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“If I knew what was going on with me, then I probably wouldn’t feel so sad or scared”: A CBPR Study Addressing Health Disparities for Black Pregnant Women

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Introduction

According to the 2021 National Vital Statistics system, the maternal mortality rate for women who identify as non-Hispanic Black (subsequently, Black) was 69.9 deaths per 100,000 live births, 2.6 times the rate for women who identify as non-Hispanic White (subsequently, White) with 26.6 deaths per 100,000 live births (Hoyert, 2021). Maternal mortality rates for Black women were significantly higher than rates for women who identify as Hispanic as well (subsequently, Hispanic; Hoyert, 2021). Mental health conditions, namely suicide and overdose, are the leading cause of pregnancy-related deaths, and four out of the five deaths are preventable (Hoyert, 2021). Adverse birth outcomes are also significantly higher for Black infants, with a premature birth rate of 14.39%, compared to White (9.26%) and Hispanic (9.97%) infants (Martin et al., 2020). Preterm birth is the second leading cause of infant mortality, indicated by the number of 0- to 1-year-old deaths per 1,000 live births, and is a contributing factor to Black infants dying at more than twice the number (10.8) compared to White infants (4.6) and Hispanic infants (4.9; Driscoll & Ely, 2022). Exposure to structural racism, implicit biases of health care providers (Chambers et al., 2020), and racial barriers to access of perinatal care (Gadson et al., 2017) are contributing factors for adverse maternal and infant health disparities.

Due to the widespread health disparities between Black, Hispanic, and White women's birth outcomes, a qualitative study was designed using an intersectionality framework. The purpose of this community-based participatory research (CBPR) study was to enhance racial equity for Black women who are pregnant. We recruited 20 Black mothers in three Florida counties who would be co-researchers in this study. The goal was to support self-advocacy, including developing a toolkit, for Black mothers with culturally relevant and nondiscriminatory approaches.

Exposure to Structural Racism

Structural racism, as defined by Chambers et al. (2020), is "a systematic approach used to influence laws and process to unequally allocate access to goods, opportunities, and services in society by racial groups" (p. 214). Structural racism within a society results in discriminatory practices of inequity in health care, education, housing, wealth, and employment (Chambers et al., 2020). Racism, resulting from both implicit and explicit biases, that permeates the health care system leads to such discriminatory practices as unfair, inadequate, and poor care (Chambers et al., 2020). Research findings indicate that more than 54% of Black pregnant women

experience racism in school and public settings (Ertel et al., 2012). Over time, chronic stress, an unfavorable effect of structural racism, places Black pregnant women at risk for adverse maternal and infant outcomes (Chambers et al., 2020; Dominguez, 2011; Rosenthal & Lobel, 2014). Moreover, the influence of racism in health care policies and practices has resulted in using power to oppress and devalue women of color (Taylor, 2020).

Implicit Biases of Health Care Providers

Implicit biases, stereotypes, and stigmatization by health care providers who provide care to Black pregnant women result in inequitable care (Rosenthal & Lobel, 2014; Maina et al., 2018). In a study by Mehra et al. (2020), Black pregnant women described how various assumptions made by health care providers impeded their ability to access resources needed to support a healthy pregnancy. These women were more than twice as likely to use federal assistance such as Medicaid for their insurance (65.1%) compared to White pregnant women (29.4%; Martin et al., 2020). In addition, Black pregnant women who relied on government assistance reported experiencing stigmatization and feeling devalued when interacting with health care providers (Altman et al., 2019; Mehra et al., 2020). Many women reported that health care providers spoke to them with domineering and condescending tones during their prenatal visits, which the women found disrespectful, and which evoked in them fear and a sense of powerlessness to participate in decisions regarding their care (Altman et al., 2019). Women stated that communicating with health care providers resulted in a lack of sufficient knowledge about the pregnancy, leaving them with partial or misleading information, and causing them to feel uncertain and confused (Altman et al., 2019).

Black pregnant women who used federal insurance reported seeing multiple health care providers throughout their prenatal care, which impeded continuity of care. Inconsistencies among health care providers made the delivery of care fragmented and made it difficult for women to develop trusting relationships with providers. This lack of trust and feeling devalued and powerless hindered the women's ability to ask for help. Implicit biases displayed by health care providers resulted in poor patient–provider interactions, loss of patient autonomy, and ultimately lower quality of maternal care (Altman et al., 2019).

Racial Barriers to Accessing Perinatal Care

Accessing prenatal care in early pregnancy is recognized as vital to a healthy pregnancy outcome. However, Martin et al. (2020) reported that Black women are less likely to access prenatal care in their first trimester

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(67.6%) than Hispanic (72.1%) or White women (82.8%). Delay in accessing early prenatal care for Black women is related to difficulties in obtaining insurance coverage and finding providers who accept government insurance (Gadson et al., 2017). Further, for women living in underserved communities, access to prenatal care is impeded by limited maternal health care services, leading to long wait times for prenatal appointments, as well as potentially long travel distances (Gadson et al., 2018). These obstacles result in underutilization or placing prenatal care out of reach for some mothers, which increases the risk of adverse pregnancy and birth related outcomes (Gadson et al., 2018; Mehra et al., 2020).

