

The Ethics of Perinatal Care for Black Women

Dismantling the Structural Racism in “Mother Blame” Narratives

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ABSTRACT

Perinatal and neonatal nurses have a critical role to play in effectively addressing the disproportionate prevalence of adverse pregnancy outcomes experienced by black child-bearing families. Upstream inequities in maternal health must be better understood and addressed to achieve this goal. The importance of maternal health before, during, and after pregnancy is illustrated with the growing and inequitable prevalence of 2 common illnesses, pregestational diabetes and chronic hypertension, and 2 common conditions during and after pregnancy, gestational diabetes

and preterm birth. New care models are needed and must be structured on appropriate ethical principles for serving black families in partnership with nurses. The overarching purpose of this article is to describe the ethics of perinatal care for black women; to discuss how social determinants of health, health disparities, and health inequities affecting women contribute to poor outcomes among their children; and to provide tools to dismantle structural racism specific to “mother blame” narratives. Finally, strategies are presented to enhance the provision of ethical perinatal care for black women by nurses.

Key Words: African/black American women, chronic disease, diabetes, health disparities, health inequities, hypertension, pregnancy, social determinants of health

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The American Academy of Nursing, the American College of Obstetricians and Gynecologists, and the American College of Nurse Midwives have recognized the unacceptable health disparities in maternal health.^{1–3} These professional organizations recommend that the healthcare workforce providing care during pregnancy understand health inequities and strategies for amelioration.^{1–3} These recommendations are also relevant to providers and public health professionals who specialize in neonatal and perinatal health, where inequities may be downstream from maternal health inequities. In addition, the American Nurses Association (ANA) Code of Ethics⁴ outlines the role of the professional nurse and includes the concept that nurses practice with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, without exceptions for socioeconomic status, personal attributes, or the nature of the individual’s health problem. The ANA Code guides practice for all nurses and is one of many documents to inform ethical principles in the care of black women.

Table 1. Key concepts

- Social determinants of health are the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.⁵
- Health disparities are defined as preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.⁶
- Health inequities are avoidable inequalities in health between groups of people within countries and between countries. These inequities arise from inequalities within and between societies.⁷
- Structural racism is systematic laws and processes used to differentiate access to services, goods, and opportunities in society by racial groups.⁸

Over the last 20 years, research has carefully documented the impact of social determinants of health. Core concepts in social determinants of health are defined in Table 1. In addition, Figure 1 illustrates how social and economic can influence risk factors of illness and the actions taken to prevent or treat illness when it occurs through the lifetime.⁶ There has also been increasing recognition that the racism, discrimination, and mistreatment experienced by many black women have a distinct relationship to health outcomes.⁸ Specific to the perinatal period, economic vulnerability, stress, and experiences of discrimination have been identified as racism-related risk factors associated with

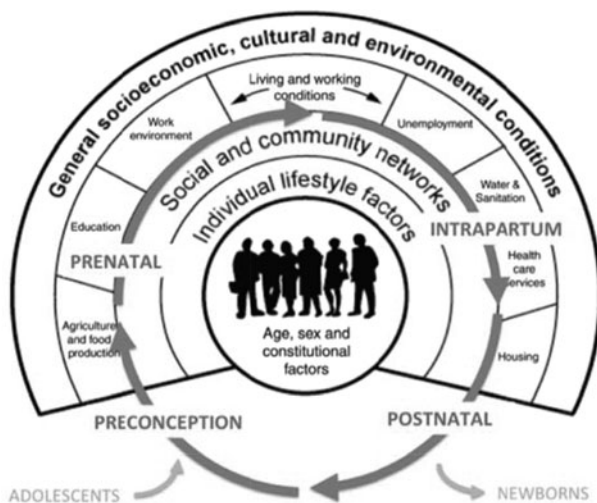


Figure 1. Social determinants of health, health disparities, and inequities across the reproductive life course. Adapted with permission from the Preterm Birth Initiative—California, the San Francisco Department of Public Health, and the Centers for Disease Control and Prevention framework on social determinants of health.

pregnancy-related mortality.⁸ Given the burden of poor perinatal outcomes is experienced most greatly by black women, this discussion focuses on the health of black women. However, individuals who do not identify as women or mothers, including transgender and gender nonconfirming individuals, also need structurally competent and evidence-based improvements in perinatal care to optimize pregnancy outcomes.

