly pigmented infants (AAP, 2004; Canadian Pediatric Society, 2007; Muchowski, 2014). More recently, a randomized controlled trial conducted in a diverse set of South African newborns found that there was a significant reduction in readmission for jaundice management with the use of transcutaneous bilirubin (TcB) screening in comparison to visual inspection alone (Okwundu et al., 2020). There is debate among healthcare providers over how often to draw total serum bilirubin (TSB) which many consider painful and invasive to the infant but most accurate, and when to use TcB. TcB is less invasive and is widely accepted as more accurate than visual inspection. However, TcB readers cost thousands of dollars and are not viable at underfunded organizations. In the past, researchers have proposed dark skin pigmentation as a cause of inaccuracy in transcutaneous bilirubin meter readings (Onks et al.,1993; De Luca, et al., 2013). More recent research debunks this and supports the fact that TcB screening is a valuable substitute for more invasive TSB checks, regardless of infant skin color (Afanetti et al., 2014; Maya-Enero et al., 2021).

In the United States, many hospitals and healthcare organizations that manage birth routinely screen TSB within the first 24 hours of life. However, in the past twenty years, the length of hospital stay postpartum has decreased substantially. Where kernicterus was once thought to be nearly eradicated (Maisels, 2006), current discharge patterns for neonates and their mothers mean that bilirubin levels may not become clinically significant until the baby is at home. In 2008 the federal government implemented changes to the Newborns' and Mothers' Health Protection Act of 1996 that strengthened the protections against early hospital discharge (NCSL, 2018). However, significant hyperbilirubinemia may not become apparent until 72 hours of life or later. Post-discharge follow-up is, therefore, an important component of good neonatal jaundice care. In Canada, studies to evaluate the success of universal bilirubin screening found that missed follow-up appointments contributed to severe hyperbilirubinemia (Mah et al., 2010). More recently, Wennberg et al. (2017) found that lack of follow-up planning, inaccurate advice by providers, and delayed care-seeking by parents represent system failures contributing to kernicterus in affluent countries. In the United States follow-up guidelines are written by the AAP and depend on the infant's risk factors and course of delivery. Although the guidelines are clear, they do not account for socioeconomic factors that contribute to missing follow-up appointments and delayed care-seeking in the setting of neonatal jaundice.

Despite robust literature behind universal bilirubin screening and recommendations around when to follow up on that screening, timely follow-up for neonates with hyperbilirubinemia is lacking. In Canada, Darling et al. (2017) conducted a study to investigate whether implementation of recommended bilirubin screening was associated with improved rates of follow-up across socioeconomic status. This large retrospective cohort study found that screening had a modest effect on follow-up for newborns in Ontario. Darling et al. (2017) suggest that the lowest rates of follow-up correlated with the lowest socioeconomic status (SES). They identified barriers to timely follow-up: limited healthcare access on evenings and weekends and lack of transportation were cited. Difficulty communicating with healthcare providers related to the trust of the healthcare organization, language barriers, and lack of phone or internet access were also of concern.

More recently, a large study in Sacramento County examined the county's Comprehensive Perinatal Services Program, a federally and state-funded program to promote access to adequate prenatal care (as defined by the Adequacy of Prenatal Care Utilization Index) for low-income women who were eligible for Medicaid insurance (Thurston, Fields, & White, 2021). Racial subgroups were identified within the retrospective study. However, the authors found no evidence to support the hypothesis that ensuring access to prenatal care reduces racial disparities for important outcomes like preterm birth. They write, "We find that … low-income non-Hispanic Black females in Sacramento County have greater geographic access to and utilization of prenatal care than low-income White females, yet racial disparities in preterm birth remain" (Thurston, Fields, & White, 2021, p. 99).

The concept that access to care does not equal adequate care is an essential component of the 2018 black paper released by Black Mamas Matter Alliance (BMMA). The paper lists eight standards of holistic care for Black women, declaring these standards essential competencies for clinical care and education (BMMA, 2018). These standards are an important foundation of this DNP project and will be discussed throughout this paper. Briefly, standards one through seven include recommendations to listen to Black women, recognize the lived experiences of Black and AA women, provide care through a reproductive justice framework, undo racism within healthcare, empower patients with health literacy and autonomy, and to empower and invest in paraprofessionals. The eighth standard recognizes that access to care does not equal quality care. Adequate care includes meeting with women and families on their terms and on their time and striving to recognize the intersectional nature of human lives. Health literacy should not be assumed, nor should a lack of health literacy be shamed. Adequate care moves beyond providing equity of access to care. It addresses the patient-provider relationship, recognizes implicit bias on the part of healthcare providers, and challenges existing algorithms and structures of care delivery. The Institute for Healthcare Improvement (IHI) also supports these concepts in the 2016 white paper, "Achieving Health Equity: A Guide for Healthcare Organizations (Wyatt et al., 2016, p. 10)."

