WOMEN'S HEALTH

"I just want us to be heard": A qualitative study of perinatal experiences among women of color

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Abstract

Objectives: Long-standing racial disparities, particularly between White and Black women, in maternal and birth outcomes necessitate an examination of the factors influencing these disparities. This study aimed to understand the experiences of women of color as they relate to pregnancy and/or birth complications to inform policy and strategy to decrease racial and ethnic health disparities.

Methods: Six focus groups were conducted with women (*n* = 31) who were identified as a woman of color, were 18 years or older, self-identified as having experienced pregnancy or birth complications after 2016, and who spoke English. A focus group guide co-created with the research team, community partners, and peer researchers from the local community was utilized to elicit discussions related to barriers, successes, and existing opportunities to provide equitable care and services to families throughout the perinatal period. An inductive and iterative approach to qualitative analyses of the focus group transcripts was used to identify key themes.

Results: The seven themes identified include: lack of knowledge, mental health, communication with providers, support systems, representation, social determinants of health, and discrimination and stigma. Women shared a variety of experiences related to their health care from before pregnancy into their post-partum period, revealing many areas for improvement to extant systems.

Conclusion: The inclusion of voices of the populations most deeply affected by health disparities is crucial to understanding how care and services provided can be improved. This analysis suggests the need for change at multiple levels of the health care and social services systems. These experiences provide valuable insight into some of the many struggles and barriers that women of color face during pregnancy and beyond.

Introduction

Women of color, particularly Black women, disproportionately experience poor birth outcomes and maternal morbidity and mortality. In one of the earliest recorded maternal mortality disparity ratios, dating back to 1915, Black women were 1.8 times more likely to experience mortality after pregnancy than their White peers.[1] This disparity in maternal mortality rates has persisted for over

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100 years with Black women experiencing more than twice the maternal deaths of their White counterparts in 2019.[2] Similar disparities are documented in rates of infant mortality. The US infant mortality rate (IMR) for non-Hispanic Whites was 4.6 deaths per 1000 live births compared with 10.8 among non-Hispanic Blacks in 2018. At the state and local levels, the disparities in IMRs widely vary. Franklin County, Ohio, for example, is the most populous county in Ohio and largely comprises the city of Columbus. Over 18,000 live births occur on average each year in Franklin County and women of color account for 43% of these births.[3] In a state with one of the highest Black IMR in the country, Black infants born in Franklin County, Ohio experienced a mortality rate of 11.7 deaths per 1000 births, compared with just 4.3 deaths per 1000 births in White infants in 2020.[4]

The large and sustained inequities in infant and maternal mortality rates suggest the need for further investigation into the root causes and potential solutions for reducing adverse birth outcomes, especially for Black women and infants. Previous research suggest a multitude of factors including racism,[5–8] chronic stress throughout the life course,[6,9,10] maternal co-morbidities,[5,11] maternal health behaviors, socioeconomic factors, and access to and quality of health care as causes of inequities in maternal and infant health outcomes.[5,12] Yet, knowing these associations have not yielded substantial improvement. Historically, policy and interventions to address these inequities have been driven by quantitative research. However, qualitative research provides additional context that can lead to actionable steps to improving health outcomes. Qualitative research, for example, documents that women of color often experience negative interactions within the health care system such as their concerns being ignored, feeling disrespected, and not being a part of decisions being made regarding their health.[13–17] These findings highlight the need to center the experiences of those impacted, leaning on their expertise in what is needed to improve outcomes.

The objective of this study was to understand the experiences of women of color as they relate to pregnancy and/or birth complications to inform policy and strategy to decrease racial and ethnic health disparities as part of CelebrateOne's strategic plan. CelebrateOne is a public-private partnership that serves as the backbone of a countywide collective impact process focused on decreasing infant mortality and improving maternal and child health outcomes in Franklin County, Ohio. Through the conduct of collaborative, community-engaged research methodologies, this study has the capacity to elevate the voices of traditionally marginalized groups and help ensure that research informing policy and practice affords a seat at the table to those most deeply affected by the study topic. In this way, we can create an evidence-informed approach to intervention that is rooted in personal experience.

Throughout this article, we use the terms such as woman, women, and mother to describe people who can or could become pregnant during their lifespan. We acknowledge that some pregnant and/or birthing people do not identify with these terms. However, we use these terms here to reflect the language used by peer researchers and our study participants. Our findings are not meant to be exclusive to individuals who identify as female.

