

"Black Nurses in the Home is Working": Advocacy, Naming, and Processing Racism to Improve Black Maternal and Infant Health

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Abstract

Objectives 1) To explore how racism-related stress impacts Black women's health, pregnancy, and parenting. 2) To explore how a culturally-specific program affects the relationship between racism-related stress and Black women's health, pregnancy, and parenting.

Methods This qualitative study uses a Black Feminist approach to center the lived experiences and perspectives of Black women. Focus groups were conducted with clients and staff of a culturally-specific program that provides perinatal care for Black families. A thematic analysis was conducted using a Reproductive Justice framework as a guide.

Results Participants consisted of 23 program clients and staff who all identified as Black women. Four themes emerged from the analysis: 1) The pervasive reach of structural racism, 2) Shared identities facilitate trust and healing, 3) Racism directly impacts mental health, and 4) Advocacy on macro and micro levels is a vital service.

Conclusions for Practice Results show the chronicity and toxicity of structural racism on Black women's physical and mental health. The presence of overt and subtle forms of racism occur in multiple systems and require interventions on macro- and micro-levels. Culturally-specific perinatal care programs that prioritize racial concordance between providers and clients/ patients are well-received and effective models of care. Black perinatal care should include culturally-specific approaches, advocacy on behalf of and alongside Black people, mental health support with attention to racism-related stress, and interrogation of implicit bias. Multipronged interventions guided by Reproductive Justice principles provide a holistic framework to address interpersonal and systemic racial oppression.

Keywords Culturally-specific program · Advocacy · Racism-related stress · Perinatal healthcare · Reproductive Justice

Significance

Extant research suggests that racism-related stress may be a primary contributing factor to persistent Black maternal and infant health disparities. Some public health initiatives have adopted culturally-specific approaches to improve Black maternal and infant health disparities. This study adds Black women's perspectives on how racism-related stress impacts their health, pregnancy, and parenting. It also provides insight into how culturally-specific programs improve Black perinatal health from the perspectives of Black

women. Results suggest the critical roles of advocacy and addressing racism-related stress as components of effective perinatal care for Black people.

Introduction

Structural racism impacts the health and well-being of Black Americans by creating and perpetuating social inequality and repeated exposure to trauma and unsafe communities. This ongoing and urgent public health crisis has led some scholars to declare racism a second pandemic (Jones, 2018; Shullman, 2020; Wallis, 2020). We affirm this position and extend it, asserting that persistent Black maternal and child health disparities reflect another manifestation of a racism pandemic.

While U.S. maternal mortality rates overall fell between 1915 and about 1990, rates have increased since then with

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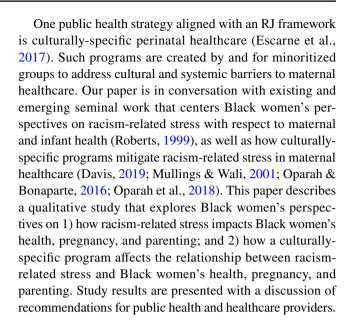
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Black women bearing 2–3 times the maternal mortality rate compared to white women (Lu et al., 2015; Petersen et al., 2019). Black Americans are about twice as likely to give birth to low weight or premature babies, and they experience more than double the rate of infant mortality compared to non-Hispanic whites (Ely & Driscoll, 2019; March of Dimes, 2020; Matthews et al., 2015). The gap between Black and white maternal mortality rates increases with maternal age and widens dramatically with educational attainment (Petersen et al., 2019). Infant mortality disparities also persist when controlling for socioeconomic position (Kothari et al., 2017).

Race-related stress refers to chronic stress associated with experiences, anticipation, and responses to racism and discrimination. These dynamic interactions occur between individuals and their environment over a sustained period of time (Mullings, 2005; Mullings & Wali, 2001; Utsey et al., 2012). This environment is multifaceted and includes one's home, community, work place, and larger social context. Thus, socioeconomic and behavioral factors only partially contribute to maternal and child health disparities and point to race-related stress, caused by chronic interlocking race, gender, and class oppression, as a primary driver of health inequities (Collins & David, 2009; Collins et al., 2000; Lu & Halfon, 2003; Nuru-Jeter et al., 2009; Rosenberg et al., 2002). Although the body has mechanisms to combat stress, the repetitive stress associated with racism may drive the body to allostatic overload, marked by an inability to recover from the damaging effects of stress (Jackson, 2007; Lu & Halfon, 2003). In this paper we modify the term race-related stress to racism-related stress to align with other scholars who argue that it is not race that causes stress, but the direct and indirect discrimination of racism (Jones, 2018). Further research is needed to understand the sources of racismrelated stress and how they manifest over the life course to affect maternal and infant health (Nuru-Jeter et al., 2009).