Racial Disparities

Why are rates of kernicterus disproportionately elevated in Black infants? Importantly, there is a misperception among clinicians that Black neonates are at lower risk for hazardous hyperbilirubinemia. The AAP guidelines cited earlier in this paper list Black race (maternally self-reported) as a factor associated with decreased risk for severe hyperbilirubinemia. Other documents repeatedly observe that Black neonates are at lower risk as well, reinforcing clinician misperceptions of the need to follow Black infants with elevated total serum bilirubin (TSB) closely (Newman et al., 2005; Newman, et al., 2000). However, misperception around race and risk for significant hyperbilirubinemia is not the only reason for kernicterus racial disparity. Other physiological factors contribute, including late preterm delivery and G6PD deficiency. Late preterm delivery is a well-documented risk factor for severe hyperbilirubinemia and kernicterus (Newman et al., 1999). Late preterm delivery is overrepresented among Black mothers. It is associated with immature neonatal hepatic function and varying causes of lactation failure, including problems with milk production and milk transfer, for example, latching difficulty (Shapiro-Mendoza & Lackritz, 2012; Abrams & Hurst, 2021).

Evidence suggests Black and AA infants are at higher risk for Glucose-6-phosphate dehydrogenase (G6PD) deficiency (Watchko et al., 2013). G6PD is an enzyme that protects red blood cells against oxidative injury. G6PD deficiency is an X-linked genetic disorder that increases a person's risk for hemolytic anemia. Bhutani et al. (2015) note that although the World Health Organization has recommended G6PD screening for newborns at high risk of deficiency (WHO Working Group, 1989), the cost of quantitative enzyme assay is high due to the cost of staffing and administration needed to oversee the process. Watchko et al. (2013) discuss that suitable screening tests are available but that birthing hospitals are inexperienced with G6PD screening and have not reached a national consensus on effectiveness and best approach.

Twelve percent of AA males and four percent of AA females have G6PD deficiency. Two-thirds of kernicterus cases among Black infants are secondary to G6PD deficiency (Johnson et al., 2009). The condition is known to present with sudden and unpredictable levels of hyperbilirubinemia due to hemolysis that presents spontaneously in the setting of oxidative stress. Triggers may include maternal ingestion of fava beans, certain herbal teas, exposure to henna, some lotions, and camphor (Kaplan & Hammerman, 2010; Wennberg et al., 2020;). This means that identifying hazardous hyperbilirubinemia may be delayed and sudden in onset among African American babies, occurring long after discharge. Without urgent recognition and timely treatment, kernicterus occurs, and brain damage or even death may result.

Non-biologic factors contribute to kernicterus racial disparity as well. These socioeconomic and systemic factors are the focus of this particular DNP project. While literature specific to improving follow-up and health literacy for Black and AA babies with hyperbilirubinemia in the United States has been limited, this area of research is growing, and we do know that health outcomes are closely tied to health literacy (Yin et al., 2009; CDC, 2021). As evidenced above, organizational health literacy regarding the risk of hazardous hyperbilirubinemia in Black infants is poor. Political systems and social structures in the U.S. were created to keep people of color at the lowest socioeconomic levels in our society. There is well-documented evidence that Black and AA families in the U.S. routinely experience subpar healthcare (Tobin-Tyler & Teitelbaum, 2019, Chapter 2). Lack of timely follow-up, health illiteracy, and socioeconomic barriers, including systemic racism, all contribute to the racial disparity in rates of kernicterus (Brown et al., 2019). As leaders in care for the whole patient, advanced practice nurses are well-positioned to identify and address socioeconomic and systemic factors contributing to racial health disparities. Strategies to mitigate racial disparities are detailed in the next section.

Management Strategies

The CDC defines organizational health literacy as, "The degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (Health People, 2030, How does Healthy People define health literacy?). There is a gap in provider knowledge around risk for kernicterus in Black infants and their families. If providers themselves do not understand the risk, they are not equipping their patients with knowledge and resources to mitigate that risk.

