



# A Community Collaborative for the Exploration of Local Factors Affecting Black Mothers' Experiences with Perinatal Care

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## Abstract

**Objectives** Black women face disparities in maternal morbidity and mortality when compared to White women. Multiple factors contribute to these disparities. This study examines the perspectives of Black women who have given birth in the last 5 years, to understand their pregnancy and birth experiences as a means of ascertaining factors that may be contributing to these disparities.

**Methods** The Consortium to End Black Maternal Mortality was established as a collaborative table of cross-sector stakeholders and Black mothers to effectively conduct community-based participatory research focused on Black maternal health. Between January and March 2020, Black mothers who had given birth in the last 5 years facilitated Listening Sessions (LS) with other Black mothers in Rochester, NY. Participants reported on details of their pregnancy and delivery, including interaction with providers, personal relationships and their individual experience. The qualitative data captured during these sessions were coded to draw out key themes which were validated with LS participants and the Consortium.

**Results** The key themes that emerged clustered into four groups, including: (1) Mother-Provider Communication; (2) Social Support; (3) Systemic factors and (4) Maternal Emotional & Mental Health. Mother-provider communication was the most salient factor affecting the maternal experience and was found to be influenced primarily by maternal health literacy and provider discriminatory attitudes and behaviors.

**Conclusions for Practice** As a result of the Listening Sessions conducted with Black women, we identified mother-provider communication as the most important factor influencing the maternal experience.

**Keywords** Black maternal experiences · Discrimination in perinatal health · Patient-provider communication in perinatal health · Black maternal mortality/morbidity · Racial disparities in maternal mortality/morbidity · Community based participatory research · Partnerships in health research

## Significance Statement

Racial disparities in pregnancy outcomes necessitate a better understanding of Black women's experiences during the perinatal period. Very little community-based research has

been conducted to elevate Black voices and thus inform solutions to this problem.

Our community-based participatory study identified mother-provider communication as a key factor affecting Black mothers' experiences with perinatal care. Maternal

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health literacy and racial discrimination in perinatal practices influenced interactions with providers. This study should guide further interventions to address racial disparities, specifically to improve patient-provider communication through maternal health literacy and provider training in implicit racial bias and cross-cultural communications skills.

## Introduction

Pregnancy-related mortality in the U.S. has more than doubled in the past 3 decades, from a rate of 7.2 deaths per 100,000 live births in 1987 to 17.2 deaths per 100,000 live births in 2015 (Wiltsey Stirman et al., 2019). Overall, there are approximately 700 maternal deaths per year in the U.S. and the number is rising. Striking racial disparities exist, with Black women dying at approximately three times the rate of whites (Petersen et al., 2019). For every woman who loses her life to pregnancy-related causes, many more suffer severe maternal morbidity (SMM), which are life-threatening conditions arising from complications of pregnancy or childbirth (Howell, 2018). These conditions may be considered “near misses” and can lead to maternal death or long-term health consequences (Howell, 2018). Like pregnancy-related mortality, rates of severe maternal morbidity have increased, with Black women at highest risk (Bornstein et al., 2020; Pathak, 2020). Black women suffer disproportionately from comorbid conditions and pregnancy complications, including hemorrhage, preeclampsia, asthma, cardiac events and infections (Bryant et al., 2005; Carroll et al., 2005; Howell, 2018; Rathore & McMahon, 2001).

Multiple factors contribute to these racial disparities in maternal outcomes (Howell, 2018; Petersen et al., 2019; Wiltsey Stirman et al., 2019). For example, pre-existing chronic conditions such as hypertension and diabetes, more common among Black women than white women, contribute to disparities in maternal mortality (Bornstein et al., 2020; Leonard et al., 2019; Petersen et al., 2019). Differences in chronic health outcomes do not fully explain the disparities in MM, since Hispanics have comparable rates of diabetes yet have lower pregnancy-related mortality ratio (PRMR) than Blacks (Petersen et al., 2019). Additionally, a national study of pregnancy complications found a similar prevalence of complications among Black and white women, but a significantly higher case-fatality rate among Black women (Petersen et al., 2019; Williams et al., 2019). Other causes include differences in access to care, quality of care and implicit bias (Bornstein et al., 2020; Pathak, 2020). Systemic factors contributing to disparities in MM may include structural racism, gaps in health insurance coverage, lack of coordinated health care, and social services, while community-level contributors include transportation for medical visits, inadequate housing, and unsafe neighborhoods,

among others (Lopez-Littleton & Sampson, 2020; Petersen et al., 2019).

