Black Paper

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Black Mamas Matter Alliance

Setting the Standard for Holistic Care of and for Black Women

BMMA

BLACK MAMAS MATTER ALLIANCE

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"When race stops being the precursor to how people will be received into the health care and other systems, the outcomes will be different… If we would lean on the voices, experiences, traditions, leadership, and ingenuity of Black women to create solutions and strategies, we would begin to successfully address this issue."

– Marsha Jones

The pervasive crisis of Black maternal mortality is making headlines. Nationally, Black women are three to four times more likely to die from pregnancy-related[1] causes than white women.[i] Black infants are over two times more likely to die in their first year of life than white infants.[ii] This epidemic of Black mothers and infants having the highest risk for maternal and infant mortality has persisted for years.[iii] In fact, Black women's risk of maternal mortality has remained higher than white women's risk for the past six decades.[iv]

In the United States overall, the rate of maternal mortality has increased for all women despite advances in medical technology and increased spending on health care.[v] Racial differences in maternal mortality are still occurring, even in states like California where there have been recent reductions in overall maternal mortality rates.[vi]

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[1] The U.S. Centers for Disease Control and Prevention (CDC) defines a pregnancy-related death as "the death of a woman while pregnant or within 1 year of the end of a pregnancy –regardless of the outcome, duration or site of the pregnancy–from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes." Source: Pregnancy Mortality Surveillance System. Centers for Disease Control and Prevention website. https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html. Accessed April 7, 2018.

New data from the U.S. Centers for Disease Control and Prevention (CDC) show that Black women who die from pregnancy-related causes are most likely to die from heart and cardiovascular conditions or events such as a heart attack, hemorrhage or excessive bleeding, and preeclampsia and eclampsia, which are conditions associated with high blood pressure.[vii] Black women are also more likely than white women to experience severe maternal morbidities, or serious pregnancy-related health events such as an infection, blood clot, or stroke.[viii]

A growing body of evidence indicates that stress from racism and racial discrimination influences maternal mortality and morbidity among Black women, regardless of their socioeconomic status. Black maternal health outcomes are not influenced solely by age, education, income, health care access, or health behaviors.[ix] Racism, racial discrimination, systemic inequities, and social determinants of health contribute to poor maternal health outcomes in the Black community. For example, it is important to note that African immigrant women have healthier birth outcomes upon arrival in the United States than their Black counterparts, but mirror Black rates of adverse birth outcomes over time.[x] Something about being Black in America is making us sick and shortening our lives.

Building a Movement to Birth a More Just and Loving World, a March 2018 report from the National Perinatal Task Force, asserts that "prioritizing the impacts of the social determinants of health is an essential part of addressing this unfair and avoidable disparity in health status and outcomes."[xi] Like other reports and articles examining this issue, it highlights the facts that the health inequities that Black people and women

face over the life course, including before, during, and after pregnancy, are interrelated and impacted by the intense and unequal racialized conditions that Black people experience on a daily basis in the United States.

Renowned public health author, Thomas LaViest, states that "Black people live sicker and die younger than any other ethnicity in this country."[xii] Research indicates that this is not a genetic flaw or inherent biological inevitability; instead, it is directly related to "weathering,"[2] toxic stress, and inadequate and disrespectful health care.[xiii] These factors wrap themselves around the very real lives and bodies of Black people in America, squeezing the life out of them through systemic, institutional, and individual bias and neglect. For Black women, these forms of systemic oppression have manifested as historical experimentation on Black women's bodies, forced sterilization, discriminatory health policies, the removal of traditional birth practices in Black communities, and other coercive reproductive practices that impact the current maternal mortality disparity rates in the United States.[xiv]

While there are many factors contributing to racial disparities in maternal mortality and morbidity rates, and the solutions to these issues may seem vast and hard to tackle, one major area of consideration is to focus on identifying and amplifying the maternity care knowledge, legacy, and work

[2] The weathering hypothesis asserts that "the health of African-American women may begin to deteriorate in early adulthood as a physical consequence of cumulative socioeconomic disadvantage." Source: Geronimus AT. The weathering hypothesis and the health of African-American women and infants: evidence and speculations. *Ethn Dis*. 1992;2(3):207-21.

of Black women. The Black Mamas Matter Alliance centers Black Mamas to advocate, drive research, build power, and shift culture for Black maternal health, rights, and justice. As the United States begins to acknowledge and address Black maternal and infant health, it is essential that all strategies involve the authentic leadership, ingenuity, research, and voices of Black women. The expertise of Black women must directly determine best practices for our own care.