Highlighting kernicterus racial disparity and encouraging organizations to redesign the way they care for Black families toward more equitable practices is imperative. Essential strategies include spending greater time with families to build trust and relationships, investing in resources and inclusive teaching materials, and recognizing the intersectional needs of families who exist at the margins of society. Organizations must implement teaching to dispel misperceptions that Black and AA babies are at lower risk for hazardous hyperbilirubinemia. It is necessary to highlight the risk for sudden and delayed hyperbilirubinemia associated with G6PD deficiency among Black and AA infants.

Once an organization is literate about the racial disparity and contributing biological and non-biologic factors, the next step is to empower parents and caregivers of Black infants at risk for kernicterus. Although the AAP cautions that visual inspection for jaundice in babies of color may lead to errors, the first step in their algorithm for managing jaundice is to inspect for jaundice every 8-12 hours. If results determine there is a concern, a serum bilirubin level is obtained. Fortunately, many healthcare organizations in the U.S. draw TSB within the first 12-24 hours of life as a matter of protocol or check TcB at the very least. There are effective ways to assess babies with darkly pigmented skin for jaundice, including blanching the tip of the nose, observing the gums, and checking the sclera. However, caregivers are frequently uneducated on these techniques and therefore ill-equipped to teach parents.

Teaching parents and caregivers about neonatal jaundice is a fundamental step toward preventing kernicterus. Notably, a recent study in Nigeria asked whether teaching mothers about neonatal jaundice, both antenatally and postpartum, would decrease the occurrence of acute bilirubin encephalopathy (ABE) among infants being followed for jaundice (Wennberg, et al., 2020). ABE is more common in sub-Saharan Africa than in more affluent parts of the continent. In Nigeria, G6PD deficiency affects an estimated 17% of newborn infants. Wennberg et al. (2020) identified delay in seeking care as a significant component in the high rates of ABE and kernicterus in Nigerian infants. In addition, mothers who received antenatal and postpartum instruction about neonatal jaundice decreased delay in care-seeking from 49% to 17%. If U.S. healthcare providers discount the risk in Black and AA families, they are less likely to provide education and miss the opportunity to empower Black and AA parents.

Hospitals remain under pressure to discharge infants and mothers who are stable and at low risk for hospital intervention. The AAP (2004) provides guidelines around when these families should follow up post-discharge relative to age discharged and provides common risk factors for hazardous hyperbilirubinemia. For example, it is recommended that all infants discharged at 48 hours of life return for a follow-up examination within five days. The guidelines also recommend that clinical judgment should guide follow-up. Earlier or more frequent follow-up should be provided for those with Risk factors for hyperbilirubinemia should also guide timing of follow-up. Leaving aside socioeconomic barriers to follow-up, the onus on the provider to determine the risk of a stable infant decompensating before day five (an extended length of time in a critical period of human life) and to ensure that the family return for evaluation is enormous. Certainly, and the AAP does recommend, healthcare organizations should strive to equip families with knowledge of their own, to empower them in reaching out to the organization from home if they see concerning signs and symptoms of hyperbilirubinemia at home.

A host of factors contribute to racially disparate rates of kernicterus. Strategies to reduce these rates should be aimed at improving patient and organizational literacy for kernicterus prevention. Good relationships must exist, as foundations to effective teaching; access to teaching does not equal quality teaching. Providers must understand the holistic needs of Black women and families first so that adequate teaching and follow-up occur. This DNP project draws upon the lived experiences of caregivers who are trusted within Black and AA communities to incorporate this knowledge into a neonatal jaundice teaching module that is holistic and tailored to the care of Black and AA infants.

Practice Gap: Equitable Neonatal Jaundice Care

Health equity involves tailoring healthcare to the lived experiences and intersectional identities of our patients. Management of neonatal jaundice is well-studied and evidence to foster best health outcomes for infants with hyperbilirubinemia is robust. Tools such as bilitool.org and Bhutani's nomogram are widely used in the U.S. due to their incorporation into the AAP clinical 2004 guidelines for neonatal jaundice. Many providers rely heavily on this guidance to manage neonatal jaundice in healthcare settings; however, since the publication of the guidelines, questions about reliability and universality have arisen (Fay et al., 2009; Muchowski, 2014). The challenge is that these guidelines present a limited one-size-fits-all approach to neonatal jaundice in a nation and healthcare systems that are not universally effective for all citizens (Tobin-Tyler & Teitelbaum, 2019, Chapter 1). These guidelines also leave aside the fact that there is an entire population for whom jaundice is challenging to observe visually and for whom healthcare is difficult to access or, when accessed, difficult to trust. These guidelines are based on research that has been constructed by a predominantly White healthcare establishment, based on assumptions of what life is like for White families who are entitled to privileges in a society where Black families are not. Therefore, clinicians must examine methods of care for AA families and introduce equitable care practices to the care of neonatal jaundice.