Intersectionality Framework

To understand the complexity of structural racism and health care disparities for Black pregnant women, we applied intersectionality theory to frame the study. Intersectionality is the study of overlapping or intersectional social identities and related systems of oppression, domination, or discrimination (Crenshaw, 2017). According to Collins (2015), the following are guiding assumptions: race, class, gender, sexuality, age, ability, nation, ethnicity, and similar categories of consideration—all of which are best understood in relational terms rather than in isolation from one another. These mutually constructing categories underlie and shape intersecting systems of power; the power relations of racism, classism, and sexism, for example, are interrelated. We used this theory to inform our interview guide and to aid in conducting interviews that were racially congruent. In accordance with CBPR practices, a study participant was included in the analysis phase. To conduct a critical analysis of Black maternal mortality, Black women's identities as both racialized and gendered beings need to be understood (Harper, 2020).

Method

In this CBPR study, we explored how to best support Black women during pregnancy and the postpartum period to decrease maternal health disparities. This study was designed in collaboration with the Florida Maternal Mental Health Collaborative (FLMMHC). It should be noted that CBPR is a collaborative effort connecting researchers and communities impacted by an issue with the goal of producing positive change and enhancing the well-being of community participants (Hacker, 2013). CBPR is a methodological approach to address health disparities and to benefit marginalized communities (Wallerstein & Duran, 2010). This strategy is effective in engaging hard-to-reach populations that may be distrustful of research (Hacker, 2013). It is imperative to understand individual, familial,

and systemic strengths and weaknesses to identify areas of perinatal care improvement for Black mothers. Through this CBPR study, we explored the perceptions of the participants regarding their utilization of maternal educational resources and peer and community supports within a 12-month period.

Planning for the study began with the FLMMHC Research Workgroup in January 2021, and data were collected from January through December 2022, following Florida Atlantic University IRB approval # 1829945-10. The Community Advisory Board (CAB) consisted of a co-researcher in maternal health disparities at a Florida higher education institution, maternal health providers, a research participant (mother), the Director of Maternal Health, March of Dimes, three community partners in maternal and infant health and wellness (Gadsden, Hillsborough, and Palm Beach counties), and a maternal mental health expert. The CAB did not have access to the interview transcripts and surveys but assisted in reviewing themes, patterns, relationships, and toolkit development.

Study Population

The sample of this study consisted of 20 mothers who identified as Black and had delivered a live infant within the 12 months prior to the study. In qualitative research, CBPR sample size ranges from 12 to 40 participants. Consistent with CBPR methodology, the participants are considered co-researchers in the process. The age range included 18-46 year-old adults of child-bearing age.

Research Aims and Questions

The following were the research aims:

Goal 1: To explore the effect of self-reported racial discrimination and racial equity by health care providers and its impact on the prenatal care they provide.

Research question 1: How do the co-researchers perceive the effect of racial discrimination (emotional and physical) by health care providers on their pregnancy and birth outcome?

Goal 2: To identify accessible and desirable supportive resources and services, including telehealth, to help educate and support pregnant women with health risks and complications associated with pregnancy.

Research question 2: What are the co-researchers' perceived barriers to accessing supportive services offered in the community? What are the desired resources and services that women can use?

Goal 3: To examine the impact of current prenatal care policies on care.

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Research question 3: Do current prenatal policies facilitate racial equity for Black women who are pregnant?
Goal 4: To create a self-advocacy toolkit that enhances racial equity for Black women who are pregnant.
Research question 4: What educational needs are required to improve interaction and communication between pregnant women and their health care providers?

Recruitment Plan

FLMMHC members expressed interest in distributing recruitment flyers to their respective community agencies and potential participants. Stakeholders who agreed to being contacted regarding the CBPR study provided contact information to the researchers. Community stakeholders were contacted in three Florida counties that represent underserved areas in the state: Hillsborough, Gadsden, and Palm Beach. These stakeholders improved recruitment success and sample generalizability. The researchers worked with community partners to keep record of how many people were approached and who declined participation to increase validity of the work and decrease sampling bias. Participants were compensated for their time and effort in the study's individual interview with a $40 food gift card.

Interview Process

One-hour Zoom interviews were conducted individually with women who consented to the study. All participants were required to read and select the electronic consent button via RedCap prior to beginning the demographic survey and interview. All 20 interviews were conducted by a nursing or social work graduate student with racial congruence. The interviews followed a semi-structured interview guide using the four research questions. Additionally, member checking was used with one research participant (mother) on the CAB to ensure credibility and agreement with major findings. There were no anticipated direct benefits to participants based on involvement in this study; however, participants contributed to enhancing dialogue and increasing positive perinatal care and birthing experiences of Black mothers. Partnership was based on power sharing in decision making, trust, respect, and equitable distribution of resources. It was the aim of the researchers to strengthen multiculturalism in prenatal care and birthing and postpartum and mental health settings and to increase equity for Black mothers.