According to the Black Mamas Matter Alliance, holistic care:

- Addresses gaps in care and ensures continuity of care
- Is affordable and accessible
- Is confidential, safe, and trauma-informed
- Ensures informed consent
- Is Black Mama-, family-, and parent-centered and patient-led
- Is culturally-informed and includes traditional practices
- Is provided by culturally competent and culturally congruent providers
- Respects spirituality and spiritual health
- Honors and fosters resilience
- Includes the voices of all Black Mamas
- Is responsive to the needs of all genders and family relationships
- Provides wraparound services and connections to social services

This Black Paper provides a summary overview of holistic care recommendations using a reproductive justice and human rights framework. The components of this Black Paper will be described further in a later report.

Recommendations

- Listen to Black women
- Recognize the historical experiences and expertise of Black women and families
- Provide care through a reproductive justice framework
- Disentangle care practices from the racist beliefs in modern medicine
- Replace white supremacy and patriarchy with a new care model
- Empower all patients with health literacy and autonomy
- Empower and invest in paraprofessionals
- Recognize that access does not equal quality care

Listen to Black Women

"What's missing from the care of Black women is their centered voice, validation of experience, and freedom to choose and be informed. Black women need respectful care that is free of implicit and explicit bias. It is the provider's responsibility to address those biases. To address the issue of maternal mortality we need care that originates from and is defined by Black women-led organizations, practitioners, and community members…care that centers our voices and evidence-based processes. This care has to encompass and be led by the voices of Black women as we see ourselves in relationship to our care. We have the ability to make decisions for ourselves, to process information and to question it."

– Jessica Roach

Historically, Black women's voices and talents have been pushed aside or regulated out of modern medicine. The expertise of Black midwives is a prime example of the way that Black women caring for one another in childbirth has been erased by modern medicine and replaced by the incorrect notion that Black women do not value midwifery or understand prenatal care.[xv] The facts are that Black women brought the tradition of midwifery with them to the United States and doctored one another through centuries of enslavement, Jim Crow, and segregation.[xvi]

Black people were not allowed into hospitals that treated white patients and relied on one another's experience and traditions for medical care for centuries in the United States.[xvii] Medicine did not originate in the absence of Black women's expertise and participation. In fact, modern day gynecology was founded, in part, on non-consensual experimentation on Black female bodies.[xviii] Black women

know their bodies and understand what ails them. The voices of Black women must be heard in individual care visits, in policy decisions, and in the design of all medical interventions targeted for Black women.

> "Most medical providers don't know Black history, don't know female Black history and aren't required to. Consequently, it's easy for providers to make a lot of racial and racist assumptions about Black women's conditions and knowledgebase (or lack thereof). This way of providing care results in providers and staff being prescriptive in ways that have very little to do with understanding Black women's reality. This type of care is not holistic or honoring. A prerequisite baseline knowledge of who Black women are and what we know would be helpful. Providers learning to ask is really important. Reverence for our profound experience as healers and as community leaders needs to emerge to redefine how Black female patients are approached and how providers hold Black female patients in their care."
>
> – Sunshine Muse

Recognize the Historical Experiences and Expertise of Black Women and Families

"Ahistorical care is (part of) how we get to a place of mistreatment and inadequate care."

– Dr. Joia Crear-Perry

In order to be accountable to Black women patients, providers must know and acknowledge the history of medical apartheid in America and the history of extensive non-consensual medical experimentation on Black people and Black women in particular.[xix] Black women have a long history of being subjected to reproductive violations, coercion, and non-consensual acts of medical violence.[xx] That history, more recent than many suspect, influences how Black people interact with health care systems and providers.

Black women also have an extensive history of being traditional and effective healers, midwives, lactation, birth and childcare advocates and experts.[xxi] In the absence of knowing about and acknowledging this robust, inspiring, and at times heart-breaking history, Black women patients are not recognized for who they are throughout their care experiences. **Improving Black women's health outcomes requires holistic care**. It is the traditional model of care for people of African descent, though it may be unknown by most western medicine providers.[xxii]

> "Prenatal care that does not also take into consideration the unique experiences of a woman/person, her/their community, and the specificities of her/their cultural background cannot produce the highest quality outcome."[xxiii]
>
> – Building a Movement to Birth a More Just and Loving World

Provide Care through a Reproductive Justice Framework

"Holistic care must be centered on Reproductive Justice because our lives require full acknowledgment of all that we are and all the ways the past and current inequities impact our lives as Black women."