The inequitable distribution of prepregnancy chronic illness and pregnancy conditions influences the reproductive and general health of black women and children across the life course. Unfortunately, individual-focused “mother blame” (defined as holding pregnant women exclusively responsible for the ill health of their children) narratives have dominated approaches to managing pregnancy conditions and chronic illness, with little success.^{9,10} Exclusively addressing individual behaviors as the basis for health outcomes, without a structural perspective, can lead to stigmatization, scapegoating, heightened surveillance, and criminalization, all of which disregard the bodily autonomy of pregnant women.⁹

The purpose of this article is to illuminate the ethics of perinatal care for black women and to provide nurses and public health professionals with tools to dismantle structural racism (ie, systematic laws and processes used to differentiate access to services, goods, and opportunities in society by racial groups¹¹) embedded in mother blame narratives. First, strategies are provided to optimize health equity in birth outcomes that are grounded in identifying and dismantling the racism deeply embedded in mother blame narratives. Next, disparities are illustrated with an overview of 2 common chronic illnesses that increasingly impact pregnant women, preeclampsia and gestational diabetes, and 2 conditions of pregnancy, gestational diabetes and preterm birth. Finally, ethical principles that are essential to providing comprehensive perinatal care to black women are described. These structural solutions have the potential to unleash the innovation of nurses and public health professionals to eliminate mother blame narratives and improve health outcomes.

CURRENT PREVAILING MOTHER BLAME NARRATIVES

Mother blame has been defined as holding pregnant women exclusively responsible for the ill health of children.^{9,10} More specifically, investigators in fields of study such as the Developmental Origins of Health and Disease (DOHaD) seek to understand epigenetic factors and other contributors to health and illness. This work has posited that the uterine environment and exposures that pregnant women have during pregnancy

are exclusively associated with health outcomes of their children. Scholars from public health, women and gender studies, policy, and sociology have cautioned that DOHaD approaches may suggest the pregnant body is a vessel or incubator, leading to a myopic focus on behaviors of pregnant women as only factors that impact the health of children.^{9,10} Other fields such as public health and epidemiology that collect population-level statistics have also inadvertently contributed to mother blame by studying individual behaviors (ie, diet, exercise, smoking, alcohol and drug use) without the larger context of social determinants of health, health disparities, and health inequities.⁹⁻¹¹ These approaches suggest that modifying the behaviors of pregnant women would alone ensure optimal outcomes for children. However, this position may be shortsighted and structurally inaccurate.

Blaming black women for poor reproductive health outcomes ignores the circumstances, environments, and situations in which each woman seeks to maintain health, to become pregnant, and to safely give birth to children. Healthcare providers may be abdicating responsibility for providing quality care by implying that negative birth outcomes are unpreventable because black women are coming to pregnancy “older, sicker, and fatter.”^{12,13} Inequities in maternal health before and during pregnancy are underappreciated but essential context for understanding inequities in the neonatal and perinatal patient populations. Figure 2 illustrates how

inequities in 2 prepregnancy illnesses and 2 perinatal conditions disproportionately affecting black women can contribute to inequities in the neonatal and perinatal patient populations. The prevalence, distribution, and implications of pregestational diabetes, chronic hypertension, gestational diabetes, and preterm birth are described in the following text.

CHRONIC ILLNESSES AND PREGNANCY CONDITIONS

Pregestational diabetes is increasingly common among women of reproductive age and associated with adverse obstetrical outcomes.^{14,15} Elevated blood glucose level increases risks of perinatal loss, congenital anomalies, preeclampsia, and macrosomia.¹⁶ Black women with diabetes are more likely than white women with diabetes to have glycated hemoglobin (HbA_{1c}) above 6.5%, which the American Diabetes Association recommends for conception (88.2% vs 26.3%) in a study of young adults.¹⁷ In 19 states in 2010, pregestational diabetes affected 0.89 in 100 births overall and 1.27 in 100 births to black women.¹⁵ Despite exhibiting a need for better support in diabetes management throughout the life course, black adults are more likely to receive lower quality of diabetes care than other groups even after adjusting for other demographic factors.¹⁸

Gestational diabetes disproportionately develops in the pregnancies of black women.¹⁹ Women with

