Framing the Public Health Problem of Maternal Morbidity and Mortality: A Social Justice and Moral Imperative

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I. Introduction

There is growing attention to the problem of maternal morbidity and mortality, both in New York State and New York City, and in the United States. Given the seriousness and magnitude of this problem for society and its public health significance, we call attention first to the critical importance of this change in policy focus, and importantly, to the need to assure that maternal morbidity and mortality will continue to be a public health policy priority. In this special issue on public health, we turn to the shifting paradigm that is emerging in addressing the nature and extent of the problem. While the dominant biomedical paradigm has no doubt shaped early understanding of maternal morbidity and mortality, the expansion of the medical frame to include diverse inter- and transdisciplinary perspectives, as reflected in the authorship of this article, is promising. The most current research and critical analyses focus more sharply on the public health, ecological, social, and cultural dimensions of the problem as they continue to affect black women and their families and communities. This evolving paradigm shift will help to inform and guide the shaping of a blueprint for more effective policy advocacy in the next decades. There are legal and ethical dimensions of maternal morbidity and mortality and it behooves the disciplines of law and public health to be at the forefront of understanding and addressing this human rights conundrum. The members of the legal community, in collaboration with other professionals in this space, will play a critical role in supporting advocacy for radical policy change.

II. Framing the Public Health Problem: Race and Culture

In 2002, the Institute of Medicine (IOM) issued a report on "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care."[1] For the next decade there was a proliferation of studies examining the association between race, culture and poor health outcomes, in search of risk factors and explanatory data that would lead to the elimination of such health disparities across racial groups.[1,2,3,4] Some research scholars argue that these persistent gaps in the rates of maternal morbidity and mortality (and infant mortality), between black and white women, stem from the inability to reconcile the intricate connection between race and culture in public health outcomes. There are some basic factors that support the persistence of racialized health care disparities and those include, but are not limited to, failure to honor patient preferences, unfair and inequitable access to health care systems,[2,3,5] as well as institutionalized racism.[6,7]

Race and culture are central to an adequate understanding of the complexities of maternal morbidity and mortality. Interdisciplinary (and interprofessional) health care is a field of practice that is evolving with much agreement across disciplines and professions concerning the priority of cultural competence as a standard of care.[4,8,9,10] Moreover, the problem of racial disparities in both access to and utilization of care during pregnancy and childbirth is a public health crisis. The perpetuation of the high incidence and prevalence of maternal morbidity[3,4,5] and mortality among black women[6,9] calls for policy and practice innovations. For example, while there are many risk factors that contribute to infant mortality, what has been reported as unique to black women is the degree to which parental stress is often the culprit, accounting for a large percentage of infant deaths in the United States.[3]

For many women, factors that influence their retrospective attitudes about the childbirth experience include their sense of control either internally or externally, decision making processes, social support and the efficacy of pain control.[11] However, black mothers, in particular, are significantly more likely than mothers of other racial groups to feel they do not have control over the decisions they face while pregnant, including the birthing process. They often feel coerced into accepting unnecessary procedures such as epidurals, episiotomies or passive delivery options, which may include lying on their backs or even cesarean delivery.[3] Such sources of chronic stress have been proven to influence adverse birth outcomes.[5]

Researchers have quantified the problem by gathering data, confirming the incidence of deaths among black women in the United States, during or after childbirth.[12] Such studies yield evidence showing that black women are three to four times more likely than white women to die during this life event.[12] According to the Centers for Disease Control and Prevention (CDC) in a 2016 report, black women in the United States experience a maternal mortality rate of 44 deaths per 100,000 live births while for white women the mortality rate is 13 deaths per

100,000 live births.[12] In a mixed methods exploration study conducted by a nonprofit organization, aimed at understanding some of the factors that influence such outcomes,[9] self-reports of community-dwelling women showed that the problem is systemic, and that the root causes may be social inequities endemic to the lives of black people, specifically, and racial minority groups, generally.[4,5]

There is evidence that the longstanding history of racism and lack of cultural competence may have a negative impact on childbirth.[4,6] Mistrust of health care systems that denied black people access in the past is still present in the minds, hearts and souls of black people.[13,14] Lifelong experiences teach black women to anticipate that race, ethnicity and socioeconomic status are, regrettably, important factors in determining worse outcomes in life expectancy, the likelihood of poverty,[13] and access to health care. In a qualitative study designed to develop measures of racism for birth outcomes, black women in the United States described their own experiences with internalized concerns about future events based on the experiences of friends and others close to them.[4] The stress and anxiety associated with racism and childbirth have significant negative implications for birth outcomes.[15] The workplaces of black women produce environmental toxins that create physical, mental and emotional stressors, including racism and discrimination, at a rate higher than other women.[3] For all women, socioeconomic status and education level are directly correlated with improved birth outcomes, and thus, women and families with greater educational attainment and/or higher incomes, experience lower rates of low birth weight and infant mortality, except for black women. This social phenomenon has only been explained by theories of racism and discrimination frameworks.[3,6,13,15] The experience of unequal treatment reminds us to prioritize professional ethics, responsibility, and the commitment to continuing education and training for skills development and responsibility. Research shows that black patients do receive substandard medical care.[6] Racism is institutionalized and discrimination widespread.[15] In designing our health care programs, we must ensure that providers are culturally competent by setting skilled-based standards, reinforced by education and training to enhance cross-cultural knowledge and awareness and reduce or eliminate health disparities in our care settings and beyond.[1,9,10] While current research does not indicate a positive relationship between cultural competency training and patient outcomes, more resources for high quality research are needed.[16]