– Dr. Joia Crear-Perry

Reproductive Justice, a term coined by Black women, is the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities.[xxiv] Its goals are to analyze power systems, address intersecting oppressions, center the most marginalized, and unify communities across issues.[xxv] Reproductive Justice recognizes the right to health and safety and defends the needs of women of color and other marginalized women.

Consent is at the crux of the patient-provider relationship, where interpersonal interactions, authority and power collide throughout the care experience. The patient-provider relationship requires trust for the critical flow of information, a flow that dries up when the personhood of a mother or family is disregarded. Care through a Reproductive Justice lens will always prioritize consent over provider bias. In order to distinguish bias from care, providers must adopt this framework and engage patients in their own care through conversation, collaboration, care partnership, and culturally congruent care[3] provision. Anything less may be a death

[3] Culturally congruent care is care that is in "agreement with the preferred cultural values, beliefs, worldview, and practices of the health care consumer and other stakeholders. Cultural competence represents the process by which [care providers] demonstrate culturally congruent practice." http://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-22-2017/No1-Jan-2017/Articles-Previous-Topics/Implementing-the-New-ANA-Standard-8.html

sentence for Black women and other disenfranchised people who, regardless of access to care, are dying at disproportionate rates.

> "Informed consent consists of two pieces that must interlock in order to be successful. 'Informed' does not refer just to the receipt of a generic, one-size-fits all information sheet. A care provider must be prepared (at the very least) to have a conversation and have the ability to address concerns without applying pressure or imposing power. We cannot have true consent if we lack transparent and engaged information provision. We cannot have true consent if the consenter feels unseen, unheard, or is experiencing pressure or some other unnamed disempowering social or power dynamic in the exchange. True consent cannot be granted on un-level playing fields between strangers that do not have a common aim, which should be comprehensive information provision, mutual respect, and empowered decision making (with and not for our patients)"
>
> – Haguerenesh Tesfa

Disentangle Care Practices from the Racist Beliefs in Modern Medicine

"Leave your socialized behaviors at the door and listen to what I am saying, follow through accordingly in partnership with me."

– Jessica Roach

"All women are different and require a different approach that is only in response to their medical condition- not to the color of their skin."

– Kay Matthews

Sterility and hierarchy as a practice or expectation across care provider roles limits the client/provider interaction and suggests or demands a continued hierarchy, which undermines partnership between patients and providers in care. It undermines the expertise of paraprofessionals, patients, and their family's lived experience, and ultimately causes harm to patients and entire communities of people.

In order to provide holistic care, providers must have the time, interest, and cultural congruency to know what questions to ask. Class, race, gender, education, and prior experience all influence a patient's ability to define their own needs and desires in the presence of their provider and medical team. Any of these variables can weaken a patient's voice. When working with Black women patients, it is essential that providers and staff adopt a lens to see more than the racialized stereotypes associated with the patient in front of them. Seeing Black women as whole, educated, loved, valued, and valuable is essential to good care. Black women deserve high quality care and must be treated as such.

"Care partnership is an essential part of building trust and effective two-way education. Providers need patients to educate them about their bodies, concerns, medical history, conditions, desires and lived experiences. In order to do that, patients need providers who listen."

– Sunshine Muse

"Part of providing holistic care is being able to support the validity of the questions our patients ask and to work with our clients to find appropriate answers for themselves as individuals. We are not monolithic. At the core, holistic health includes our patient's ability to define what they want and need included in their own individual care."

– Jessica Roach

"Holistic care must be centered on reproductive justice because when it is not, Black women are left out of the conversation and our histories and burdens are seen through a distorted lens of shortsighted assumptions and blame. When we say 'inclusive care' we mean care that includes and acknowledges the multiple every day factors and influences that shape our individual and collective health at the conscious, unconscious and sub-conscious levels."