Analysis

The research team was responsible for the qualitative analysis of data, but stakeholders had access only to final reports to ensure confidentiality of the participants. The qualitative data were analyzed using a critical intersectional analysis with the assumption that mutually constructing categories underlie and shape intersecting systems of power and that the power relations of racism, classism, and sexism are interrelated. After completing the individual interviews, three researchers entered the transcribed interviews into NVivo, a qualitative software package, and identified initial themes. To ensure multiple perspectives co-researchers (CAB members) were included in the analytic process of the interpretation, synthesis, and verification to enrich the process and improve trustworthiness and credibility. The co-researchers conducted an initial coding and generated themes individually. They discussed the emerging themes for commonality and then collectively decided on the themes prior to bringing them to the CAB. Findings were then discussed with the CAB for refinement until all were satisfied with the major themes.

Dissemination focused on developing action steps based on the findings of the study. The FLMMHC assisted in implementing the research-informed toolkit to be used for medical professionals to provide culturally relevant care. The Western Coastal Florida market of the March of Dimes, FLMMHC, and three community partners who provided advocacy, education, and support to women also assisted with dissemination of the toolkit.

Results

Study Sample

The sample for this study comprised 20 Black mothers who averaged 30.69 years old. All the participants reported their primary language as English. Sixty-eight percent of the sample had an involved partner, and therefore 32% were single mothers. The average age of the children of the mothers in this sample was 44.58 months. Regarding education levels, 85% of the mothers in the sample had at least a high school diploma, with 5% of the sample having completed a technical/vocational program, 15% attended some college, 5% had an associate degree, 15% had a bachelor's degree, and another 15% had a master's degree. The women reported working in various career fields, including IT, management, caretaking, homemaking, nursing, teaching, training, and so forth. The annual income of the mothers ranged from $0 to $69,999 (see Table 1).

Table 1
Demographic Characteristics of Participants

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Characteristic		*n* (%)
Age	[*M* (*SD*)]	30.69 (5.31)
Marital Status	Partnered	13 (68)
	Not Partnered	6 (32)
Education	Junior High School	1 (5)
	Some High School	2 (10)
	High School graduate	6 (30)
	Technical/Vocational Program	1(5)
	Some College	3 (15)
	Associate Degree	1 (5)
	Bachelor's Degree	3 (15)
	Master's Degree	3 (15)
Race/Ethnicity	Black	20 (100)
Primary Language	English	20 (100)
Occupation	IT Management	1 (5)
	Manager	2 (10)
	Homemaker	5 (25)
	Caretaker	1 (5)
	Registered Nurse	1 (5)
	Teacher	1 (5)
	Trainer	1 (5)
	Customer Service	1 (5)
	Security Officer	1 (5)
	Unemployed	1 (10)
	Missing	5 (25)
Income	Under $3,000	7 (35)
	$3,000 to $4,999	1 (5)
	$5,000 to $6,999	1 (5)
	$15,000 to $19,999	1 (5)
	$25,000 to $29,999	1 (5)
	$30,000 to $39,999	3 (15)
	$40,000 to $49,999	1 (5)
	$50,000 to $59,999	2 (10)
	$60,000 to $69,999	1 (5)
	Missing	2 (10)

Religion	Protestant	12(60)
	Catholic	3 (15)
	None	3 (15)
	Missing	2 (10)
Living Children	Yes	19(95)
	Missing	1 (5)
Child's Age in months [*M* (*SD*)]		44.58 (48.37)
Child's Sex	Female	17 (52)
	Male	15 (45)
	Missing	1 (3)

Note. N = 20

There were two major themes that emerged from the CBPR study: environment and health literacy. Regarding the first theme, prenatal and postpartum environment, the participants' responses illuminated three subthemes: lack of options with prenatal care, racial disparities, and commonly feeling dismissed during care. One subtheme emerged from the second theme: The participants expressed that increasing health literacy by asking for help and communicating specific needs was important in addressing maternal health disparities within this environment.

The following are exemplar quotes to demonstrate the themes and subthemes.

Environment Theme

The environment described by mothers was characterized by a lack of options and situations where they experienced racial disparities and feeling dismissed. As a result, the passing of judgement and providers' implicit racial bias can lead to health disparities due to inadequate or unjust care.

Lack of Options

Lori said: I really didn't choose on the prenatal care, because the one that I wanted to get, they stopped responding to my emails. That's how I ended up basically going to the one that I currently have. And whenever I told her which insurance I had, she was like, "Oh. You have to change your insurance to this so we can get it." Or "We can't get it." And I was like, "Okay." So, whenever I called them, "What's the name of the insurance?" And then, they just never returned my call or my emails.