This DNP project includes teaching for healthcare providers that centers Black infants' risk for hazardous hyperbilirubinemia, families' need for education and empowerment, and the importance of listening to and following up with those families. This project emphasizes that monitoring NNJ in Black and AA infants is slightly different from monitoring White infants in regard to both visual inspection and timing of onset.

Design

This project is rooted in Chinn and Kramer's emancipatory nursing praxis framework (2013). Emancipatory knowing extends Barbara Carper's original four ways of knowing to add emancipatory knowing (Carper, 1978). Emancipatory knowing seeks to address nursing and healthcare's social and political context. This framework provides a model for emancipatory praxis that relies on *awakening, engaging*, and *transforming*. To awaken, researchers move traditionally centered narratives to the background and invite dialogue from communities who have been silenced. This includes engagement in praxis through evaluation of current practices and health outcomes. Whose health is suffering and why? What can be learned from within the communities by those who seek to serve? Equity is achieved through awakening and engaging, thereby transforming healthcare systems. All humans flourish through this cyclical model of nursing praxis.

Knowledge is power. If science is the quest for and creation of knowledge, and if health research grounds itself in the scientific method, then health research leaders hold substantial power. Historically in the U.S., these have been White health researchers, a demographic with a poor record of practicing diversity, equity, and inclusion (Bailey et al., 2017). Currently, four of five members on the AAP executive committee are White. Ten of thirteen on the AAP board of directors are White. Of this total group of eighteen, one Black person, a man, is pictured (AAP, 2022). That is just one-half of one percent of this powerful and vocal pediatric authority being represented by the Black community today. Power is unbalanced and Black voices are not centered at the top of our healthcare systems.

The American College of Obstetrics and Gynecology (ACOG) lists its past presidents online dating back to 1951 (ACOG, 2022). For the first 35 years, every president has been male, and while they are not pictured nor race listed, it is fair to assume that the majority (if not all) of those past presidents were White men. One Luella Klein was listed in 1984, but another fifteen years before Vicki Seltzer’s name (1997) interrupts a long list of Georges, Roberts, and Williams. Just three more women serve as ACOG president between 1997 and the present. Each president serves one year, meaning that in twenty-five years, just four women have served as president, to more than twenty men moving through the position in an association dedicated to women’s bodies. Important narratives and representation are missing within this organization.

The American College of Nurse-Midwives (ACNM) represents a new leadership model in healthcare by picturing a board of eighteen women, only four of whom are unmistakably White (ACNM, 2022). This is important representation by a prominent association for women's health. Reproductive justice means asking *which community members are being served and who is being excluded?* Who holds knowledge about what life is like for families ignored by racist and oppressive healthcare systems? In addition to individuals within those communities, the midwives who serve them are valuable resources; these trusted providers and the paraprofessionals who work closely with them hold essential knowledge to be shared outward.

The Journal of Pediatric Nursing featured a study in October 2021 that invited mid-Western low-income AA parents with children ages birth to five years to participate in a focus group examining their experiences and expectations of well-child care (Koschmann et al., 2021). Distrust and low expectations in health establishments and providers were expressed. These parents felt that healthcare providers did not understand their parenting needs and their lived experiences were not well understood. They reported being more likely to rely on family and friends for knowledge and support and described feeling judged by healthcare providers for perceived lack of health literacy.

This DNP project seeks to move away from colonial healthcare models toward health equity and true human flourishing for everyone involved. Suppose we assume that knowledge is power and power is a socially embedded process. In that case, it makes sense to open up dialogues and reposition our perspectives as a starting point to engage effective praxis for better healthcare systems. Who holds knowledge? Is it good, quality knowledge that addresses diverse, rich narratives? Does it incorporate the lived experiences of everyone in the room?

Design justice, as discussed by Sasha Costanza-Chock (2018), is a framework that “rethinks design processes, centers people who are normally marginalized by design, and uses collaborative, creative practices to address the deepest challenges our communities face" (p. 2). Costanza-Chock (2018) proposes that design justice is a theory applied across many fields and industries. Among the principles outlined by the Design Justice Network in 2016 is a call to center the voices of those directly impacted by a program's design. Non-exploitative solutions are essential components of design justice and recognizing what is already working at the community level is imperative.