Reproductive Justice (RJ) is a theoretical framework that provides a useful lens through which to understand and address Black maternal and infant health disparities. The RJ movement emerged in the mid-1990's in reaction to the failure of policies and medical advancements to reduce racial disparities in reproductive health. RJ advocates for Black people to have access to the full range of reproductive options, including abortion, prenatal, and pregnancy care. It also promotes the re-imagining of reproductive healthcare for Black families through centering Black women's lived experiences and insisting on dignity and autonomy (Leonard, 2017; Ross & Solinger, 2017; SisterSong, n.d.). RJ works towards a type of corrective racial justice (Threadcraft, 2016) that is holistic and centered in honoring, restoring, and supporting the Black female reproductive body through providing the resources needed to thrive across the life course (Davis, 2019).



Methods

Research Approach and Setting

This qualitative study uses a Black Feminist approach (Collins, 1989). This theory uses embodied knowledge as a basis of information and theorizing that is critical of the systems that shape Black families' lives and seeks the transformation of those systems (Collins, 1989). A Black Feminist approach offers descriptive data that is not well represented by numbers and statistics, thus allowing for a more nuanced and complex understanding of the lived experiences of Black women. Investigators conducted focus groups in 2019 with clients and staff of Healthy Birth Initiatives (HBI), a program funded by Healthy Start and Multnomah County that provides perinatal care to Black women in Portland, Oregon. The only eligibility requirements to participate in HBI are being Black and pregnant. Through HBI, Black women and their families receive perinatal services from pregnancy through their child's 18-month birthday that include individualized in-home case management; home visiting nurses, mental health and other healthcare specialists; breastfeeding support; pregnancy, childbirth, and newborn classes; coordination with community agencies and external healthcare providers; and material support (e.g., car seats). Provider-client racial concordance is an integral element of HBI's approach—all providers and the majority of support staff and administrators identify as Black or African American.



Study Team

The principal investigators included two faculty from a school of social work located in the Pacific Northwest. One identifies as a Black, cis-gender woman, is a parent of three children, two of which are living, and is a member of the HBI community. The other identifies as a white, cis-gender woman and is a parent of three children.

Recruitment

A convenience sampling approach was used to recruit a total of 23 participants for four focus groups. We recruited client participants via listserv emails, posted fliers, and in-person advertisements during program events and client visits. Staff who work directly with clients were recruited through advertising the study during a staff meeting. All eligible staff members agreed to participate. We included 6–10 participants per focus group in order to optimize group synergy and participation. Participants provided written consent and received a \$40 gift card as a token of appreciation. During the consent process, it was reiterated that participation in the study was voluntary and in no way affected services, participation, or employment with HBI. This study was approved by the investigators' university and study site institutional review boards.

Focus Group Structure and Content

Focus groups were conducted using an iterative and recursive approach in two phases. For phase one, investigators asked three focus groups to answer open-ended questions related to racism-related stress. Two focus groups, comprised of 6 and 10 participants respectively, included only current and past HBI clients. A third focus group included only HBI staff (n=7). In phase two, a fourth focus group consisting of three staff and four clients discussed preliminary themes from phase one. We limited client participants in the fourth group to only former HBI clients to reduce potential conflicts of interest and maximize open and honest participation for all focus group members.

Phase One Data Collection

Using a semi-structured interview guide, the Black investigator asked client and staff participants to reflect on what racism-related stress meant to them; their experiences with racism-related stress; and how they believed it impacted Black women's health, pregnancy, and parenting. Participants shared what they did to help themselves in the midst of racism-related stress; how HBI helped address

racism-related stress and improve health; and how HBI services could be improved. Focus groups were audio recorded and transcribed. Detailed field notes were collected.