Kerry shared: It was just the race thing at the time. I'm thinking about, oh, the baby, and I'm not getting care, not being on the prenatal. It was so much, and my depression kicked in at the time too. So, it was a lot going on. Just to even be focused on them, I was just trying to get care from anybody. Even when I caught COVID, I dropped down in my house when I caught COVID since I didn't have insurance. So, I didn't want to go. I had to think of, "Oh, I'm going to leave my kids. There's nobody to watch my kids. I have no insurance, so let me not go to the hospital." So, I end up not going until it was the last minute. I could have ended up killing myself, and they made it impossible for me to get insurance until, "Oh, you have a baby?" And even still with the baby, then it kind of kicked in after. So being, if you don't have insurance people, a lot of people are scared to even get help due to the fact that there is no insurance.
Kerry continues to share difficulty in finding prenatal care: I was almost 30, 31 weeks, 30 weeks before I could get here. Because nobody would... Remember, I said I'm shopping around? Even with my last pregnancy, when I was 17 weeks pregnant. And I'm 17 weeks pregnant, and I'm shopping around for all these doctors. I don't care who would've taken me. I couldn't get a doctor either.
Deja shared: I am also overweight, so they didn't want to, at first they were saying, "Oh, well I don't know if we're going to help you in our practice." But since I already had my daughter through their practice, they decided to go ahead and take me. I was trying to avoid certain doctors because I know how I was treated during my last pregnancy. They pretty much made me go to the same doctors that I was trying to avoid. They kind of pushed me, so I don't feel like I was able to get much of a choice in that sense, but I was able to get seen with a provider as soon as possible.

Racial Disparities
Lily shared: It definitely felt like I received the best treatment whenever I was with my husband or anyone on his side because they are White. But when I'm going by myself or with my sister, and as we are Black women, it's like we end up getting seen an hour after the time appointments are scheduled, or we've had difficulty getting appointments in general. It's almost like I had to fight for my time.
Kerry stated: It was hard for me to get care. I had a White friend. I couldn't get any care anywhere being that. When I found out I was pregnant, I was already 25 weeks. So, my friend called, she could have received service, and I called, I didn't get any service. I told her to call this specific office to see if she could get care, because they said they don't go over a certain amount of days. You have months—they can't care for you. So, when she

called and she ended up talking to them, she ended up getting an appointment with them. She wasn't pregnant. I just told her to call. But when I called, they told me they couldn't take me. I just had to call around. By that time, when I was 25 weeks, then 26 weeks passed, 27 weeks passed. I literally had no care until just at the last minute. St. Mary's, outside the outskirt of St. Mary's, there's an office out there. They ended up taking me.
Mary stated: I think it impacted a lot because I could see how there was a difference in the way that people that look like me were treated versus how non-minorities were treated.
Wendy shared: I don't know if it was racism, but I just feel like automatically as Black and brown women, people look at us, and they feel like it's something that we should be able to handle. I just feel like it was just that automatic predisposed bias that women of color face in the medical field.

Dismissed
Wendy stated: You can tell them about stress. You can tell them that you're hurting. You can tell them that you can't get out of bed, or you can't get up out of the chair, because your pelvic floor feels like it's about to fall out of you. They don't care. It's normal, they tell you. I experienced terrible migraines. Like I said that my support came from family.
Deja shared: I feel like in health care they expect a lot out of Black women. They expect us to be really strong and have this high pain tolerance or whatever and my pregnancy, throughout my pregnancy I would have a lot of issues with pain starting early in my pregnancy, and it was pretty much dismissed, and I don’t know if it was because they feel like we complain too much. I don’t know what the underlying reason is, but I do feel like that played a little bit of the factor of why some of my complaints weren’t taken as seriously. But I feel like he didn’t really get where I was coming from, and he kind of dismissed a lot of issues I was having.
Fiona shared: The specialist I was seeing shoved it off. It took me two visits to go see to have my transfusions done. There could have been more care, especially as I have underlying conditions. My main concern was having a seizure during labor and delivery. I felt like a number to them, another case. They did not respect what I was asking as far as unmedicated birthing practices and doula services. They said they did not work with doulas. That idea was shot down. They handle this, and they can do what a doula does.
Kerry shared: And due to my depression, I didn't expect to have another baby. I'm 40 years old. I didn't expect to have another baby. But they said, "Oh, you're depressed. Oh, let me get a psychiatrist." That's not what I want. I want you to check me out. I need service. I need to make sure the baby that I'm carrying is okay. I couldn't get service either.

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Lori shared: “Is there a way that we can test for this to try to do something that's more preventative early on before I just have to take something." And she instantly [midwife] said, "No." She just was kind of like, "What I say versus how you say, and whatever you say." That's basically what she told me. Because I asked her about the natural herbs. Because I wanted to do something that was more natural. And she said, "That's not FDA regulated." She was very defensive about it. So then, she left, and she had a total attitude. When she came back, and I said, "Well, there's certain things that I don't want to take because I don't eat meat from pork. I don't eat that." And then, she said, "Well, the thyroid medicine is made from pork byproducts," or something she was saying. And I said, "You know what I'd rather speak to a pharmacologist about all this, because that is out of your scope of practice." And when I told her that, she left out of the room, she just stormed out, and I didn't see her after that particular visit.

Sasha shared: “I feel as though he would've never done that if it was someone else of another race. He would've addressed their issues and answered the question and been patient. But I feel like it does have something to do, especially because I'm a single mom.”