Methods

Study design

This study was a collaboration including an academic medical center-based research team, a maternal and infant health agency (CelebrateOne), a community-centered design organization (Design Impact), and peer researchers from the local community. To inform its strategic planning process, CelebrateOne engaged researchers and experts in community collaboration to engage women in the community in understanding the lived experiences of women of color. Design Impact is a nonprofit organization that works with groups to use community-centered design to create systems change. The peer researchers were women of color from the community with lived experiences of pregnancy and/or birth complications, like the study participants. Peer researchers completed facilitation and human subjects research trainings, co-created the focus group guide with assistance from the collaborative team, and facilitated the focus groups. Peer researchers completed human subjects training and an orientation to qualitative research and were compensated for their work as part of the research team.

Recruitment and data collection

Women were eligible to participate if they: (1) identified as a woman of color, (2) were 18 years of age or older, (3) self-identified as having experienced pregnancy or birth complications or capable of sharing knowledge of a close friend/family member who experienced pregnancy or birth complications after 2016, (4) resided in Franklin County at the time of pregnancy and/or birth of their child, and (5) were able to speak and understand English. Inclusion was limited to women with these pregnancy/birthing experiences after 2016 to capture the timeframe since CelebrateOne's most recent strategic plan.

Recruitment for the focus group was led by CelebrateOne and the peer researchers using convenience sampling methods. Recruitment fliers were distributed throughout their network of other organizations that aim to improve health among women and infants. In addition, peer researchers were asked to share the fliers with their personal networks. Potential participants self-identified and were directed to complete an eligibility survey online, which prompted the study team to contact and complete the verbal informed

consent process over the phone. Due to the virtual nature of this study while continuing to navigate research during the COVID-19 pandemic, verbal consent was proposed and approved by the Institutional Review Board.

Peer researchers facilitated six virtual focus groups between June and August 2021 with 3–8 women in each group (*n*=31). Only peer researchers, members of the research team and participants were present during the focus groups. Each focus group lasted approximately 90 min and used a facilitation guide that aimed to elicit information related to barriers, successes, and existing opportunities to provide equitable care and services to families during pregnancy, labor and delivery, and post-partum timeframes. Participants received a $50 gift card for their time. The scheduling of focus groups was concluded when the research team, inclusive of the peer researchers, felt that saturation had been reached. The focus groups were recorded, transcribed verbatim, de-identified, and reviewed by the research team for accuracy. The Nationwide Children's Hospital Institutional Review Board approved all study activities (STUDY00001668).

Analysis

An inductive and iterative approach to coding was utilized. The first author (K.B.) created an initial codebook based on a first coding of one transcript, and second author (A.B.) used this codebook as a guide for coding the same transcript. In addition, other codes that may not have been included in the first author's codebook were added. After coding the first transcript, the authors met to revise the codebook, ensuring agreement of codes and consolidation of those that seemed to be used in the same way. Upon finalization of the codebook, each author coded the remaining transcripts and met again to discuss. After consensus on coding, a thematic analytical approach was used to organize the codes into themes that were derived from the data.[18] Finally, themes were organized into interrelated concepts that represent the different levels of interventions (i.e., individual, interpersonal, and macro levels) required to address the identified themes.

Description of researchers' background

The focus groups were facilitated by one of the five peer researchers who were all women of color from the community with lived experiences of pregnancy and/or birth complications. A.B, a White female senior research associate, and T.M., a Black female medical student, assisted the peer researchers in the focus groups and took field notes. Two of the authors (K.B. and A.B) coded the data. K.B is a Black female research scientist. Other members of the team include two Black females (D.C., who is a faculty member in pediatrics and public health, and M.S., who is the executive director of CelebrateOne) and one White female (C.S., who is the senior director of infant and child

wellness at the academic medical center) who provided input on the design and analyses of this study. All of the authors focus their efforts on improving health equity for families through community programming or research that can be translated into actionable steps to improve health outcomes.

Results

Participants

Thirty-one women, age 25–45, participated in the six focus groups. A total of 58% of the women had attended at least some college, and approximately 65% of the women utilized public health insurance at the time of their pregnancy. These and other characteristics of the focus group participants are described in Table 1.

Findings

Seven themes were identified from the focus group discussions (Table 2). Themes describe the experiences of women of color at the individual, interpersonal, and macro level.

Lack of knowledge. A lack of knowledge in terms of knowing what to expect during pregnancy and delivery was a common theme in the focus groups. This was most often voiced among first-time moms and/or when participants described their first pregnancy. Participants reported that no one had explained the changes they would experience both physically and emotionally during and after their pregnancy. Often, this left participants feeling scared and unprepared. One participant said:

> I had my first child at the age of 30. [I] was scared, didn't know what to do at all. . . Being a first-time mom is, it's really scary and it's life-changing. – (Focus Group #4)

Participants also shared that, as new moms, they were not aware of the various services or birthing options available to them.