The foundation of this project is reproductive justice and design justice within an emancipatory nursing framework. This study is designed to investigate midwife-led healthcare teams' experiences in providing healthcare to marginalized populations in the Pacific Northwest. The partner organization is established and trusted by women of color and immigrant families within this community. They are already working effectively at the community level. This project has been designed with this in mind: that these midwives and paraprofessionals are on the ground seeking to build health equity and that their experiences and knowledge are important to share outwardly with other healthcare providers and organizations.

Further, to build non-exploitative solutions, this project is designed to move the burden of emotional labor away from the families they serve by aiming a story completion process at clinicians within the partner organization. While the point of reproductive justice is to listen to Black women, that does not mean that Black women owe the world a teaching moment. This project has intentionally partnered with an organization where trust is established within the community to ask, What are the lived experiences of Black midwives and doulas in relationship with Black and AA families within a predominantly White city and county?

The Black Mamas Matter Alliance (BMMA) has been an important source in designing this project. The eight standards of holistic healthcare for Black women have been discussed elsewhere in this paper but it bears repeating that the number one standard of care is to listen to Black women. More than half of the providers at the partner organization identify as Black. Well over 60% of the organization's patient population identify as Black or AA. These providers and this organization are an important source of knowledge and understanding about what it means to navigate the healthcare systems in the PNW while Black.

This project uses principles of design justice and reproductive justice for Black women within an emancipatory nursing praxis framework to demonstrate a new model of care for neonatal jaundice. The purpose of this project is to improve professional and organizational literacy regarding neonatal jaundice care (NNJ) for Black families in the U.S. Project aims include collecting stories of best care by midwives and paraprofessionals among oppressed demographics and creating a self-study module for clinicians who wish to provide better neonatal jaundice care within Black and AA communities. What can the stories and narratives of these clinicians teach others about building trust and centering the lives of the families they meet? Can this meaning be incorporated into better neonatal jaundice care for Black and AA infants?

Method

Story completion is a qualitative research tool to mine dominant assumptions and understandings of subjects that may be triggering, divisive, or otherwise difficult to ask about directly (Braun & Clarke, 2013). It was originally conceived as a tool for eliciting psychological projections; Rorschach's Ink Blot Test (1942) is perhaps the most famous example of story completion at work. An ambiguous inkblot is presented to the subject, who is then asked to describe what they see represented within the image. In the second half of the 20th century, feminist scholars adapted the approach to investigate social constructs and understandings indirectly, thereby eliciting participants' attitudes and assumptions about otherwise triggering material (Braun et al., 2018). Story prompts (also called stems) are created, and participants are asked to complete the narrative in the third person. Stems are designed to be broad and ambiguous. As participants provide detail and flesh out the story, their choices reveal underlying attitudes and assumptions about the scenario. The indirect nature of story completion lends an element of safety to the participant; stories are completed in the third person, thereby removing personal implications from potentially divisive, sensitive, or triggering story cues.

The overall goal of this project is to elicit stories and narratives from the partner organization and to keep those stories intact as much as possible. Thematic analysis within story mapping is recommended as an approach to analyzing the collected data and mining the experiences, values, and dominant assumptions of those who complete the stories (Braun & Clarke, 2013). Mapping the stories out before analysis lets the narratives remain intact as much as possible. Events and actors within the narratives were mapped out, and through mapping, the first round of data familiarization occurred. Two rounds of traditional thematic analysis followed and narratives were coded for positive and negative feelings, interactions, and outcomes.

This project also involves creating and implementing a study module for dissemination to other organizations, complete with a PDF handout for families of Black and AA infants at risk for neonatal jaundice (Appendix). The module incorporates data collected through story completion together with the best evidence to prevent kernicterus, to be used by healthcare providers to reduce rates of severe hyperbilirubinemia in their communities. The module will be piloted at the partner organization, and provider use of the module/family handout will be measured at six months and one-year post-intervention. Seattle University's Institutional Review Board has determined that this project does not constitute human participant research.

Setting and Recruitment

This project is in partnership with a midwifery organization trusted within local Black and AA communities. The organization ministers to women and families of color, immigrants, and other marginalized demographics. Clinicians at the organization include nine midwives and ten doulas. More than half of these providers identify as Black or AA. The organization has a mission to engage in transformative change as a continuous process that is centered on discussion, compassion, and shared power. More than 60% of their patient population identify as Black or AA.