Culture influences the contexts of what we do every day, how we behave, speak, relate to others and make sense of the world. Understanding one's self is fundamental to understanding how to relate to others. A step in developing cultural competence is acknowledging that differences in expectations may exist between oneself and a woman seeking care. Moreover, some outcomes cannot be explained by income or access. Therefore, strategies for assessing one's own implicit biases and prejudices are important in setting goals with persons seeking care from the health systems.

III. Maternal Morbidity and Mortality Data Trends

While maternal death represents the most tragic and devastating event in obstetrical practice, it is often thought of as the "tip of the iceberg," compared to many more cases of severe life-threatening pregnancy-related complications, known as near-misses or maternal morbidities. Severe maternal morbidity (SMM) is described as the unintended outcomes of the process of labor and delivery that result in significant short-term or long-term consequences to a woman's health.[17] SMM, such as hemorrhage, blood transfusion, embolism, severe infection or acute organ failure requiring ICU admission, is 50-100 times more common than maternal mortality, and accounts for an increased risk of death.[18,19]

Significant racial and ethnic disparities exist in the indicators of maternal morbidity. A review of a database from seven states demonstrated that non-Hispanic black women had the highest rates of SMM, compared to other racial and ethnic groups. Overall, the SMM rate in non-Hispanic black women was 2.5 times higher compared to non-Hispanic white women.[20] A recent review of a national dataset, specifically focused on women who experienced post-partum hemorrhage, showed that non-Hispanic black women were at 28% higher risk for severe morbidity and at five times higher risk of death compared to non-Hispanic white women.[21]

Even though non-Hispanic black women make up one-fifth of the live births in New York City, they have the highest SMM rate, that is, in one-third of these births. More specifically, a review of data in New York City from 2008-2012 showed that non-Hispanic black women have the highest SMM rate; that is, 386.9 per 10,000 deliveries. This comprises 35.6 percent of the cases of SMM relative to 21.1 percent of live births. For white, non-Latina women, the SMM rate is 126.7 per 10,000 deliveries. The latter comprises 16.8 percent of cases relative to 30.4 percent of live births for white, non-Latina women. The SMM rate is also high for Puerto Rican women (272.0 per 10,000 deliveries), or women of other Latina origin (248.5 per 10,000 deliveries). Furthermore, women with an underlying chronic condition, such as hypertension, diabetes or heart disease, are three times as likely to have SMM as women with no chronic conditions. Contributing factors that disproportionally affect black women and also increase

the SMM rate include the following: pre-conception health status, obesity and other related co-morbidities, access to care, inadequate housing, residential segregation, lower educational attainment, and racism and its attendant stresses. Most research has focused on black-white disparities, but other demographic groups, such as immigrants, have similar poor maternal outcomes.[22]

In the last decade, hemorrhage, hypertensive disorders of pregnancy and thromboembolism were the leading causes of pregnancy-related deaths; these are considered to be most potentially preventable complications.[23] However, more recent data show that maternal deaths related to infection (sepsis), cardiovascular and other chronic medical conditions are on the rise and are among the top reasons for maternal mortality. These trends are not surprising, as more women in the United States delay childbearing and conceive at a later age. Also, increasing proportions of pregnant women are obese and/or have pre-existing medical conditions, such as diabetes, hypertension and heart disease.[24,25]

In New York State, 42 percent of pregnancy-related deaths were of black mothers. A pregnancy-related death is defined as a death of a woman during pregnancy or within one year from a termination of pregnancy directly caused or exacerbated by the pregnancy.[22] From 2012-2013, the New York State Maternal Mortality Review Board identified 62 pregnancy-related and 104 pregnancy-associated deaths. A pregnancy-associated death is defined as the death of a woman, from any cause, while she is pregnant or within one year of the termination of pregnancy.[22]