Initial Analysis

We used a reflexive approach to conduct a thematic analysis at a semantic level. Investigators independently coded transcripts then met to discuss and reconcile codes, identify potential themes, and process reactions to the data. Preliminary themes were developed after completing analyses of the initial three transcripts.

Phase Two Data Collection

The fourth focus group served a member-checking function and helped the investigators explore the research questions in more depth. Investigators shared the preliminary themes and asked participants to respond to how the themes did and did not reflect their experiences; what should be changed or enriched; how HBI facilitates healing from racism-related stress; and how HBI could improve efforts to address racism-related stress. Participants also shared what it was like for them to participate in the study.

Phase Two Analysis

The same analytic procedure was followed for phase two as was used in phase one up to the point of synthesizing codes into themes. Investigators then invited a home visiting nurse and graduate student to join the analytic process. She provides perinatal care to HBI clients, identifies as a Black, cis-gender woman, and has three children.

The research team discussed codes, reviewed field notes, and refined a second iteration of themes. For further member checking, this second iteration of themes was presented to HBI staff and HBI's community action network, which is a meeting of staff, clients, and community members. Feedback from these groups was incorporated into final results, which were included along with recommendations in a written report for HBI.

Results

Participants consisted of 16 HBI clients and 7 staff. Clients and staff all identified as Black women. Staff consisted of community health workers, nurses, and an office manager. Focus groups lasted an average of two hours. Four themes emerged from the analysis: 1) The pervasive reach of structural racism, 2) Shared identities facilitate trust and healing, 3) Racism directly impacts mental health, and 4) Advocacy on macro and micro levels is a vital service.



The Pervasive Reach of Structural Racism

"You feel this unspoken pressure" – HBI staff. Participants offered vivid descriptions of how they experienced racism within their communities, medical systems, and workplaces. They reported stress about rising racial tensions in the region and described exposure to overt and subtle forms of racism. They illustrated how the chronic presence of racism impacted them as people, as parents, and as professionals. A nurse shared, "The other thing that's frustrating is that just being Black in America, it's almost like we always are in a position where we feel like we have to justify who we are and why we are."

They described overt forms of racism such as racial slurs from strangers and a need to protect themselves from unexpected racialized violence and discrimination. Further, they explained how openly racist expression increased following the 2016 U.S. presidential election. A client said, "I had like about five different altercations with white people after Donald Trump became president. I got called a n** like two or three times." Subtle forms of racism included being followed by clerks when they went to stores, stereotyped as less qualified for their jobs, treated as incompetent, encountering surprise or suspicion of their intelligence, and having their ability and right to parent questioned.

Focus group discussions identified the pervasive and systemic impacts of structural racism. Participants described challenges of maintaining employment and housing costs. They worried about their Black children's safety in regards to police brutality and in school settings. A staff participant explained, "It's just like there's this heaviness all the time, whether it's just going to the store, or being in the work environment, or even with your home and your family...I've had this conversation a lot lately with my boys about, 'I will never as a Black woman, Black mother, I will never be able to stop worrying about you.' [...] So, it's all of the time, just that layer."

Participants explained how HBI's work in community settings with a strengths-based approach combatted isolation and created a positive sense of Blackness. They felt like HBI partnered with clients and built on their attributes, resources, and community relationships. For example, a client said, "I like that HBI is able to relate to us, and they don't make us feel as if there's something wrong with us or we need all this extra help. And then when they do ask us, you don't feel as if you're being pressured to do something you don't want to do." A staff member further explained, "[People] focus on the negative, which the healthcare system does, which child welfare does, everybody does...We're constantly fighting an uphill battle...Let's focus on, 'You're healthy. Your baby's healthy. You're doing everything you're supposed to do. You have a roof over your head.' Things like that rather than this laundry list that's going to keep holding you down." Clients experienced HBI as culturallyresponsive and trauma-informed; meaning they felt that their lives as Black women were understood by the Black providers who worked with them. Participants said they wanted medical providers to openly acknowledge the reality of racism within their institutions and directly with Black women. This included addressing policies and practices that failed to care for Black patients.