> Prior to my first pregnancy, I did utilize hospital tours and things of that nature, but ya know, I wasn't knowledgeable in the doulas. I didn't know that I had choices on whether or not I wanted to do water birth, home birth, or that I didn't have to lay in some position to have a baby or things of that nature – (Focus Group #1)

Participants who experienced more than one pregnancy, however, shared that their previous experiences helped them better navigate their most recent pregnancy. They felt more knowledgeable about services available to them, what questions to ask during prenatal visits, and what to expect overall during pregnancy and delivery. For example, one participant discussed her experience immediately after delivery and feeling tired. She shared that with her

Table 1. Focus group participants demographics.

Variable	%	Variable	%
Age (*n* = 31)		Household income (*n* = 29)	
18–24	29%	Less than $25,000	48%
25–31	35%	$25,000–$49,000	21%
32–38	23%	$50,000–$74,999	21%
39–45	13%	$75,000–$99,999	3%
		$100,000–$149,999	7%
Race and ethnicity (*n* = 31)			
Non-Hispanic Black or African American	81%	Health insurance (*n* = 31)	
Hispanic, Latinx, or Spanish	6%	Medicaid or Medicare	65%
Two or more races or ethnicities	13%	Private Insurance	29%
		No public or private insurance	6%
Highest level of education (*n* = 31)			
Less than grade 12	10%	Number of pregnancies (*n* = 30)	
Grade 12 or GED (high school graduate)	19%	1	20%
Some college, Associate's degree, or technical school	48%	2	30%
4-year college graduate or advanced degree	10%	3	10%
		4	27%
Marital Status (*n* = 31)		5 or more	13%
Single, never married	48%		
Member of an unmarried or partnered couple	23%	Number of live births (*n* = 30)	
Married	19%	0	13%
Divorced or Separated	10%	1	30%
		2	30%
Employment status (*n* = 29)		3	23%
Employed for wages (part-time or full-time)	55%	4	3%
Out of work for less than 1 year	21%		
Out of work for 1 year or more	10%		
Homemaker	7%		
Self-employed	3%		
Student	3%		

previous births, she did not know she had the option to have her newborn taken to the nursery to allow her to rest. However, with her third child, she was aware of this option and felt prepared:

> [W]ith my third, I knew better, and I was like "uh, yeah, can you guys just keep the baby in the nursery?" 'Cause I was tired that I didn't even have the energy to even really bond with the baby because I was so tired all the time. . . My first and second one, I felt guilty. Like, are they gonna think I'm a bad mom because I keep asking them to take my baby to the nursery? But, on baby 3, I was like, "uh uh, can you come get him?," ya know. So I'm definitely prepared for this one." – (Focus Group #6)

Communicating with providers. Many participants brought up issues of lacking communication with the clinicians providing their care during pregnancy, labor and delivery, and post-partum periods. Experiences of being ignored, lack of empathy displayed by doctors or nurses, instances of negativity, and the need for self-advocacy were frequently mentioned by participants.

The most common experience of participants is best described as not being heard. This depicts a variety of

instances in which women voiced a concern or a particular desire related to their care but were ignored or dismissed by providers.

> . . .And even though I had called my doctor and said, "Hey, something's not right. You know, I don't feel right." They equated it to round ligament pains. And because I had never been pregnant, I didn't know how to express what I was feeling, I guess, appropriately enough for them to understand that something was more serious than what round ligament pains were because I have had round ligament pains. And they say, "oh, it feels like a rubber band." So, I said, "Well, no, that's not what I'm trying to say." But I couldn't ever convey. . . – (Focus Group #5)

Dismissing concerns and requests from women during their care often resulted in a greater need for women to practice self-advocacy. Women who experienced multiple pregnancies often felt more empowered and could better voice their concerns and demands for the care they required. One participant described needing the provider to acknowledge that she knows her body and how she advocated for herself:

Table 2. Themes and related codes.