Ava shared: “And since they made a mistake they did not even apologize; I almost lost my life; you did not apologize. But the one thing that I was mad about, beside that they did not apologize: They have the nerves to send their social worker coordinator to call me to ask me what the level of my education and the level of education on his dad is. So then, I was like, “None of us are illiterate, we are all educated,” I said, and I hung up. And then the third time that they call me, and I said, “Okay, I have a science degree, and then his dad also has a degree in law. He also has a master's degree. He went to USF and had a sociology degree too, so which degree are you looking for?” And then the person stopped talking and said, “Thank you so much. We will. We will get back to you.”

Health Literacy Theme

Health literacy is a form of advocacy. Empowering patients with knowledge helps to give them a voice in advocating for themselves because they are aware of the subtle changes within their body that can be early warning signs of greater issues that have yet to manifest. The women expressed that health literacy included asking for help and communicating their needs to providers.

Lori shared: I feel like, as the Black culture and some Spanish culture, we are not really taught to pay attention to our bodies, to pay attention to how food affect us, how we feel after we ate certain things, and what we can do to not feel certain ways. We're not taught all these things. We turn to the

doctor, and doc say, "Here. Take this, take this, take this." And so, people will be like, "Oh, well, I am not going to take it, because I don't like to take medicine," or, "I'll just get me some ginger ale, and call it a day," type thing.
Deja shared: About two weeks before I delivered, I started complaining about swelling, and they dismissed me, “Oh you know that’s typical pregnancy,” or whatever, so I started having like anxiety about it. Like something’s going on, you know, something’s going to happen to the baby, you know, all this extra stuff, and so I ended up having a C-section, which was already planned. They never gave me an option about not having a C-section, like it was already planned. I had a C-section. I'm looking at my legs, I am still very, very swollen, I could barely walk. Two weeks later, I found out that I have preeclampsia. If they would have listened to me a little bit more, I don’t think I would have had the experience that I had. Just having support, I didn’t know that you could have preeclampsia afterwards.
Fiona shared: My doula educated me, and more women need to know about doulas. They give you breathing techniques, homeopathic to help prevent before they rush you to a C-section or take medicine to rush your labor. Let it happen naturally as possible without interference.
Nancy shared again about her experience with high blood pressure: I have to say, especially Black moms, if you don't feel right on them, you know you have the right to ask questions; I have the right to ask questions. Even as a nurse doesn't mean I know everything. Giving each patient that voice to be able to speak and giving them time to ask questions about why this plan of care and opening that discussion, because a lot of the times you're being rushed you get to go to the next person.
Wendy shared: Honestly, I would want them to know to advocate for yourself and do your best to try and get the resources that you need for yourself. When I was going to see these people again who did not look like me, I've seen midwives who did not look like me. They weren't telling me about different things that I could do to empower myself and advocate for myself as a mother. It was more, they weren't even really telling me anything that I could do through the process for my child when he gets here. They weren't telling me about things like WIC. They weren't trying to see if I had insurance for my son. They just, like I said, it was just they were, "Hey, your baby's doing good. Here's your due date." Things like that and so I would just tell women to educate themselves.
Lily shared: We need to have more education concerning how pregnancy differs for African American women and other women because it seems like our pregnancies are usually with us having high blood pressure and it comes down to, well, why do all of these Black women have high blood pressure? What's attributing to it?

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Andrea said: Overall, just educating yourself and being proactive with everything to make sure you understand what's being done and what's being said, so that you can make informed decisions from there. You must do your due diligence and not just sit around, letting people make options for you. You must do your own options.

Ask for Help/Communication

Health care providers should pay more attention to their patients and give them the appropriate and required care per visit. They should also be willing to answer questions and explain their decisions clearly.

Deja shared: Just having open communication, trusting your provider and you know, that they're going to do what's best for you. The most thing that I have taken back from this experience is that it's okay not to be okay. You know? And it's okay to have moments where, like, not so much that you regret your pregnancy, but you have these mental moments like, you know, it gets overwhelming at times and it's okay to be like, what did I just get myself into? Cause I had a lot of those moments where, like, you know, I felt like that way. But I feel bad for feeling that way, but at the same time, you know, your whole life has just changed. I feel like if I would've had somebody in my ear like, "It's okay for you to feel overwhelmed, it's okay for her to be screaming and you to be crying, it's okay for that, you know." Just, I guess having that support and asking for help when you need it. You know, being strong women, we don't want to ask for help sometimes, we want to feel like we got it all and we can handle it all and just being able to, you know, ask for help, instead of drowning, you know.

Lily shared: Talk to your doctor because I spoke to mine, and he saw in my medical file that I used to be on something for my mood swings, and he started prescribing that to me, and it really helped regulate my moods to where they're now stable.

Aniya stated: My health care provider? Just them, you know, paying more attention to us and you know, hearing us for the most part. Hearing us and don't rush us out of there because, sometimes, we need to know that the baby's okay.

Recommended Resources

The participants had three major recommendations to improve prenatal and postpartum care for Black mothers: (a) address mental health, (b) be culturally sensitive, (c) and increase Black representation in health care.