Shared Identities Facilitate Trust, Health, and Healing

"As Black women, we like to feel secure" – HBI client. Distrust, disconnection, and disrespect characterized relationships within mainstream, predominantly white health-care settings for Black women. Clients reported experiencing microaggressions and feelings of being exploited, lied to, and disbelieved. These painful experiences contributed to medical distrust and misinformation. Because of their awareness of historical medical racism, clients worried that involvement with mainstream medical providers could lead to entanglement with other systems.

Participants noted that racial and gender concordance between staff and clients helped develop trust. Clients felt that HBI staff understood them and had their best interests in mind, which facilitated more immediate, productive, and trusting relationships. Through its birth classes, breastfeeding classes, and prenatal and postpartum visits, HBI offered comprehensive information about prenatal and birth options, how to advocate for one's rights with mainstream healthcare providers, and how to heal during the postpartum period. A nurse said, "We look like the people we're actually serving, so we experience what they experience. We have first-hand knowledge of it, and most of the stuff we do and teach and learn is kind of what we've learned through the days of being here or in our own lives."

Clients shared accounts of traumatic birth experiences and how the pervasiveness of medicalized birth trauma affected individuals and communities. In our sample of 16 clients, participants described personal experiences with emergency c-sections, preeclampsia, preterm birth, still-birth, and gestational diabetes. One client said, "That was one of my biggest fears. You know, dying while giving birth." Focus groups included lengthy discussions of medical misinformation and confusion such as the possibility of vaginal delivery after c-section delivery, pain medicine dosage, and the purpose of infant heel sticks. Clients were more likely to believe pregnancy-related myths shared through informal social networks and be suspicious of recommendations offered by mainstream, white medical providers.

Participants told us that they feared their interactions with mainstream, white medical providers would lead to



system entanglement, particularly with the child welfare system. One staff person shared how a healthcare provider reported an HBI client to child protective services (CPS) because she did not have a phone. The client did not want a phone because of complicated family dynamics completely unrelated to her pregnancy or parenting. Participants gave numerous examples of how asking for mental health support or mentioning prior engagement in mental health services led to CPS referrals.

Women expressed appreciation for this study's groups as a way to talk deeply about birth trauma and racism-related stress. They were eager to share insights and to hear each other's experiences. They recommended peer support groups as a way to process birth trauma and build community support. Clients also stated that involving doulas in perinatal care facilitated more trusting relationships with white, mainstream medical providers. Doulas and HBI staff acted as advocates for clients with these providers, which reduced clients' anxiety during perinatal care. A client explained that HBI referred her to a doula and said, "What happened is they gave me a doula, which that was the best thing. That was my support sister. If I didn't have a doula, I don't know how I would have made it through that last hospital stay."

Participants noted that, at times, it was difficult to form relationships of mutual positive regard with white medical providers. A client said, "It's not to say that a white person can't come and help a Black person, but the way that they come in trying to help a Black woman is where it goes wrong. [...] As Black women, we like to feel secure. We like to feel that. We don't want you coming into our life, telling us what we are, who we are. We already know who we are, we just need help or a little understanding." Clients said that they wanted access to the best care and choice. They felt that having public health insurance and/or being Black meant that they received inferior care and fewer options.

HBI staff shared that they often knew more about their clients than their clients' mainstream healthcare providers. They went into clients' homes and openly discussed the many issues impacting their lives. Staff were able to meet with clients at least once a month for an hour or more, and they engaged with clients from their pregnancy through the child's 18-month birthday. This meant that staff were able to triage health complications, promote perinatal health, strategize with clients about how to engage with mainstream medical providers, and act as liaisons with medical teams.

Racism Directly Impacts Mental Health

"We're finally starting to see that it's okay to go talk about our problems"- HBI staff. Racism is physically, psychologically and emotionally damaging. The "strong Black woman" stereotype is a harmful myth—the pressure for Black women to always be strong made it hard

for participants to ask for help and expect a compassionate response. Participants acknowledged that they repressed, hid, and intentionally did not acknowledge racism-related stress. They wanted dedicated mental health support that was empowering, trauma-informed, and caring.