Theoretical level	Theme	Codes
Individual	Lack of knowledge	
Interpersonal	Communicating with providers	Not being heard
		Self-advocacy
		Negative communication
		Lack of empathy from providers
	Support systems	Programs and services
		Support from family members, partners, and others (peers, etc.)
		Not receiving support from providers
	Representation	
Macro	Mental health	Post-partum depression
		Trauma/stress
	Social determinants of health	Maternity leave
		Insurance
		Employment
		Childcare
		Systemic barriers
	Discrimination and stigma	Racial discrimination
		Gender discrimination
		Age discrimination
		Stigma based on marital status

. . . I had my first one at 27 and I'm having my third one at 34, so at this point, if I tell you, as a provider, that something is uncomfortable for me, or I don't feel as though I need this medication because a lot of the times you can tell a provider that you're nauseous. They'll try to write you up something real quick, and it's like, you know what, what else can I do that's just a bit more, ya know, safe for me, rather than me having to take a medication. I don't wanna take so many medications. So, I let them know, as far as I know my body as well. Like, I get that you people are degree-having individuals and all that, that's fine. I've been in my body for almost 35 years at this point, so if you can work with me as far as what I know I know, and what you think you know, then I think we can get on a level playing field. – (Focus Group #4)

The importance of communication between providers and their patients was emphasized by most participants, but it was clear that there were experiences of both positive and negative communication. Women appreciated when their providers were forthcoming with information and when providers listened to their concerns. However, some instances of communication during rushed visits were understandably viewed as negative:

I think the doctors don't really have time with their patients. Sometimes you have something to tell them, they are really quick, to like, okay, just do this and go. They don't really take time to communicate with their patients so that you can be free to let them know what's going on. – (Focus Group #2)

The ability of providers to form a trusting relationship with their patients seemed especially important to women but was lacking from many of the participants' experiences.

Women expected that providers would spend time listening to them and be able to acknowledge when they had gone through a difficult pregnancy or labor and delivery. One woman describes a lack of connection with her provider and even feeling disrespected during her labor and delivery:

. . .I was in labor and then I felt even more violated because they gave me a pill to induce my labor even more, and then after that, there were students in the room while I was delivering. Laughing in the background, smiling while I was in the process of delivering this baby, and once the doctor delivered the baby it was just like "I'm done, bye." Don't even know his name, don't remember him. – (Focus Group #1)

Support systems. Women discussed several types of support they received before, during, and after their pregnancies, while also noting where they often lacked support. Support came in the form of programs and services offered in the community, but also from family members, partners, or peers who provided assistance and emotional support when women needed it most.

Several organizations in the community, including CelebrateOne, were noted frequently as having provided support and additional connections to resources that women may not have otherwise known were available to them. Help Me Grow, which provides home visiting and early intervention services, was a program noted as highly supportive and helpful for numerous participants.

Help Me Grow, the lady, me and her have developed a relationship to where I feel like I can tell her anything. – (Focus Group #3)

Participants often mentioned instances of having family members nearby that offered tangible and emotional support during and after pregnancy. There were also instances of women who noted not having support from their family, and instead receiving support from their partner or their partner's family.

One mother reported having physical support from her mother when she experienced childbirth at a younger age:

So, when I had my first one, like I said I was young, I was still with my mom. So, she pretty much did everything for me, so I was blessed for that, that I didn't really have to wake up in the middle of the night because she was doing everything 'cause she knew I just had a c section, so I really was in a lot of pain and couldn't really do too much. – (Focus Group #6)

There were multiple participants who shared experiences of not being supported by their provider or nursing staff. Health care staff were typically described as not providing information to women or leaving women alone when they needed attention. One mom describes trying to tell providers that she was getting close to delivery and being dismissed:

. . . Y'all aren't listening to me. I know that you can't experience it. I don't know what you're seeing, but she is coming right now." And so, the stir-ups were not down, there was no medical staff in the room. . .there was like, um, a. . . the bed that they have for the NICU in there already because they knew that I was in pre-term labor, so they did have that, but there was no staff there. – (Focus Group #5)

Representation. Across focus groups, participants shared their desire to have health care providers who looked like them. Many of the participants described specifically seeking out health providers who were Black and/or women of color.

Once I found out I was pregnant there was a big push for me to have a woman of color for my OB simply because of the medical racism like I want somebody that's for lack of better terms, familiar with my culture. . . and understanding of my body. – (Focus Group #3)

As participants shared their experiences interacting with health providers throughout their pregnancies and deliveries, many acknowledged when the provider was a person of color and how that positively shaped their experience. Having a provider who reflected their racial/gender identify made the participants feel more comfortable and as if their concerns were being heard. One participant described her experience of requesting that a particular Black nurse stay assigned to her during her hospital stay:

I wanted her and she knew I wanted her because she was Black and I was Black, and I'm like "I really want you to be there because I feel safer." I feel comfortable. Um. . .yeah, so

I want somebody that looks like me in the room when it's something that like life or death. – (Focus Group #1)

Mental health. Mental health was frequently mentioned throughout the focus groups. Participants discussed experiencing anxiety and/or depression, stressful events that impacted their mental health, and the need for mental health resources and services. Their mental health during different phases including pre-pregnancy, pregnancy, and post-partum was explored.