– Haguerenesh Tesfa

Replace White Supremacy and Patriarchy with a New Care Model

"Care that addresses the gaps must become the norm and not a set-aside program. Care that addresses the gaps for Black women looks like centering us in its creation and its accountability metrics. It is the only way forward."

– Dr. Joia Crear-Perry

The non-consensual aspects of historical medical provision for and on people of color still influences how patients are treated today. For example, research has shown that beliefs among medical students that Black people have higher pain tolerance than their white counter parts affects care provision, patient experience and satisfaction.[xxvi] Studies show that the strongest indicator for whether a patient receives pain medication or not is race, and that Black patients are less likely to receive pain medication than white patients.[xxvii] Racist beliefs about Black people directly impact how care is provided to Black women, but these beliefs do not have to be the norm.

Models of care exist in communities of color as an alternative to hierarchical, rushed, and profit-centered models of care that are impacted by unconscious bias and historically racist beliefs. Some of these models are pioneered by Black women and must be included as part of a comprehensive approach to care.

The JJ Way® is an example of a community-based model of health care delivery featuring innovative but adaptable components. Developed by midwife Jennie Joseph ("JJ"), the primary purpose of the model is to ensure that every woman has a full-term, healthy, and positive pregnancy

experience and baby. Developed over the span of 25 years, the JJ Way® provides wrap-around care that allows pregnant women, family, and friends to participate fully in a woman's care utilizing a trauma-informed approach that prioritizes four main tenets: *access*, *connections*, *knowledge*, and *empowerment*. These tenets are central to the model and embedded in every aspect of the JJ Way®.[xxviii] The model has been shown to improve birth outcomes.[xxix]

Research indicates that peer-to-peer education and accountability in maternal health care produces results, including a reduction in the likelihood of suboptimal prenatal care, significantly better prenatal knowledge, increased patient readiness for labor and delivery, and greater patient satisfaction with care.[xxx] Breastfeeding initiation and duration is often higher in women who have received group care, or another peer-to-peer support model, and the impact on Black health in particular is notable.[xxxi]

MommyUp, Mamatoto Village, and the Black Midwives Care(r) Model are three models of providing holistic care to Black women.[xxxii]

> *"We want to help Black Mamas be their best selves. We do this through offering intentional space and place for moms to open up the world of possibilities to holistic well-being. From parenting, education, advocacy, organizing, entrepreneurship, perinatal and postpartum care, children's health, community health, doulas and midwifery, mental health, and wellness. In providing the information, space, and place, we look at what we have in*

community and we put that in front of the mothers and we also ask the mothers what they need from community as well. The goal is to not have dreams deferred but to actualize the dreams. We do this by utilizing communal economic and social resources to achieve the best practices for mothers to be whole, and having that manifest into our children, families, and the larger community."

– Tanay Harris

Empower All Patients with Health Literacy and Autonomy

"Women like me are dying. I need to take all precautions to ensure that I do not become a statistic. My life depends on me being informed."

– Kay Matthews

"It is essential that Black female patients – and all patients ideally – feel comfortable and empowered in this exchange to ask questions, get clarification, or challenge the information provided with their own research, traditions, and/or personal beliefs. What's missing from the care of Black women is depth, caring and trusted exchange."

– Haguerenesh Tesfa

The daily churn of patients and the US model of health care limits the amount of time that medical providers and support staff can spend with patients, but time spent lends itself to care partnerships that foster trust, honesty, and increased value perception. Provider productivity and rushed or dismissive care provision can contribute to patient dissatisfaction and poor outcomes. Practitioners seeking to provide holistic care should avoid being dismissive, correcting beliefs out of cultural superiority or bias, and rushing through visits. Care providers should also be willing to refer women to all the services they need as determined by a thoughtful interaction.

A 2018 study by Dr. Monica McLemore and colleagues examined the pregnancy-related health care experiences of women of color. These women described their health care as disrespectful and stressful, and recommended that care providers listen to patients more and give more attention to patient birth plans.[xxxiii]

Empowering Black women with clear information about their health status, risk factors, and various options for disease prevention and management could help to mitigate a system that often dismisses their care concerns as incorrect or undereducated. Care partnership – where Black female patients plan for their care alongside their provider – is the only way forward.