Inclusion criteria required the participant to identify as a clinician affiliated with the identified midwifery organization. Emails were sent out with a link to the online story completion prompts. Informational consent was provided at each intervention, with an option to decline participation included.

Intervention

Story cues were designed to be broad and as ambiguous as possible (see Table 1). Three optional, hypothetical scenarios involving neonates of color were posed in one to two sentences. The wording of the stem was designed to be as vague as possible while still prompting thoughts about race and social roles within healthcare systems. Story prompts were embedded into a Qualtrics survey, and the survey was distributed to providers within the midwifery organization. Informational consent was provided, along with an option to decline participation. Three different stems were provided to participants, and they were instructed to complete any or all of the prompts. At each story cue, instructions to complete the prompt in the form of a story were provided, including the explicit permission to write as much or as little as one wanted.

Table 1

Story Prompts

Prompt 1 (P1)	**Prompt 2 (P2)**	**Prompt 3 (P3)**
Taylor is meeting with an East African family who recently arrived in the U.S. and are expecting their new baby any day now. How is this family doing? What are Taylor's priorities?	Angela is a woman of color and the mother of a darkly pigmented two-day old infant who is highly irritable and will not feed. Maria arrives to the home for a routine postpartum check.	Angela is a woman of color and the mother of a darkly pigmented nine-day old infant who is highly irritable and will not feed. Her pediatrician has advised her to take the baby to the E.R.

The author then created a brief self-study module focused on NNJ care tailored to Black and AA infants and their parents and caregivers. Care outlined in the module is based on current literature for best neonatal jaundice care combined with the experiences of the providers within the partner organization. A handout PDF for the families has been created, at the organization's request (see appendix for these deliverables). Both the module and the PDF will be distributed to the organization. Surveys at six months and one-year post-intervention will be sent, to evaluate the use of these materials among providers at the organization.

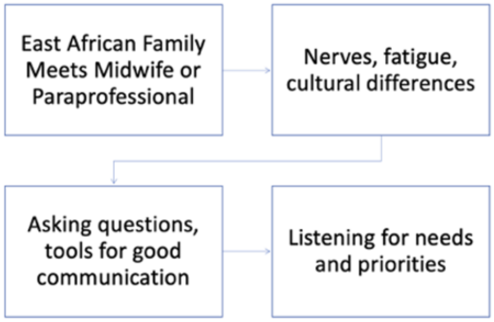
Results and Analysis

The distributed survey received six responses in total (N=6). All participants completed every story stem, most in one paragraph or less. As stories were completed, the author mapped out actions and actors as they occurred in the narratives, along with any feelings or surroundings that were described (Figures 1, 2, and 3). Who was involved (the actors), what they did or did not do (actions), and feelings described throughout are important clues to dominant attitudes, assumptions, and the meaning that these clinicians hold around the care of their patients and families.

Standard thematic analysis may obscure the narrative character of story completion research. The sequencing of related events is not retained in the analysis (Braun & Clarke 2013). Braun and Clarke (2013) proposed a story mapping technique, which aims "to capture patterns in the temporal, causal, and evaluative organization of the stories, particularly in how the central character is depicted, and the story (moral) resolution or coda (p. 245)." Mapping stories out first facilitated typical thematic analysis data familiarization and coding for meanings and themes. Discussion of this analysis follows, interspersed with selected narratives as examples (Tables 2, 3, and 4).

Figure 1

P1 Story Map



Of note, P1 concerned the antepartum period, P2 occurred at day two postpartum, and P3 took place at nine days postpartum. Completed narratives in the antepartum scenario revealed an immigrant family that was tired, overwhelmed, and cautious in seeking perinatal care. Trust on the part of the family toward the healthcare provider, organization, or system is not assumed. In all completions, Taylor's priority was to establish trust through cultural respect and clear communication (interpretive services were cited).

Table 2

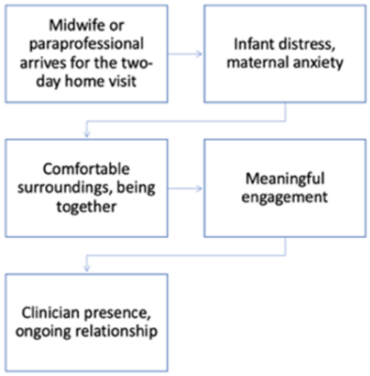
P1 Examples

Assumptions, attitudes, and meanings	Example Quote
• Taylor does not assume that trust is automatic • Cultural differences • The family sets the priority	Taylor's priority is to build trust with the family. There are extended family present at this meeting and she welcomes them all into the discussion. Their priorities will be her priority.
• Reservations, anxiety • Communication barriers • Listening for family's needs	The parents seem shy and have trouble with English. Taylor uses an interpretive service to communicate and asks the family what their needs are.