Several participants shared that they had anxiety and/or depression prior to becoming pregnant. This was concerning for them as they were unsure of the impact pregnancy would have on their mental health, especially when it required discontinuation of medication previously prescribed to them. In several cases, health providers warned participants that their mental health may worsen during pregnancy. Many participants reported working with their providers and receiving support from partners and/or family to manage how the pregnancy would impact their preexisting mental health conditions. However, other participants faced challenges throughout their pregnancy due to their mental health state. One participant, for example, shared how her depression during pregnancy impacted her ability to receive prenatal care:

With this pregnancy, I've been really more depressed than usual. . . I've been having trouble keeping up with appointments and stuff. . . It's just like a mental thing, I just didn't feel like it. Getting up and going to these appointments. That's the part that was hard. Trying to wind myself up to do what I need to do has been a problem. – (Focus Group #2)

Some participants also expressed that interactions with health care providers during their pregnancy negatively impacted their mental health. For example, after receiving a rare diagnosis for her son during her pregnancy and choosing not to terminate the pregnancy despite recommendations from her provider, one participant talked about the stress she experienced during subsequent prenatal visits:

It was super, super mentally and emotionally draining knowing every time you go to the doctor, they're going to say something negative. – (Focus Group #2)

Experiencing post-partum depression was common among participants. Several participants discussed the challenge of managing the demands of daily life and caring for their children and themselves while experiencing post-partum depression. This challenge was exacerbated when participants experienced complications after delivery.

It kinda messed with my mental a little bit. And, I would say that I know some people get postpartum and stuff, even just with a regular, without any infection. But I felt like it was ten

times worse because I had an infection on top of that. – (Focus Group #2)

The need for mental health resources and services was also identified among participants. This included screening and diagnosing women with post-partum depression and providing resources and support once women are diagnosed.

> I definitely had post-partum. I just wish there was a little more resources on post-partum. And I didn't even know I had it until I looked back I'm like: Oh wow. That's why I couldn't get out of bed. Or that's why I was so sad. Or that's why I cried constantly and that kind of thing. – (Focus Group #3)

Social determinants of health. Social determinants of health were repeatedly discussed throughout all focus groups, and it was clear women desire changes in the way that current systems and policies function.

Of particular concern to nearly every group was the topic of maternity leave, and the need for better policies around this benefit in the United States. Many women mentioned policies in other countries that give mothers the time off they needed to be with their newborns, with a general sentiment that the 6-8 weeks currently allotted is not enough.

> . . .My last one, it was like, I really wanted to be home more with her, and I couldn't. I wasn't able to because of my job. I wasn't going to have a job. They only was letting me off for 6 weeks, and I was high risk pregnancy,[so] already took a lot of my PTO time while I was pregnant. I didn't have no help on that end. But, I felt like if I would have been home more, longer when she was younger, it'll just make me feel way better. But, I had to rush and get back to work. – (Focus Group #1)

Employment was another concern for many women, primarily in conjunction with thinking about maternity leave and childcare options.

> . . .I wanna find a stay at home job so. . .the job I'm at now, I've been there for 9 years, and I was already having some issues with them. So, I had it in my calendar in January, I was gonna put my 2 weeks in, and then I found out I was pregnant. So, I was so happy I didn't put my 2 weeks in then. So, I kind of had to just stick it out and just swallow my pride and stay there, so now that the baby's coming, and I don't want to have to look for any type of daycare any time soon, I'm just gonna not go back after my maternity leave. – (Focus Group #6)

Insurance was often cited as a barrier to quality care for mothers and their children, with public insurance sometimes considered to be the cause of worse care for some mothers. In one instance, a mother shares that a change from private to public insurance resulted in differential treatment:

> . . .I was unfortunately laid off from my job in February so therefore my insurance changed, and I had to switch over to government insurance. His [the provider] entire attitude completely changed when I switched over to the [Medicaid Managed Care plan name redacted] insurance. Where my visits were him being 10-15 minutes in the room with me, they ended up being a minute, two minutes and he refused to answer any of my questions regarding my pregnancy. . . – (Focus Group #3)

Many of the issues frequently mentioned by mothers can be attributed to barriers created by systems and policies that are inequitable in their design. Numerous women mentioned that the income thresholds to qualify for certain benefits and programs make them ineligible, and that the process to apply for benefits such as WIC or Medicaid are often overly complicated. A mom of a son with special needs mentions the high cost of his nutritional needs and the struggle to afford everything without additional benefits:

> . . .I really wish I could get like assistance with food, and I don't, that's the only thing. . .I'm over the income, but they don't take into account of everything that I pay. Like. . .that was something that was kind of difficult. Is just because it's like, my son's milk is $700. So, to not even be able to have any type of benefits for him, like, I couldn't get [Medicaid Managed Care plan names redacted] or anything like that because I'm over income. So, what they did was, they put him because he was in the hospital so long, his insurance is in his name. So, I never have to show verification of my income or they would kick him right off, which I think is, it's a systematic problem, so that's not of course something that we could fix overnight. Um, but. . .it's very, it's a lot. . . – (Focus Group #2)

Discrimination and stigma. Experiences of discrimination and stigma were common among the participants. They shared stories of being discriminated against based on their race/ethnicity, gender, age, marital status, and insurance type. After learning she was pregnant, one participant recognized the need to do more research to combat the discrimination she anticipated facing:

> I just started looking into different things, because I knew that there was a stigma when it comes to Black women. – (Focus group #5)

The discrimination was multi-faceted and often occurred at the intersection of multiple identities. Participants conveyed experiences of discrimination because of a combination of their race, gender, age, and other identities.

> I think that being a young mom, and being a woman of color, I just did not, I did not feel valued or heard. I was concerned for my daughter's safety during my pregnancy – (Focus group #5)

Much of the discrimination participants shared occurred during visits with their health providers. This manifested as inequities in the care they received.

"I had a White friend that was pregnant with me. We went to the exact same doctor, exact same location. And when it came time for us to get ultrasounds, she got this really fancy ultrasound and I got a basic regular ultrasound. . . [T]o me it felt like she got extra care. Like she got extra time in there and all of that. Like she was always there longer than me, getting more checkups than me, you know. I think and like I said I was high risk so there's no reason why you're going to the doctor twice as much and quicker than I am." – (Focus group #3)

Stereotyping by health providers who made assumptions about insurance status based on race was also communicated. As previously mentioned, insurance type was a barrier that impacted the quality of care women received.

I really had never experienced anything so blatantly, just racist, and all these perceptions about who I was and. . .it was just not a pleasant experience at all. [I]t was unfortunate that once I had shared that I had private insurance. The experience changed, and I just felt, that was just, it just made me sick to my stomach that, it was just these assumptions and how they were treating me based on what they thought. And, even if those assumptions were true, that doesn't negate the fact that quality healthcare for myself and my child. . .it was just, when I tell you horrible and just everything that you can think of from the time that I walked in, no eye contact, rushing me. The questions that they asked, it was just, something I just hadn't experienced from my other provider where I lived previously – (Focus group #4)

Stigma related to being unmarried and pregnant was also discussed. Participants described being judged negatively by health providers because either they were single, or their partners were unable attend the doctor's appointment. One participant shared how she was encouraged to terminate the pregnancy because she was unmarried and how this stigma shaped how she viewed her pregnancy:

I've seen it with myself and I've seen it with others that, you know, there seems to be a stigma attached to it. And then with that stigma, it causes the woman to think we've done something wrong. – (Focus group #3)

Discussion

The racial inequities in maternal and infant health outcomes are long-standing. This analysis reflects the experiences of women of color across the perinatal period in a midwestern county. The identified themes are consistent with findings from previous research and provide direction for future interventions and strategies to improve maternal and child health outcomes. Themes can be discussed at three levels: the individual, interpersonal, and macro level.

Individual level

At the individual level, new or first-time moms frequently expressed not knowing what to expect. The lack of knowledge spanned several topics including knowing the ways their bodies would physically and mentally change during and after pregnancy, understanding the birthing process, and feeling prepared to care for a newborn. Participants explicitly stated that no one prepared them for what would happen and this resulted in fear and in some cases, anxiety. Future interventions for pregnant women of color, especially for first-time moms, should aim to close this knowledge gap by providing women with education regarding changes they may experience throughout the perinatal period and birthing options available to them. Some of the focus group participants from this study mentioned existing local programs that helped them prepare during their pregnancies. However, these programs were not widely known among participants and increased utilization would be beneficial.