Turning to the U.S. picture, according to a retrospective, observational study of the CDC Health Statistics database and Detailed Mortality Cause of Death database, the United States has had increases in its maternal mortality ratio (MMR) since 2005; that is, 15 per 100,000 live births in 2005 and 21-22 per 100,000 live births in 2013 and 2014, respectively.[26] In Canada, the MMR is 10 per 100,000 live births, which is less than half of that in the United States. MMR is the number of maternal deaths per 100,000 live births.[26] There has been a significant correlation between the state mortality ranking and the percentage of the non-Hispanic, black women delivery population. Cesarean deliveries, unintended pregnancies, unmarried status, percentage of deliveries to non-Hispanic, black women, and four or fewer prenatal visits are significantly associated with the maternal mortality ratio ($p<0.05$). Although this is not causative, the weak correlation between cesarean delivery and maternal deaths may be due to the underlying complications of the pregnancy that resulted in the cesarean section itself, and not from complications of the operation.[26]

There is no statistical correlation between state-specific maternal mortality and either rural status or poverty. There have been demonstrated lower mortality rates in Hispanic women, which might be due to a large immigrant population with unique support systems and family support. Some authors have found that the wide variation in the state maternal mortality ratio is related to social and not medical or geographic factors, such as unintended pregnancies, unmarried status, and non-Hispanic, black race. Certain states with low MMR (such as California, Massachusetts, Nevada, Connecticut, and Colorado)[27] may reflect a state-specific excellence in quality, leadership, organization and funding for obstetric care.[26]

Many prior studies on racial/ethnic disparities in obstetrics have attributed differences in outcomes to social and biologic/genetic factors, but this has not been borne out by data.[26] Several recent publications have examined the relationship of socioeconomic factors to racial and ethnic discrepancies in maternal and neonatal morbidities. A study of 2.2 million women concluded that higher education was not protective, and that college-educated non-Hispanic black women had 28 percent higher risk of adverse outcomes compared to similarly educated non-Hispanic white women.[28] Another study from 25 hospitals has also demonstrated higher rates of adverse outcomes in non-Hispanic black women, independent of their demographic characteristics or the delivery hospital.[29] Similarly, a review of data in New York City showed that college-educated, non-Hispanic black women were 2.6 times more likely to experience severe maternal morbidity compared to college-educated white women.[22]

IV. A Call for Action: Clinical Guidelines, Best Practices, Systems of Care and Institutional Change

Disparities in health care may involve complexities across multiple ecosystems in which mothers, providers and health care systems interact. Recent national and local efforts have focused on reducing maternal morbidity and mortality related to preventable causes by improving identification and standardizing the management of these conditions.

Currently, maternal mortality data are collected, stored, and shared via several federal, state, and local sources including but not limited to the CDC, state health departments, and private health care systems.[30] The CDC uses its Pregnancy Mortality Surveillance System (PMSS) to collect and code data regarding pregnancy-related deaths and associated risk factors from 50 states, New York City, and Washington, D.C. However, there are a number of problems that exist, including but not limited to: reporting from jurisdictions is not mandatory, the data must be complete at the state level to feed into the

national system, and the use of the data is limited due to confidentiality issues under Section 308(d) Assurance of Confidentiality of the Public Health Service Act.[30]

Key maternal health variables need to be standardized and aggregated at the national level to bring about necessary and effective efforts against maternal deaths and health disparities. Despite reported increases in maternal mortality rates and the potential for Maternal Mortality Review Committees to identify causes, a 2017 study published in *Obstetrics & Gynecology* identified that only 29 of the 50 states currently have such committees.[30] Still, there are certain state efforts that might be driving the change in how we assess maternal mortality and morbidity in light of racial disparities.

For example, in California, maternal mortality rates declined by 55 percent between 2006 and 2013, even as the national maternal mortality rates increased.[31] Together, the California Department of Public Health and the California Maternal Quality Care Collaborative focused on three major components: research gathered from the California Pregnancy-Associated Mortality Review (CA-PAMR), the development of quality improvement toolkits based upon the CA-PAMR findings, and the creation of a maternal data center used by 90 percent of California's hospitals.[30]

The Alliance for Innovation on Maternal Health (AIM) created several "bundles" of best practices for improving safety in maternity care.[32] In 2013, the Safe Motherhood Initiative was launched in New York State by the American College of Obstetricians and Gynecologists (ACOG) District 2, supporting the implementation of similar best-practice "bundles" focused on obstetric hemorrhage, severe hypertension and thromboembolism.[32] One hundred seventeen out of 124 hospitals in New York State are currently participating in this program.[32]

In February 2019, ACOG District 2 issued a statement in support of meaningful legislation to establish a statewide maternal mortality review board and called for such legislation to ensure that the board's reviews are kept confidential to enable thoughtful and thorough reviews of the maternal deaths in New York State.[33] In that statement, ACOG District 2 stressed the confidentiality of the board's proceedings as critical to conducting meaningful maternal health quality improvement work and ultimately, achieving a reduction in preventable maternal deaths. Such legislation is currently pending in the New York State Senate.[34]

The New York City Department of Health and Mental Hygiene (NYC DOHMH) has also developed a comprehensive, geographically coordinated structured system of care organized around a series of Regional Perinatal Centers (RPCs), each supporting and providing clinical expertise, education and quality improvement to a group of affiliate hospitals. This system ensures that women and their babies have ready access to the services they need, including medical teams with experts in the management of complex maternal and fetal conditions. Maternal mortality review boards at the state level have begun a multidisciplinary review of each maternal death in New York State, aimed at identifying not only causes of death, but also other factors leading to maternal death, including its preventability and opportunities for intervention.