Participants described constant levels of stress, anxiety, and fear associated with racism that impacted their mental health. They used phrases like, "There is no off-switch" to refer to the way racism permeated their lives, regardless of class and other sociodemographic factors. A nurse explained, "It's always something that we have to deal with. That's why it doesn't matter if you have health insurance or don't have health insurance, if you have a college degree, if you don't have a college degree. Your risk being a Black woman, it's the same. Those stressors, they don't go away and so how do we...even though we say, 'I don't let it bother me, I go on about my [business] because they don't need to know. I go about what I'm doing.' It's still there. That's the part I'm trying to figure out, even in my own life. It doesn't matter. It's not going away. Yeah, I learn to cope, but it's still there."

At the same time, participants expressed a desire for mental health support. Another staff participant explained, "I'm surprised how many people be like, 'Oh, yeah, refer me. I'll talk to someone.' And probably, to me, that's like a light at the end, that we're finally starting to see that it's okay to go talk about our problems." Participants identified a barrier to discussing mental health needs with medical providers was the potential for that information to be used against them. For example, one mother and her children were subjected to a punitive CPS experience because she had a mental health condition, despite having well-managed mental healthcare.

HBI has a Black mental health professional who provides client services and space for staff to process some of their work stress. Her clinical approach is to directly acknowledge racism-related stress as a part of mental health services. Clients and staff described this as a critically important element of HBI. A staff member said, "Some of these clients didn't even know they were getting impacted by systemic racism, to be honest. They didn't even know that this could affect their birth outcome. Because I think, as a race, we've been conditioned to be resilient, because it's that or find a cliff to jump off. [...] A lot of people never even consider mental health until we brought it up."

Clients expressed the importance of being mental health supports for each other and wanted access to peer support groups. They wanted white, mainstream providers to explicitly ask Black women about their well-being in a way that acknowledged the impact of structural racism on mental health. A client said, "I think that's what's lacking with the Black women. There's no place for them to go and speak and not be judged. [...] It is something that we need."



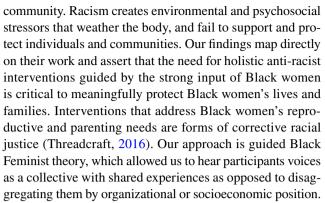
Advocacy on Macro and Micro Levels is a Vital Service

"You want someone to be able to speak up for you if you need, if you're just too tired to do it for yourself." - HBI client. Anti-racism advocacy is the critical work of public health and healthcare. Staff explained that perinatal healthcare for Black people required engagement with systems inside and outside of healthcare because these systems withhold vital resources and often actively harm the Black community. Participants recounted how racism-related stress manifested as a result of racism experienced in housing, employment, and child welfare systems. Anti-racism advocacy within these systems was just as important of a health intervention as was providing individual perinatal care. Staff described advocacy for policy change on federal, state, county, and institutional levels. They identified training of mainstream medical providers in implicit bias and culturallyresponsive care as examples of macro-level advocacy.

Participants also described the effectiveness of HBI's micro-level advocacy efforts. Advocacy occurred through HBI's culturally-specific approach including access to Black nurses and community health workers; pregnancy and child birth classes; referrals to Black doulas, therapists, and specialists; long-term holistic perinatal care in clients' homes and communities; and active engagement with clients' medical teams. Participants shared powerful stories of how the staff taught clients about their rights within various systems (e.g., housing, child welfare, education) and the necessary self-advocacy skills to obtain those rights through effective communication with providers and those with institutional power. One staff member explained, "Black nurses in the home is working. I think that has opened the doors tremendously, because not only are we teaching them how to advocate, but we're giving them almost permission to use their voice, and to know that you can affect change in your own life."