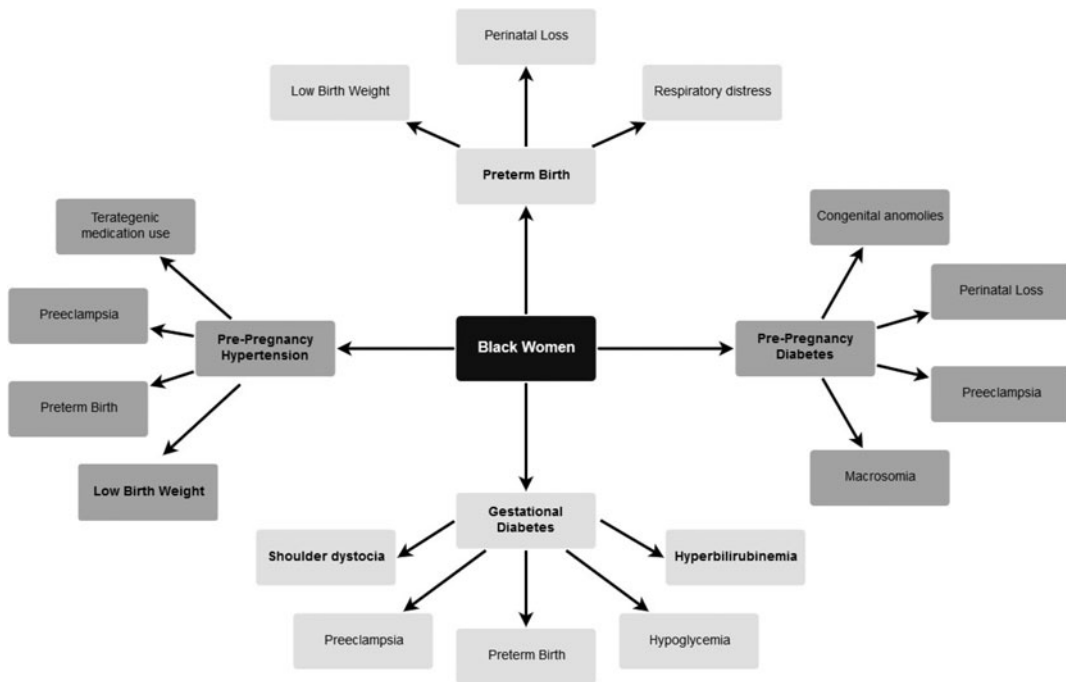


Figure 2. Factors that influence reproductive outcomes for black women.

gestational diabetes are at elevated risk of subsequent development of serious health consequences including development or worsening end-organ damage affecting eyes, kidneys, intestines, and blood vessels. In addition, women with gestational diabetes are at increased risk for hypertension and preeclampsia, cardiovascular disease such as congestive heart failure and ischemic coronary syndrome, ketoacidosis, and having a preterm birth, defined as a delivery before 37 weeks of gestation.²⁰

Similar to diabetes, chronic hypertension established before pregnancy is increasingly common among women of reproductive age.^{21,22} Chronic hypertension increases risks of perinatal loss, preterm birth, low birth weight, and neonatal unit admission.²³ The prevalence of chronic hypertension among pregnant women varies depending on age, race, body mass index, and presence of diabetes. Chronic hypertension affects 1% to 10% of pregnancies among women without diabetes²⁴ and 2% to 18% of pregnancies among women with pregestational diabetes.²⁵ Current data show that pregestational and gestational diabetes further increase the risk of hypertension-related conditions in pregnancy, impacting the pregnant woman, fetus, and placenta (ie, preeclampsia, preterm birth, intrauterine growth restriction). Maternal characteristics such as prepregnancy obesity, advanced maternal age, black race, and chronic hypertension and other cardiovascular risk factors are thought to contribute to the etiology of preeclampsia due to associations with oxidative stress, inflammation, vascular inflammation, and insulin resistance.^{25,26}

Pregnant women with both chronic hypertension and pregestational diabetes appear to have higher risks of adverse obstetrical outcomes, including preterm birth and preterm birth before 32 weeks, than among women who only have 1 condition.²⁷ Thus, it is hypothesized that diabetes and preeclampsia synergistically act through a common pathway of inflammation and insulin resistance, whereby preterm birth may be the outcome of vascular dysfunction among pregnant women with chronic hypertension and diabetes.