Understanding the impact of structural racism, implicit bias, and the sociocultural and historical contexts of social determinants of health on inequitable care has been addressed by New York State, NYC DOHMH and community-based organizations, such as Black Mamas Matter and the National Birth Equity Collaborative. According to Dr. Devine, "bias is the "implicit" aspect of prejudice… [the] unconscious activation of prejudice notions of race, gender, ethnicity, age and other stereotypes that influences our judgment and decision-making capacity."[35] Listening to the voices of mothers is an important step toward achieving reproductive and birth justice, and subsequently, birth equity. Birth equity has been defined by Dr. Joia Crear-Perry as "the assurance of the conditions of optimal births for all people with a willingness to address racial and social inequalities in a sustained effort."[35]

Under the leadership of Governor Andrew Cuomo, New York State established Medicaid pilot projects to study the role of doulas in the birth experience. Implicit bias training programs for medical schools, academic medical centers, and health care providers at all levels have been proposed. New York State created the Taskforce on Maternal Mortality and Disparate Racial Outcomes, a multidisciplinary group of obstetrician-gynecologists, midwives, internists, community stakeholders, insurers, and professional organizations, such as ACOG District 2, Greater New York Hospital Association and the like, to identify a multi-pronged approach to review and better address maternal deaths with a focus on racial disparities, expanding community outreach and actions to increase prenatal and perinatal care. In 2010, New York State was 46th in the United States for lowest maternal mortality rate, and currently stands as 30th. The New York State Taskforce expanded the community health worker program, and plans to develop an Expert Workgroup on Postpartum Care in collaboration with NYC DOHMH and ACOG District 2 and create a data workhouse to house this information.[36]

The NYC DOHMH has addressed respectful and accountable care by their New York City Birth Equity Initiative and the Sexual and Reproductive Justice Com-

munity Engagement Group Birth Equity Campaign. The latter three-year campaign from September 2017-2019 has engaged community members as "birth justice defenders," who are provider champions to advocate for respectful care at birth. They have provided education and training to address the design and implementation of best practices within health care institutions, and have supported changes in institutional policies and practices that support these community-led initiatives.[37]

The Society for Maternal-Fetal Medicine has published a special report on disparities in maternal morbidity and mortality, providing recommendations about immediate actions in clinical care, and describing existing research gaps. Health care system recommendations include supportive services and improved access to care with an emphasis on patient education, cultural competencies, telemedicine, and community-based initiatives. Clinical provider-specific recommendations include adherence to evidence-based clinical guidelines, the use of available preventive therapies, and early identification of women at higher risk for complications in pregnancy. Hospital-specific recommendations include the implementation of best-practice "bundles" to standardize care for common preventable complications, partnerships with low resource hospitals, implementation of multidisciplinary reviews of all cases of maternal death and severe morbidity, and a sharing of lessons learned from these reviews.[38] An analysis of a large national sample of community hospitals showed that most black women delivered in a concentrated set of hospitals, and these hospitals had a higher severe maternal morbidity rate. Preventive community-based programs and quality improvement efforts at these hospitals may result in improved outcomes.[39]

Expanded insurance coverage for postpartum care, improved pre-conception and interconception care,[40] family planning and contraception to prevent unintended pregnancies,[40] including long-acting reversible contraception initiatives,[41] the identification and optimization of chronic medical conditions, and the prolongation of breastfeeding as a strategy for chronic disease prevention are other critical steps. The New York State Perinatal Quality Collaborative was developed by the NYS Department of Health in order to ensure that evidence-based guidelines translate to clinical practice with the input of birthing hospitals, perinatal care providers, professional organizations, and other stakeholders.[38] Finally, funding for well-designed research studies is urgently needed to evaluate possible interventions, treatments, policies or actions that can reduce disparities.

V. Conclusion

Under social justice and human rights frameworks, all persons are entitled to have their basic human needs met, regardless of differences, such as economic disparity, class, gender identity, race, ethnicity, sexual orientation, citizenship, religion, age, disability or health status.[42] We call upon the legal, social work, psychology, medical, nursing, midwifery and allied professional communities to join in robust advocacy for change in social policy aimed at decreasing maternal morbidity and mortality. This is nothing less than a moral imperative in this twenty-first century.

Endnotes

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