Interpersonal level

Participants frequently discussed concerns regarding communicating with health care providers. The multi-faceted approach required for effective communication and trust-building between health care providers and their patients is often complicated by external factors. COVID-19 had a particularly detrimental effect on clinicians' abilities to form rapport with their patients given many of the guidelines put in place by clinics and hospitals to keep everyone safe. Moving typically in-person visits to virtual visits, while perhaps more convenient, may have resulted in less personal interactions. Outside of pandemic restrictions, clinic schedules that necessitate providers to stay on time with their appointments can cause difficulties when patients feel that they require more time than the provider is able to give during appointments. These factors should be acknowledged and considered when considering policy change and new recommendations.

This study is not the first to identify deficiencies in communication and a lack of connection between providers and women of color.[13–15] Findings from previous research document that women of color often feel disconnected from their health providers, feel unheard, and want to be included in the decision-making process with the provider.[14] Similar to what others have documented, participants attributed some of the communication issues to a lack of Black women in the health care workforce, suggesting the need to increase accessibility to medical education and training programs for women of color. According to the American Association of Medical Colleges in 2018, there were 45,488 Black physicians compared with 515,814 White physicians.[19] Of the 45,488 Black physicians, just 2,973 of these were women practicing obstetrics/gynecology, acknowledging that this does not include nurse practitioners or certified nurse midwives who may also deliver care. In the 2018–2019 academic year, 6.2% of medical school graduates were Black, again demonstrating the need to advocate

for increased racial diversity in the health care workforce.[19] Lightfoote et al.[20] suggest that racial concordance results in better health outcomes, and Shen et al.[21] suggest that it is associated with better communication.

Supportive connections outside of the health care system also benefit women during pregnancy, delivery, and in the post-partum period. Low social support during pregnancy has been associated with risk of depression, anxiety, and self-harm.[22] Identification of women who may not have social support outside of the health care system may lead to lower risks through provision of services or programs. Social support during the post-partum period has previously been found to be a strong protective factor against post-partum depression,[23] which aligns with comments from participants in the current study who found relief or comfort from friends or family after their child was born.

Macro level

Focus group participants discussed a range of issues at the macro level that call for policy changes at the state, local, or institutional level to improve maternal and child health outcomes. Mental health concerns were very common among participants. Nationally, one in eight women experience symptoms of post-partum depression and rates of post-partum depression are higher among women of color compared to White women.[24] It is also important to note that the rates of depression and anxiety that women experience, particularly women of color, are higher during pregnancy than post-partum.[25,26] Data from the Ohio Pregnancy Assessment Survey in 2020 showed that 9.7% of women reported experiencing post-partum depression compared with 20.7% of women who reported experiencing depression during their pregnancy.[27] This state-level data mirrors the experiences shared by participants of our focus groups and suggests the need for interventions that expand mental health outreach across the perinatal period. Despite the frequency of women experiencing depression and/or anxiety across the perinatal period, these concerns are not universally discussed with health providers. National data from the 2018 Pregnancy Risk Assessment Monitoring System documents that one in five women reported that a health provider did not ask them about experiencing depression during their prenatal visit. In addition, one in eight women report not being asked about depression during their post-partum visit.[24] As expressed by focus group participants, there is a need for more mental health services for women before, during and after their pregnancies. This also includes changes in institutional policies to improve mental health screenings during prenatal and post-partum visits.

In addition, many of the challenges participants faced center on policies related to employment such as maternity leave, the need for childcare, and health insurance status. Maternity leave was frequently discussed among participants. Women felt that they did not have the time they needed to bond with their infants and care for themselves before returning to work. Data from the Bureau of Labor Statistics documents that only 21% of US workers have access to paid family leave.[28] Given this, it is not surprising that 23% of employed women in the US report returning to work within 10 days of giving birth.[29] Policies that aim to expand access to paid leave for women is shown to improve health outcomes for both women and infants. A recent study in California, for example, showed an improvement in new mothers' mental health and overall child health after paid leave went into effect in the state in 2004.[30] In addition, a national survey of women who gave birth between 2011 and 2012 found that paid maternity leave significantly reduced the odds of re-hospitalization for moms and babies compared with women who took unpaid leave or no leave at all.[31]

Childcare was another barrier faced by participants that impacted employment opportunities and their ability to attend prenatal appointments. There is a need for federal, state, and local legislation that supports affordable and reliable high-quality childcare options for women. Most recently, the federal government has discussed improving access to affordable childcare through the Build Back Better Framework; however, this remains in debate with legislators. Beyond access to affordable childcare, families should have more support from health care systems that are willing to exercise flexibility when families do not have alternative care for their children during scheduled health care appointments. This is of particular interest during the COVID-19 pandemic when health care systems are limiting the number of people who can attend appointments with the patient.