A recent study of the effect of chronic hypertension on preterm birth by race/ethnicity found that chronic hypertension was significantly associated with overall rate of preterm birth and medically indicated preterm birth regardless of race. However, there were greater increased odds of spontaneous preterm birth, as rates were higher among black and Asian/Pacific islander women with chronic hypertension than among those without chronic hypertension.²⁸ The authors reflected that preterm birth appears to be the outcome of a complex myriad of factors among black pregnant women and recommended improved knowledge about the relationships of preterm birth and structural determinants

of disparities in healthcare and experiences; presence and severity of hypertension, preeclampsia, or both; and glycemic control.

Currently, in the United States, black women have the highest rates of preterm birth, which is one of the leading causes of infant mortality, and is associated with long-term negative health impacts on the cognitive developmental and adult health of the child.²⁹⁻³¹ Women with a prior preterm birth have preexisting, and possibly a long-standing history of, low-grade inflammation, a known predictor for subsequent development of type 2 diabetes.

STRATEGIES TO OPTIMIZE HEALTH EQUITY IN BIRTH OUTCOMES

Several efforts have been developed to identify ethical principles for perinatal care, specific to the reduction of preventable factors that contribute to maternal morbidity and mortality. Tool kits³² from the California Maternal Care Quality Collaborative and Bundles³³ from the Alliance on Innovations in Maternal Health have been instrumental in clinical care, particularly reduction of several cases of maternal morbidity associated with obstetric hemorrhage. In addition, these strategies have been adapted for pregnant women with chronic illness to improve care before, during, and after the pregnancy.

Preconception care, which includes pursuing pregnancy-specific clinical targets and transitioning off teratogenic medications, can mitigate the risks of adverse pregnancy outcomes.^{34,35} Peterson et al³⁶ estimated that universal preconception care for all women with pregestational diabetes could annually prevent more than 3000 birth defects, 1800 perinatal deaths, and 8000 preterm birth deliveries, which would save more than \$900 million in direct costs and \$4.5 billion in lost productivity. Failing to optimize preconception care for women with chronic illnesses perpetuates tremendous cost, suffering, and inequity.^{34,36} Although the ideal preconception care program has not been identified and remains an important area of research,³⁵ it is clear that women need services to optimize health before conception occurs, particularly to prevent organ malformation that occurs before many women recognize pregnancy or initiate prenatal care.³⁷ With a broader view of pregnancy care, providers in the perinatal and neonatal settings can consider providers in specialty care and primary care as essential collaborative partners for supporting women to manage chronic illnesses that threaten wellness during pregnancy.

Unfortunately, preconception care is not universally available to individuals due to lack of insurance coverage. Half of the births in the United States are currently covered by public insurance,³⁸ which is limited to

60 days postpartum and does not include comprehensive preconception care. Studies have documented that nationally, 25% of women of reproductive age, regardless of pregnancy status, were uninsured at some point in the previous year.^{38,39} Black women are most likely to be uninsured and thus least likely to have access to preconception care.

Several nonpharmacologic strategies exist to reduce negative pregnancy outcomes for black women, including innovative nursing and public health programs such as group prenatal care,^{40,41} kangaroo maternal care,⁴² and Nurse-Family Partnership (NFP).⁴³ Group prenatal care is the provision of the 10-visit schedule of prenatal care in cohort groups of people with similar gestational ages and estimated due dates.^{38,39} Several models for group care exist, including Expect with Me and CenteringPregnancy, which have the strongest evidence for term pregnancies, normal birth weight for newborns, and reduced infant mortality.⁴⁰ Among a low-risk population in a southern state, participation in group prenatal care significantly reduced risk of preterm birth by 36%, a low-birth-weight infant by 44%, and hospitalization of infants within the neonatal intensive care unit stay by 28%.⁴⁰ In a subgroup analysis, black women experienced significantly lower rates of preterm birth than their peers in traditional prenatal care. The authors suggested that one potential explanation for favorable outcomes among black participants is the provision of social support, coping strategies, and stress reduction through group prenatal care. Data have also shown that participants in group prenatal care reported fewer pregnancies within 6 months of last birth, increased use of condoms, and less unprotected sexual intercourse, demonstrating the benefits of group support, assessment, and education beyond the index pregnancy.^{44,45}