Lack of Mental Health Services

Deja explained: I really pulled on my family support more than anything. I did have issues like maybe at my 7-month mark with depression, and so

I'm... they tried to send me to some places; but a lot of the people in network either didn't have appointments or was doing virtual, and I needed more of, like, an in-person experience. So, I never did really find therapy or counseling, and I was suffered really bad afterward with postpartum depression; and I never really did get a whole lot of support other than family.

Fiona shared: They treat moms a lot more fragile and nicer when they are pregnant. And after I had my baby, I feel we are expected to go back to normal and go back to the person I was before I had the baby and then some. I think it is my age. I am 24. Because I am so young people believe that I should snap back and that hasn't been the case. Postpartum is where I am finding my challenges. Obtaining support is difficult. I have not reached out to the practice, and I thought I would have more checkups, but they said they don't need to see me until my yearly exam. I reached out to a therapist as I felt like I was slipping into postpartum depression. The one that I am seeing is nonchalant and what she told me she was going to be doing she really hasn't. It is not helping me. I feel like I am just paying her just to talk and not productive talk online. My insurance gave me the referral. I am going to have to seek out one on my own. Their recommendations are not the best. That is the problem anything that is easily accessible is not. Everyone that says they are a postpartum therapist, but nothing is directed towards postpartum. Nothing specific to Postpartum. I feel alone.

Kerry shared: I was so depressed and not thinking that I wanted another child, and my aunt talked to me, and she was like, "I'm young, I'm still 50 something years old. And our grandmother never gave away none of us, or she ever had an abortion. And we got 10 of us." And she was like, if you don't want the baby, I will take her. I will take her." And I was like, "It's good to have the backup if I need it." Because I wasn't attached to the baby until after the baby was born. That's how bad my depression was. I did not attach to myself to the baby because I had other young ones running after. I'm just starting to get out with them.

Mary stated: Oh, yeah. I had anxiety and a little bit of depression, just sad about not being able to be at home. I didn't think my pregnancy was going to go the way that it went, so I ended up being in the hospital for a long time. I think if they would provide mental health services or at least some case management to try to help when the expecting moms are going through different mental health issues or when they're afraid, so that they can help them calm down. That way they can get their questions answered because if I knew what was going on with me, then I probably wouldn't feel so sad or scared, so just having that support…

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Wendy stated: I actually switched practices in my 36th week, because like I said, it was well into my pregnancy that I was experiencing the anxiety and the stress and everything. I did not want that on me so close to giving birth. I felt unsafe and uncomfortable with the response that I got from them. That's why I made the decision to switch practices.
Beth stated: I was in denial when I was going through a major depression. Like I didn't need help, and I was not crying out for help, and I really did need help. I want them to recognize when they really need help and don't be afraid to open up to someone. Everybody needs somebody to talk to or lean on—you know, different people that they can trust.
Nancy stated: Don't jump to the next person, allow each person to tell you the background. This holistic care is not just about what the person is coming in with as a pregnant person, but what other aspects is being affected with this pregnancy, also. So, I feel like it should be a holistic approach. Mental and physical… whole-body care to be the forefront, not just the pregnancy, and not just the baby, what else is affecting them in this current state.

Culturally Sensitive
Nancy recommended: The biggest barrier's language and culture barriers. If there's a way for that to be penetrated and said to open doors for the cultural groups that are there, even for me as a Haitian. The first time I became pregnant, I had my own barriers like what to expect compared to what my parents used to do and what American does. And to take that into consideration, I feel that should be another thing to put into resource, like what this culture does after the delivery. We [Haitian] specifically listen differently, and I had to talk to friends: Okay, this is what we do in our culture. Just being able to talk about those differences. A mom should be able to ask your doctor or midwife those kinds of questions.

Racial Representation
Deja shared: I was typically looking for someone that looks like me. You know? And it's really hard to find that. I was looking for an African American OB, and it was just mission impossible in this area. They have all these like parenting classes and all, but they really don't have any geared towards different races, we eat different things, our bodies are different, just having more of that stuff. Even if it's only in pictures and books you know, just having more representation.
Fiona shared: I made it a point to have female doctors of color except my OB, and I brought that up as the mortality rate of woman of color is high. I did a lot of extensive research with the practice I went to.

Wendy stated: In the beginning of my pregnancy, I had started at one office and all of the staff were White. There was no other ethnicity or anything else on the staff. I never really felt connected, because I felt like they just kind of want to get you in and out. I feel like it impacted my experience, because I couldn't really talk to them about things that I was dealing with. For example, perinatal anxiety and depression. They basically told me that as long as my baby's okay, that I'm okay. I feel like if I wasn't who I am and I was maybe a different race, things would've been looked at a bit differently.