Providers completing P1 were concerned with honoring the family's cultural practices and language preferences as a means to establishing trust first and foremost. All of the responses required that Taylor listen to the family carefully for their needs. Narratives echoed each other in establishing that the family's priorities are Taylor's first priorities. Unwritten but understood is the action of listening for what those priorities are. Importantly, the dominant assumption in this interaction is that trust is not assumed on the part of the provider; Taylor knows that she must earn the family's trust at the outset.

Figure 2

P2 Story Map



In P2, stakes are a little higher with an irritable, possibly inconsolable two-day old infant. The trusted clinician arrived for the postpartum home check. Two of the six respondents described the two adult women hugging. The provider listens to the mother and assesses the baby. Feelings of comfort were described whether it's a comfortable living room, comforting the infant, or comforting Angela.

Table 3

P2 Examples

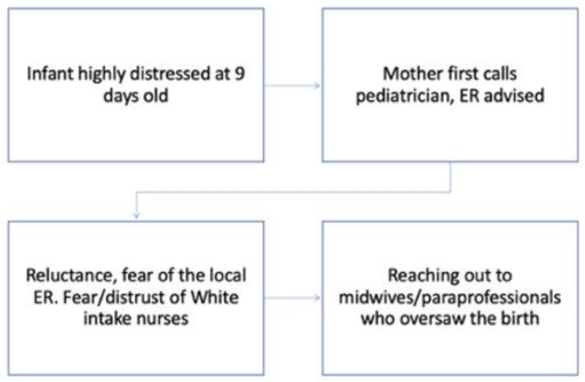
Assumptions, attitudes, and meanings	Example Quote
• Midwife arrival and comfort • Infant assessment	Maria and Angela hug. The baby is crying and won't take breast or bottle. His weight

• Remaining together	today is reassuring. The women sit together in the comfortable living room.
• Midwife arrival and comfort • Infant assessment • Remaining together	Maria smiles and takes the baby. She hugs Angela. They change the baby's diaper and weigh him. Maria stays as long as Angela needs.

Interestingly, the narratives do not focus on resolving the infant's irritability. The stories describe a clinician arriving and a mother being comforted, or surroundings that are comfortable. Five out of six of these stories finish with the two women sitting together. Arriving and being present are the two main actions of the clinician in this scenario, both being very positive actions that confer comfort on the family.

Figure 3

P3 Story Map



P3 is uniformly negative in the tone of completed stories. Three out of six completions described Angela's fear and distrust of White intake nurses at a local E.R. The scenario in P3 is moving out of midwifery expertise and into the domain of pediatric medicine. This may account for some of the fear and anxiety expressed by the clinicians through their stories. However, the fact that fifty percent of these responses name the same local E.R. and describe its all-White nursing staff is hard to miss. Angela's feelings of anxiety and apprehension about the care she and her baby will receive from White professionals at the established local hospital are consistent with current understandings of what it is like to be Black in the U.S.

Table 4

P3 Examples

Assumptions, attitudes, and meanings	Example Quote
• Anxiety • Fear that distress won't be taken seriously by White nurses	Angela arrives with the baby at [the] E.R. The intake nurses are all white. They don't seem very worried about her baby.
• Reluctance to visit the E.R. • Perceived coldness by White nurses	She reluctantly presents to [the] E.R. White nurses doing intake are brusque.
• Reluctance to visit the E.R. • Feeling alone, isolated • Perception that White nurses are unfriendly	She reluctantly presents to [the] E.R. alone – pandemic protocols are in place, preventing anyone but parents from accompanying patients. The intake nurses there are white and unfriendly toward her.

Discussion

The narratives were quite similar throughout. All of the stories featured a Black or AA infant and mother of color. All prompts began with a neonate in distress, and a mother who was unsure what steps to take. Responses echoed each other in describing mothers' reluctance to seek care outside of the midwifery organization. About half described the mother reaching out to her midwifery clinician at the moment of distress.