Nurse-Family Partnership provides first-time parents with in-home support by nurses for 2 years, peer-to-peer learning, provider surveillance, assets-based protocols to improve knowledge and skills, and care coordination.⁴³ While the 3 foundational NFP trials lacked adequate statistical power to demonstrate an impact of preterm birth, a more recent study compared contemporary NFP clients with a reference cohort of first-time mothers from publicly available birth data, yielding evidence of the program effect at the national level during replication and expansion of NFP implementation sites.⁴⁵ The rate of preterm birth was significantly lower among participants in NFP than rates observed in matched controls.⁴⁵ In addition, in the early trials, participants demonstrated longer intervals between the births of children, improved pregnancy planning, higher rates of on-time vaccinations, and greater readiness for school for the children of participants in the program.^{45,46}

Group prenatal care, such as CenteringPregnancy, and home-based interventions, such as NFP, provide the capacity for increased interpersonal knowledge production and sharing and social support and the immediacy of being linked within the healthcare system prior to the next pregnancy. Thus, participation in one or both types of interventions has the potential to attenuate the occurrence and effect of delayed entry to prenatal care and community-level isolation, while supporting assessment and management of comorbidities and linkage to sociocultural and mental health supports.

Kangaroo maternal care includes several interventions including immediate skin-to-skin care, on-demand breastfeeding, and minimal intervention for the child-bearing family and newborn immediately after birth.⁴² However, all of these interventions may be insufficient if not paired with essential ethical principles developed to set the standard for holistic care of black women.

ESSENTIAL ETHICAL PRINCIPLES FOR PERINATAL CARE OF BLACK WOMEN

A new black paper was released in 2018 from the Black Mamas Matter Alliance (BMMA), titled “Setting the Standard for Holistic Care of and for Black Women.”⁴⁷ This article is grounded in evidence and uses reproductive justice, an intersectional framework that centers human rights at its foundation. Briefly, reproductive justice affirms a human right to become pregnant; to avoid, end, or prevent pregnancy; to parent children with dignity—free from violence from individuals and the state; and to disassociate sex from reproduction, including consent, healthy sexuality, and pleasure. Distinct from reproductive health (service provision) and reproductive rights (legal protections), reproductive justice is a broad set of human rights principles that similar to the ANA Code of Ethics centers bodily autonomy and self-determination as a foundational ethical principle. The 8 standards that are essential competencies for both clinical care and education should be taught to the current and future healthcare workforce specific to the care of black women. The standards include the following: (1) Listen to black women; (2) Recognize the historical experiences and expertise of black women and families; (3) Provide care through a reproductive justice framework; (4) Disentangle care practices from the racist beliefs in modern medicine; (5) Replace white supremacy and patriarchy with a new care model; (6) Empower all patients with health literacy and autonomy; (7) Empower and invest in paraprofessionals; and (8) Recognize that access does not equal quality care.

The BMMA paper and the ANA Code of Ethics align on key points. The first 2 standards from the BMMA paper are consistent with the ANA Code of Ethics requiring nurses to provide respectful, compassionate, and dignified care (Provision 1.1 Respect for Human Dignity and Provision 1.4 The Right to Self-Determination). The BMMA paper is aligned with the ANA Code of Ethics, as described in Provision 1.2 Relationships with Patients, which asserts that nurses do not have to support or agree with all patient choices but will provide all options and health information across the reproductive spectrum.

WORKFORCE CONSIDERATIONS

The BMMA standards 3 through 6 are structural in nature and call for provision of reproductive health-care through a reproductive justice lens, which includes representation of black women among healthcare staff and providers. Diversification of the healthcare workforce, including professionals and paraprofessionals, is an essential component to improving health outcomes for black women. Racial discordance between clinical providers, clinician-scholars, and communities has profound implications for interpersonal processes of care, including social concordance and communication, which have been shown to be significant aspects of quality care.⁴⁸⁻⁵⁰ In addition, people of color in the health professions are more likely to serve minority populations⁵¹; healthcare providers who are people of color are more likely to work with publicly insured⁵¹ and minority populations; and programs that provide financial incentives to any healthcare provider who serves minority populations have not been more successful than programs that develop concordant healthcare providers to ensure adequate workforce serving in underresourced settings.⁵¹