Discussion

Environment

As described previously, the first major theme was the prenatal and postpartum environment that the participants experienced. This was characterized by a lack of options, racial disparities, and feeling dismissed. To address these issues, a scoping review suggested that it would be beneficial to examine more deeply how denying racism in health care leads to reproducing racism (Hamed et al., 2022). Although racial disparities play a major role in the care that Black women receive, health care staff have difficulty discussing and accepting racism as part of health care interactions (Hamed et al., 2022). Health care as a system may not be overtly racist, but microaggressions and implicit biases may lead to poor treatment and adverse outcomes. Recently, a tool was developed to report racism in maternal health for the CDC Maternal Mortality Review Information Application (MMRIA), which may assist in addressing structural racism in maternal health (Hardeman et al., 2022). Another recent qualitative study examined Black mothers' (*N* = 20) perspectives of racism in the NICU (Witt et al., 2022). Like our study, mothers recommended increasing Black representation and improving education to providers on the impact of structural, institutional, and interpersonal racism in the NICU. Our study shows that even though these women did not experience overt and active discrimination, their encounters were filled with implicit biases. As one of the women mentioned, "There was a difference in the way people that looked like me were treated" during her perinatal care visits. Similarly, the inability to obtain an appointment at 25 weeks because of one's race compared to a White friend or receiving better care when accompanied by a White partner demonstrates a few examples of these biases.

Many health care organizations have individual-level antiracism trainings, but these have not demonstrated effectiveness decreasing racial bias (Hassen et al., 2021). Another recent scoping review suggested that organizations should avoid individual-level training and shift focus to

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practices that can dismantle racism at multiple levels as well as increase representation within the health care system (Hassen et al., 2021). Similarly, a major recommendation made by the women in our study was to increase racially diverse representation; as expressed by one mother, “There was no other ethnicity or anything else on the staff.” Many of the participants wanted providers who looked like them to have trust and believe that their providers would understand their culture and how it impacts them during pregnancy. However, they explained that finding an obstetrician who was Black or even a woman of color was difficult; and women whose provider was racially incongruent reported feeling unable to voice their concerns or connect with their providers. Increasing racial representation in health care, not only with providers but also with nurses, health care social workers, and clinic staff, may allow these women to feel more comfortable at their perinatal visits.

Health Literacy

Health literacy emerged as the second major theme. Health literacy is defined as the “cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (NUTBEAM, 2000). Increasing health literacy is a strategy to improve asking for help, self-advocating, and communicating concerns to maternal health providers. However, health literacy is not easily attained if patients are not given just and quality care. When providers fail to give patients sufficient education, it can lead to incomplete or inappropriate management of care, as patients are not informed about preventive measures for high-risk conditions. Issues with the current health care system, such as lack of communication and incomplete or inappropriate management of care, are among the most preventable factors affecting maternal death and morbidity rates in minorities (Howell & Ahmed, 2019; Howell & Zeitlin, 2017; Howell et al., 2016).

In our study, it was demonstrated how important health literacy is, As one woman shared:

> We need to have more education concerning how pregnancy differs for African American women and other women because it seems like our pregnancies are usually with us having high blood pressure, and it comes down to, well, why do all of these Black women have high blood pressure? What’s attributing to it?

Education needs to be a top priority during patient encounters throughout pregnancy to possibly resolve the issues surrounding maternal death and

morbidity rates in minorities. It is important that this is fostered through effective and safe communication. Black women have unique wants and needs regarding communication with their providers to establish trust and mutual respect due to many social determinants of health that affect them (Altman et al., 2019). Providers are obligated to prioritize the experiences of those affected by health disparities to ensure better health outcomes. Consequently, poor communication in the patient-provider relationship ultimately can be detrimental to the overall health of the patient (Altman et al., 2020). Therefore, missing opportunities to educate—or clarify patient understanding of education—can lead to managing a condition rather than preventing it. In Black populations, provider and system failures account for a significant percentage of maternal deaths and near misses, which is indicative of missed opportunities for prevention and screening through comprehensive education (Howell & Zeitlin, 2017). Health literacy is an important component in a patient's ability to attain wellness and better health outcomes; however, it is influenced by the patient–provider relationship and therefore requires mutual respect, trust, open communication, continuity of care, and moments of clarification between the provider and patient.

Addressing Maternal Mental Health

Many of the mothers in the present study shared that the lack of mental health treatment and support was a significant area of difficulty, with mental health concerns such as depression, anxiety, and general distress being raised by almost every participant. Consistently, participants felt that their mental health suffered and that their concerns in this area were left unaddressed. "I was in denial when I was going through a major depression, like I didn't need help, and I was not crying out for help, and I really did need help." Research has shown that Black women are twice as likely to experience perinatal mood and anxiety disorders (Howell et al., 2005), yet are less likely to receive adequate screening and treatment (Kozhimannil et al., 2011). Although a definitive causal factor for this has not yet been determined, the disparities remain, even when controlling for factors such as history of depression, socioeconomic status, and level of education. This suggests that potential root causes for heightened levels of perinatal mood and anxiety disorders among Black women are inequities and structural determinants of health (Crear-Perry et al., 2021), such as systemic racism, implicit bias, pressure to embody the "Strong Black Woman" trope, and reluctance to disclose mental health symptoms for fear of having one's baby taken away.