Insurance was also a barrier for women. Particularly, participants discussed being discriminated against based on their insurance type. This is a common experience among women who receive Medicaid or other forms of public insurance. Previous qualitative studies of women of color also documented that those with public insurance felt that their insurance type contributed to the negative and differential treatment they received from health care providers.[14] In addition, a study found that women with public health insurance reported having less control over their maternity care experience compared with women with commercial insurance. This included having less choice of prenatal provider (adjusted odds ratio (AOR) 1.61 95%C.I. 1.20, 2.17), or being able to have a vaginal birth after cesarean (AOR 2.93 95%C.I. 1.49, 5.73). Furthermore, the study concluded that women with public insurance were less likely to be encouraged by staff to make their own decisions (AOR 0.63 95%C.I. 0.47, 0.85).[32] These findings reflect the narratives heard in the present study. Future interventions should aim to improve the care, specifically for women who receive public insurance and close the gap in quality of care based on insurance type.

In addition to insurance status, participants also experienced discrimination by health care providers because of their race, age, gender, and marital status. These experiences manifested in inequities in care they received and feeling unheard or ignored by health providers. Many of the participants also faced discrimination at the intersection of these identities, making it difficult to disentangle the root cause of the mistreatment they faced. However, these experiences are similar to those documented in previous studies.[14,16,33–35] Previous literature links exposure to racism and discrimination to poor maternal and infant outcomes.[36,37] Unfortunately, these experiences are common among women of color. While most of the discrimination shared in this study was in the context of the health care setting, it is important to acknowledge that these experiences happen outside of this environment, as well. For example, between 11.6% and 25.4% of women of color surveyed in Ohio reported feeling upset due to how they were treated because of their race in the 12 months before their baby was born.[27] Future research and interventions are needed to understand how women of color are coping with these experiences and find solutions that can mitigate the negative impact they have on health outcomes.

Limitations

It is relevant to note that a sample size of 31 women in 6 focus groups to describe the experiences of all women of color in the United States is limited, especially when these experiences occurred in the same Midwest County. However, many of the themes identified in this study mirror what was previously documented by others across the United States. The intention of this study was to identify shared experiences that could inform policy and practice in the delivery of care and services locally, rather than generalizing the results to all women of color. It is also of note that these groups were only inclusive of English-speaking participants, which limits the ability to understand the experience of women who have the added complexity of language barriers or stigmas associated with speaking another language. Due to available resources and timeline of the project, conducting groups in additional languages or utilizing translational services was not feasible. Additionally, the size of each group varied, and the authors acknowledge that some of the groups were smaller than what is preferred for a focus group. Each focus group planned initially had at least 6 participants confirmed, but there were some instances in which participants had last minute conflicts that they reported, and others that simply did not log in for the virtual focus group session. Cancelation of these particular sessions after some participants had already logged on was not advisable given the difficulty of scheduling, so a decision was made to hold these sessions, despite the smaller group size. The authors feel that these participants of the smaller groups still

engaged in discussion with one another and shared a collective experience, despite a lack in number. Self-selection for participation in the focus groups also suggests that women who participated may have been more likely to have negative experiences related to pregnancy, which could contribute to bias in our results. To minimize bias related to sharing only negative experiences, the focus group guide included questions that asked women to share what went well during this period, if anything. The authors also acknowledge that we all have unique lenses in which we view the data, which naturally may introduce additional bias into the coding and interpretation process. Using the consensus process described in the methods, we hope to have minimized individual level biases as much as possible.

Conclusion

The findings from this study are not unlike others that identify a system, which often creates disparities in maternal and child health outcomes. By elevating the voices of women with lived experiences, their desires for improvements in the health care system and local community are brought to the forefront, allowing for a more strongly informed set of recommendations. The narratives participants shared in this study, for example, informed the strategic plan that will guide the work of CelebrateOne as the backbone of the collective impact process to reduce infant mortality in the next 5 years and beyond. This project directly engaged community members in the design and implementation of focus groups for this study. The input from these peer researchers influenced what was asked and how it was asked. We feel strongly that the quality and authenticity of our data were positively impacted by this study approach. This study approach serves as a model of a collaborative approach to improving health outcomes and reducing disparities by involving the community to inform system and policy change.

Declarations

Author contribution(s)

Kierra S Barnett: Formal analysis; Writing—original draft; Writing—review & editing.

Ashley R Banks: Conceptualization; Formal analysis; Investigation; Methodology; Writing—original draft; Writing—review & editing.
Tiffany Morton: Investigation; Writing—original draft; Writing—review & editing.
Christine Sander: Conceptualization; Writing—review & editing.
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Supplemental material

Supplemental material for this article is available online.

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