DISCUSSION

Nurses, in partnership with public health and other health professions, have the capacity to heed the calls of professional organizations to address inequities¹⁻³ and make significant contributions to maternal and child health equity. Ethical perinatal care for all pregnant women is clearly outlined in the ANA Code of Ethics; however, social determinants of health, including structural racism and discrimination, are not equally experienced by pregnant women. Data clearly show disparities in perinatal outcomes for black women. Specifically, pregestational diabetes, chronic hypertension, gestational diabetes, and preterm birth are 4 examples of maternal health concerns before and during pregnancy that are unequally distributed in the United

States. These conditions and their management emphasize the need for transdisciplinary collaborations in the design and implementation of assessments and multi-level interventions that consider black women's perinatal experiences and outcomes within the entire life course.⁸

Perinatal and neonatal nurses will likely see an increasing number of infants whose mothers had a chronic illness or pregnancy condition. Infants are linked to mothers and bear disproportionate risk of adverse outcomes when mothers disparately experience prepregnancy chronic illnesses or pregnancy conditions. Blaming women for poor health outcomes without addressing structural inequality is common but has not optimized maternal and child health. Particularly, when caring for women at risk of negative outcomes due to chronic illness or pregnancy conditions, perinatal and neonatal nurses may better serve patients and families by adopting strategies that are responsive to structural inequality in the distribution of prepregnancy chronic illness, pregnancy conditions, and negative maternal-child outcomes.

Two frameworks^{48,49} have been developed and shown to be effective in guiding the ethical conduct of researchers and teams that include community members of black women as coresearchers. The first is the approach from the Birth Place Lab, titled Giving Voice to Mothers.⁴⁸ The Giving Voice to Mothers teams have produced 2 validated and reliable measures, the Mother's Autonomy in Decision Making scale, which is a patient-developed instrument to evaluate experience of maternity care, and the Mothers on Respect index, which measures quality, safety, and human rights in childbirth. These measures have been used to highlight gaps in the provision of perinatal care and provide a clear roadmap for interventions geared to developing respectful care.

The second approach is a research prioritization protocol, titled "Research Prioritization for Affected Communities (RPAC)."⁴⁹ The RPAC method is a systematic approach for eliciting the priority unanswered questions about a health issue from communities that are most affected but not represented among funders and researchers. This open-source, freely available protocol is simple to learn and relatively low cost—developed by nurse scholars to demystify a process to work with community members to identify areas of research important to black women and other women of color. It is critical that research is driven by patients and provides leaders in practice and policy with rigorous evidence that moves the science forward where it matters most to communities.

Addressing maternal health issues with mother blame will not achieve equity. Nurses can provide better care

with structurally competent approaches. Understanding the concepts of social determinants of health, health disparities, and health inequities equips nurses with the foundational language needed to provide ethical care. Bundles and tool kits have been widely adopted for inpatient obstetric units and birth centers, but much less attention and focus have been afforded to the implementation of standardized prenatal, postpartum, and preconception care. Nurses have been on the forefront of innovation in health promotion as both Centering Pregnancy and NFP were designed with, for, and by nurses. Deploying evidence-based programs universally, regardless of geographic location and insurance status, could begin to resolve perinatal health disparities. However, if innovations in care provision cannot align with the ethical principles specified with, for, and by communities of black women, equity in health outcomes is unlikely to be achieved.

Nurses need to be accountable to the ethical principles that guide nursing practice. Reproductive justice principles are deeply embedded in the BMMA paper, which is aligned with the ANA Code of Ethics; faculties of nursing must be using these standards and ethical guidelines in the didactic and clinical instructions of new nurses. Nurses currently in practice must review these materials in journal and book clubs as well as at professional conferences. Nurses and public health professionals are uniquely equipped to bring forth novel ideas about models of care. Partnering with patients, families, and the communities in which people are born, live, learn, work, play, worship, and age should allow nurses and public health professionals to do better design, implement, test, and evaluate population-level innovative programs and nurse the nation—a requisite for health equity.

CONCLUSION

Nurses are uniquely positioned to lead health equity efforts specific to the resolution of perinatal health disparities. The power of nursing including our code of ethics is aligned with strategies, bundles, and tool kits developed to improve perinatal outcomes in partnership with the most impacted communities. Ethical care of black women in the perinatal, prenatal, postpartum, and preconception periods requires a well-educated and diverse workforce with foundational knowledge of social determinants of health, health disparities, health inequity, and community engagement.

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