Interestingly, the stories did not end with the baby's medical emergency completely taken care of. Instead, narratives ended with scenes of togetherness in the face of crisis. For instance, one story finished with the mother and clinician sitting together in a comfortable living room to discuss the next steps. Descriptions of the story setting were frequently given, and all were based within the family's home. Words such as *comfortable, warm,* and *safe* were frequently used as descriptors of the home.

The point of this project was to methodically gather current knowledge and attitudes around neonatal care and race at one organization in the Pacific Northwest. Attitudes of mistrust and fear arose when families were described as seeking care outside of the trusted organization. Within the organization, trust was never assumed at the outset. Instead, providers assume that they will need to build trust as a matter of course and work to do so every step. Listening and presence on the part of the clinician were identified as paramount to quality care for Black and AA populations. Listening to families fosters the trust upon which these patient-provider relationships thrive. These findings are consistent with much that is already in best holistic care for Black and AA women.

Limitations

Limitations of this study included the small size of the data set. In story completion research, piloting the stems before implementation is ideal; however, time constraints necessitated that this is the pilot project for these particular prompts. This DNP project was conducted during the second wave of the global coronavirus pandemic, and the author was conscious that the burden of multiple rounds of story completion was an unreasonable ask of these providers at the time.

Recommendations

The problem of disparate kernicterus rates among Black neonates in the United States is multifaceted and complex. Teaching providers and organizations to recognize that hyperbilirubinemia may escalate late and quickly in Black infants is an important step. Timely follow-up when hyperbilirubinemia is suspected is imperative. The provider's responsibility is to educate families on identifying jaundice in darkly pigmented infants and what to do when they find it. Materials to facilitate this education should be provided in the family's primary language and presented in easily understandable terms to the layperson.

It is no longer acceptable to send Black and AA families home pamphlets featuring White babies who look jaundiced. Instead, organizations and providers must strive to help caregivers understand that infant jaundice may not be easily spotted by simple visual inspection. Referral and access to lactation services should be abundant. Adequate feeds and the number of wet diapers and stools in a day should be carefully gone over by the clinicians and nurses in clear and compassionate terms; providers should examine their own implicit biases and strive to mitigate those, to ensure trust between families of color and the largely white healthcare establishment.

Overall, the steps needed to mitigate the current racial disparity in kernicterus rates are based largely on creating equitable care practices in neonatal jaundice. Health literacy rates on both patient and provider sides need improving. Strategies should be rooted in empowering Black and AA families to recognize hyperbilirubinemia. Listening and support are critical. Provider and organizational awareness of kernicterus disparity and examination of the care Black and AA families receive are crucial recommendations to making kernicterus a true “never event.”

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Appendix: Supplemental Materials

PowerPoint Module for Providers

EQUITABLE CARE FOR NEONATAL JAUNDICE

Sarah Christensen, BSN, CPN, DNP Student
Seattle University – College of Nursing

Note. Click the image above to view the module

PDF Handout for Families and Caregivers

NEONATAL JAUNDICE

UNIQUELY AFFECTS BLACK INFANTS

VERY COMMON

60% of all newborns develop jaundice in the first few days of life.

OFTEN HARMLESS

For Black infants, jaundice levels peak at 2 to 4 days of life.

If your baby is feeding and voiding adequately, jaundice is likely to resolve on its own!

KNOW THE RISKS

- Sometimes, jaundice progresses beyond what is normal and harmless. Kernicterus is a devastating condition that you can prevent by recognizing jaundice early and involving a healthcare provider.
- Black infants are at risk for a unique type of jaundice that present later than expected (after they are one week old). This may come on suddenly and you will need to act right away. Know who to call!

Neonatal Jaundice
Severe Hyperbilirubinemia
Kernicterus

IDENTIFY JAUNDICE

Studies have shown that parents are great at recognizing jaundice!

INSPECT

- Use a well-lighted room
- Press the tip of your baby's nose lightly. If she is jaundiced, the skin will look yellow when you remove your finger
- Check the whites of baby's eyes for any yellowing.
- If you see jaundice, call your infant's healthcare provider

FEEDING PLAN

Whether you choose breastmilk or formula, make sure your newborn is eating every 2-3 hours in the first week of life.

Lactation specialists are experts on infant nutrition and can help prevent the progression of jaundice

BE SURE TO CALL

Rarely, Black infants develop severe jaundice at 2-3 weeks of age. They may refuse to feed and be extremely irritable when this happens.

Learn more about neonatal jaundice at https://www.cdc.gov/ncbddd/jaundice/facts.html or by calling Rainier Valley Midwives at (206) 712-7352