> "Black women have a right to be informed when it comes to our bodies and a right to be informed if there are health issues that we are at risk for."
>
> – Kay Matthews

Empower and Invest in Health Paraprofessionals

"The work is being done by the paraprofessional. They can suggest the navigation points that make care plans realistic. It's not just poking bellies and listening to heartbeats. The staff as a team creates a patient centered model."

– Jennie Joseph

An interdisciplinary team approach is what Black women need for high quality, holistic care. There are several reasons why many people of color function as paraprofessionals, such as:

- lack of access to advanced degree options and financial and time constraints to obtain the degree;
- a desire to work "the front lines" or perform "community work" in a specific and less prescribed way;
- needing a more flexible schedule to parent or pursue multiple career interests; and
- racial discrimination or discouragement in educational and professional settings.

Whatever the reasons, the presence, commitment, and frequent cultural congruency of many paraprofessionals allows them to form bonds with their patients that providers often don't have the time, skills, or cultural competency to cultivate.

Models of care that value and implement partnerships between patients, providers, and paraprofessionals – like the JJ Way® and Centering® health care – have improved health outcomes for pregnant woman and

their babies.[xxxiv] Many paraprofessionals, for the reasons outlined above, share the lived and cultural experiences of the patients they serve. When health systems understand this as a strength, they are better equipped to provide patients with essential aspects of holistic care including: cultural congruency, dialogue, reduced unconscious bias, respect for patients' questions and desires, and a sense of community as opposed to detached hierarchy.

> "Holistic care requires respect for all levels of care providers understanding that all of us are necessary…. for Black women's health."
>
> – Dr. Joia Crear-Perry

> "Black women are already stigmatized for simply being Black. There must be an insertion of compassion when it comes to Black Mamas. It's simple: we want the same treatment that white women receive without having to demand it."
>
> – Kay Matthews

Recognize that Access Does Not Equal Quality Care

Although holistic care practices – such as natural medicine, breastfeeding, whole foods, family support system involvement, doula services, birthing assistants and midwifery – are all traditional practices of Black women, in the last half century they have become fields and practices dominated by middle-class white women as both providers and informed consumers. Licensure and regulation of midwifery – along with low or no reimbursement for services provided by birthing paraprofessionals – results in high out-of-pocket costs for services in an economic climate where Black families continue to be disproportionately affected by poverty and lack of wealth.[xxxv] As a result, holistic care has become an economic right and not a human one. For some Black people, comprehensive and holistic care that meets all their needs is simply unaffordable.

Black women want holistic and alternative care options made accessible to them. Out of hospital birth, midwifery services, doula services and functional medicine practices are resources that have traditionally been important in communities of color and worth reintroducing to Black women in accessible and culturally congruent ways. Black women don't just need care, we need care that is equal in order for it to be adequate.

> "Adequate care includes meeting people where they are. It's multi-dimensional, practical, integrated and able to hit the needs of people in their everyday lives. For effective care, providers and staff must challenge the algorithms and structures of care provision that limit the interview and undermine the value of the time spent and information exchanged."
>
> – Haguerenesh Tesfa

Conclusion

Holistic care for Black women requires that providers, practices, and medical staff understand the cultural context, historical richness and complexity that Black women embody and live with every day. In order to provide holistic care, providers and medical staff must unlearn and self-correct implicit and unconscious bias. They must also continue to push back against a productivity model that does not give them enough time to build strong relationships with their patients. Implicit bias trainings may not change behavior, but they can increase awareness of one's position within the spectrum of advantage, privilege, and responsibility. A harm-reduction approach to how care is delivered is extremely important. It will help to create a medical system that supports systemic policies and behavior to address the social determinants of health and promote health equity.

Fear tactics and "best practices" that do not include research and recommendations from Black providers and women mirror glaring remnants of a slave culture that deprioritizes Black bodies and distorts the intelligence of Black minds, including the ability of Black women to direct, question consent, and understand what is best for their bodies.

Black women are more than our data. We are whole, loving, and lovable beings who require compassionate and thoughtful health care approaches that center justice, quality, power, autonomy, relationship, cultural congruency and care partnership between patients and the entire medical team. In the absence of these things, even the best intentions will not change Black women's health outcomes. Black women's leadership is key to advancing holistic care and achieving good maternal health outcomes.

It is our voice and lived experience, not the interpretation of it, that must inform all facets of our care.

> "Black isn't the risk factor, racism is."
>
> – Dr. Joia Crear-Perry

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