Given the concern about postpartum and mental health issues for

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Black women, a recent qualitative study of 10 Black perinatal mental health stakeholders demonstrated five key pathways to expand access to antiracist maternal mental health care: a) educating and training practitioners, b) investing in Black women-led community-based organizations, c) valuing, honoring, and investing in community and traditional healing practices, d) promoting integrated care and shared decision making, and e) investing in the Black women mental health workforce (Matthews et al., 2021). In December 2022, the U.S. Congress passed the TRIUMPH for New Moms Act, which calls for creating a national maternal mental health task force and a national strategy to address the maternal mental health crisis (Maternal Mental Health Leadership Alliance, 2023). Our CBPR study similarly found that Black mothers desire to improve mental health access by especially honoring traditional and holistic healing practice and increasing the Black women mental health workforce.

It is important to assess mental health symptomatology during pregnancy because of the significant impact of maternal mental health on the biological and psychological health of the developing fetus (Aktar et al., 2019; Orr et al., 2002) as well as on the general quality of life of the mother. Postpartum depression is the most common complication of childbirth, with rates twice as high as gestational diabetes and preeclampsia (Wisner et al., 2013). Therefore, it is imperative that women receive frequent mental health screenings during pregnancy and in the first year postpartum. Given that Black women are at a higher risk for experiencing postpartum mental distress (Howell et al., 2005), psychiatric screenings should be incorporated in perinatal care at a more frequent rate for Black mothers so that treatment can be initiated expeditiously.

Toolkit

A web-based toolkit was developed from the results of the study to improve maternal health for Black mothers (https://maternalresources.weebly.com/). The CAB met several times to discuss themes and agree on the deliverables. The CAB included one of the interviewed participants. It was collaboratively decided that the toolkit would include examples of how to communicate to health care providers to promote self-advocacy. One example addresses how to speak up for oneself to a health professional, such as “My provider didn’t allow me to ask questions.” A suggested response is, “I understand I am the patient, and you are the professional, but it is important for me to get my questions answered.” The toolkit also includes exemplars for providers on how to communicate to Black women to decrease health disparities. For example, if a patient says, “I feel like you are treating me poorly because of my racial identity,” a provider may

respond by stating, “I am sorry if I have offended you, it was not my intention to do so. I can’t imagine how it must feel to feel disregarded due to your race. Maybe you can educate me, so I don’t make the same mistake again.”

The final section of the toolkit is for fathers and other support persons on how to provide emotional support. A section on how to advocate for mothers during pregnancy is included. As previously mentioned, the prevalence of gestational hypertension, gestational diabetes, and mental health for Black women during pregnancy is a valid concern. Therefore, it is imperative that fathers are prepared to offer reinforcement with follow-up questions. Mothers are ultimately empowered when fathers are provided educational information and resources on how to monitor and track a mother’s numbers and how to support her at provider visits with the information gathered. Resources and suggestions for self-care, such as journaling and mommy support groups, are also provided in the web-based toolkit.

Limitations

The study participants represented three Florida counties: Palm Beach, Gadsden, and Hillsborough. Further representation from other counties and an increased sample size would have been beneficial. However, the findings are credible and trustworthy, and the toolkit was circulated to the FLMMH, March of Dimes, and community partners from one rural county and two urban counties in Florida.

Conclusions

The purpose of this community-based participatory research (CBPR) was to develop and implement a toolkit that would increase knowledge and empower pregnant Black women in medically underserved counties in Florida to self-advocate for better maternal health care. These results suggest that interventions aimed at deepening obstetrical providers’ knowledge base of perinatal mental health risk factors, screening tools, and treatment options may help to optimize the care that Black mothers receive. By equipping obstetrical providers and mental health clinicians with tools to screen and adequately treat perinatal mental health issues, appropriate action can be taken to begin closing this gap while easing the burden of responsibility for mothers. Feeling dismissed because of one’s race was a common theme woven through the participants’ responses. Perhaps the most vital intervention providers can make is to listen to Black women and take their concerns seriously.

This CBPR study demonstrated the impact of intersectionality on maternal health, especially the intersection of race, class, and gender. The distinctive social inequalities experienced by many of the participants, such

as the difficulty of accessing prenatal care and mental health services, often led to a delay in prenatal care. As a result of these experiences, many women felt devalued, especially if they had public insurance. A lack of trust in providers made it difficult for the participants to ask for help. Despite the environment described with the lack of options, racial disparities, and feeling dismissed, the women provided strategies by increasing health literacy. As a result, a web-based toolkit was informed by these mothers to promote self-advocacy and health literacy.

Policy Implications and Next Steps

The study highlights the critical need for policies aimed at dismantling racism at multiple levels as well as increasing representation for Black mothers within the health care system. Given that almost all participants shared unaddressed mental health concerns, it is important to develop policies offering and improving access to mental health treatment and support. This should include education during patient encounters throughout pregnancy to possibly resolve the issues surrounding maternal death and morbidity rates in minorities. Moreover, there is a significant need indicated for health practitioners to gain understanding about specific concerns and needs Black pregnant women experience. Policy geared toward enhancing education focused on this would be beneficial.

In addition to such policy potential, the toolkit could be distributed to Healthy Start Coalitions statewide, home visiting programs, and community resource agencies that work with families. Further research could explore the impact of the toolkit for Black mothers, providers, and partners to support the reduction of health care disparities for Black mothers.

Declaration of Interest Statement

The authors report there are no competing interests to declare.

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