Discussion and Recommendations

Participants' reflections on their experiences and the impacts of structural racism on themselves as Black women, as well as the broader community, build on key understandings of racism-related stress, provide insight into how it affects Black women's health, pregnancy, and parenting, and inform practice recommendations that may ameliorate racism-related stress. Our discussion of racism-related stress aligns with the environmental stressors framework used by Mullings and Leith (2001) that asserts that to reduce racism-related stress in Black women's lives, public health must holistically address women's exposure to risk in the medical moment, as well as the domestic sphere, work, and



This study affirmed the importance of relationships between providers and clients/patients, as well as the pernicious nature of implicit bias. Authentic relationship-building based on positive regard can transform provider-client/patient relationships across race and class difference and facilitate the acquisition of accurate health information. Because of the history of medical racism, medical myths and misconceptions may take stronger root in Black communities. Organizations should listen for and address medical misconceptions related to maternal and child health. They must also address implicit bias within their systems of care, including racist assumptions of Black women and communities. Implicit bias and anti-Blackness training may be one strategy to challenge bias within healthcare.

One of the most inspiring findings was HBI's advocacy on behalf of and alongside Black women as an effective public health strategy. Organizations serving Black people should consider providing advocacy training for clients and identify areas for policy change in healthcare, child welfare, housing, and education systems. Structural anti-racist change is needed to support provider change and stronger outcomes. Medical institutions must examine the structural ways Black women are pushed out and failed by these systems— change is needed and demanded.

Participants spoke directly to the value of Black nurses, doulas, and therapists as part of their reproductive care as a way of mitigating the impacts of racism and racism-related stress around medicalized experiences of pregnancy and birth. Our findings align with Davis' (2019) recommendations on the necessity, efficacy and need to bolster the efforts of Black birth workers. For participants, these relationships were a source of compassion, validation, care, and protection.

Participant narratives reflected that increasing trust of the healthcare system requires macro-level interventions. Public health and healthcare providers should ensure that Black women receive the same information, services, and options as white women. These systems should study outcomes with Black patients and assess services provided, and in particular, Black people's satisfaction with and continued use of those services.



Findings demonstrate the direct impacts of racism on Black mental health and its subsequent effects on health and parenting. Mullings (2001; 2005) developed the term "Sojourner Syndrome" to describe the behavioral coping strategies Black women employ to manage the enormous psychosocial environmental stressors they encounter. This description is a way of conceptualizing the intersecting influences that racism and sexism and the resultant stress has on Black women and the health risks which emerge. Our findings illustrate the Sojourner Syndrome and describe how discrimination and being under-resourced takes a toll on Black women. Alleviating this burden requires fortifying the web of support around women.

Finally, mental health care for Black women should explicitly name, validate, and address the impacts of racism-related stress on mental health. Providers should offer opportunities for Black people to process racism and birth trauma through peer support mechanisms (e.g., peer coaches, support groups), as well as mental health support during the perinatal period. Providers must confront the disproportionate and unjust involvement of Black families in the child welfare system. This work could begin by tracing referrals to CPS, identifying where they originate, and working as hard to seek alternative supports for Black families as for white families.

Limitations

This study reflects the perspectives of one set of Black women involved in a culturally-specific perinatal program in Portland, Oregon. Our convenience sample does not reflect the entire HBI community and is not intended to be generalizable to all Black people or all culturally-specific programs. In addition, racism-related stress is among multiple factors that contribute to racial health disparities. Racism-related stress is a complex and exacerbating factor in Black women's health that is difficult to tease out in analysis.

Conclusion

Reproductive Justice is the right to have a child, not to have a child, to parent in a safe and sustainable environment, and to bodily autonomy. This study provided first-hand, personal accounts of Black women's experiences of racism-related stress, their perceptions of how racism-related stress impacts pregnancy, health, and parenting, and how one culturally-specific perinatal program ameliorates these effects by embodying RJ tenets. Participants pointed to the need for compassionate, responsive care for and by Black people as critical to ameliorating the impacts of racism-related stress during pregnancy and beyond. Black lives matter when we support the autonomy and well-being of Black pregnant

people to thrive in the perinatal period and to raise their children in a safe environment. Addressing racism-related stress requires programs like HBI, which work alongside Black pregnant people for individual and systemic change.

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Data Availability This study's data is not available for distribution.

Code Availability Not applicable.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval This study was approved by the Portland State University Institutional Review Board (#184701). It was reviewed and determined not engaged research by the Public Health Division/Multnomah County Health Department Institutional Review Board (IRB-18-17).

Consent to Participate All study participants gave written informed consent to participate in this study prior to inclusion in the study.

Consent for Publication Not applicable.

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