Despite decades of research and a variety of interventions aimed to reduce rates of MM in general, and specifically for Black women (Smedley & Syme, 2001), racial disparities in SMM and MM persist and in some cases are widening (Crear-Perry et al., 2021; Hawkins et al., 2020). A well-established strategy for improving understanding of socio-economic disparities has been the full engagement and equitable participation of community stakeholders in research, intervention and policy development (Harrison et al., 2019; Ortiz et al., 2020). Community-based collaboratives that bring together diverse clinical and nonclinical leaders have recently gained a great deal of interest. Although they have formed in several states (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010; Ratzan & Parker, 2000), these collaboratives have not yet generated outcomes data related to SMM/MM (Ricklan et al., 2019). Researchers inside and outside of the maternity care field have identified a need for deeper examinations of Black women’s experiences with maternity care to inform local efforts towards reducing health inequities in maternal outcomes (Keefe et al., 2016; Lupattelli et al., 2014; Taheri et al., 2020).

In an effort to identify potential areas of research and intervention, our community-based and community-engaged project brought together researchers, clinicians, patients and community stakeholders to collaboratively examine disparities in Black maternal morbidity and mortality at the local level. In Monroe County, New York, especially in the greater metropolitan area of Rochester, racial disparities in SMM and MM mirror those of the nation, with Black women having up to three times the rates MM and twice the rates of SMM when compared with white women (New York State Department of Health, 2014). To supplement medical and epidemiological data on SMM and MM in the region, our newly established collaborative sought better to understand birthing experiences of Black women in order to inform future directions for research and interventions.

## Study Objectives

We used a community-based participatory research (CBPR) approach to identify local factors associated with Black SMM/MM (Collins et al., 2018). CBPR principles call for equitable engagement and participation of all stakeholders in all stages of research. Our project aimed to establish a community consortium charged with the development of a research agenda to address racial inequities leading to SMM/MM in the greater Rochester area. The Consortium developed and implemented an initial qualitative inquiry to identify and to prioritize factors affecting Black mothers’ experiences with maternity care. In this study, the term “Black

mothers” refers to persons who self-identify as female, African American, and/or of African or Caribbean descent, and have had a child or been pregnant.

## Methods

### Building a Consortium

We built the Consortium to End Black Maternal Mortality through the existing Healthy Baby Network (HBN) and Rochester-Monroe Anti-Poverty Initiative networks. The Consortium included stakeholders across many sectors in Monroe County, NY, the University of Rochester (UR), and local Black mothers who had given birth in the last 5 years and were available to be effective contributors to the Patient-Centered Outcomes Research Institute (PCORI) research agenda of addressing SMM/MM. The core leadership team included researchers, project leaders, community-based organization leadership, and an Appreciative Inquiry expert to provide training in communication strategies. Members used their personal networks to recruit additional consortium members representing various stakeholders. We invited Black mothers in the community to join the consortium using their personal and/or organization social media accounts, and distributing hard copies of explanatory materials at various community events and sites. Mothers who joined the consortium were compensated \$15 per hour and provided with meals, childcare, and transportation. Consortium included 21 actively engaged members of multiple gender, ethnic and racial identifications, including eleven Black women, seven of whom are mothers. We considered having multiple community-based groups involved in this project as essential in creating a dynamic consortium consisting of individuals with diverse educational and career backgrounds.

To identify local factors contributing to disproportionately high rates of maternal morbidity among Black mothers, we utilized a community engaged, CBPR approach. This methodology allowed for researchers, clinicians and members of the community to establish strong bonds and equally participate in all aspects of the process. Involving community members in vital aspects of the project ensured that the goals and objectives of the project aligned with those of the surrounding community.

Consortium leaders established communication protocols for record keeping, member input, and reporting. Consortium meetings highlighted the importance of open dialogue and utilized regular feedback surveys to gauge effectiveness of the meetings. To build equitable collaboration through respectful and authentic dialogue, members underwent training in PCORI principles of Transparency, Honesty and Trust, Reciprocal Relationships, Implicit

Bias, Co-Learning, and Partnership; Effective Cross-sector Communication; Appreciative Inquiry; Racial Implicit Bias; and the Basics of Maternal Mortality (PCORI Engagement Rubric, 2014). We intended to equip members to become effective partners and contributors to identify local factors contributing to SMM/MM, explore testable interventions and create a research agenda.

### Listening Sessions

The Consortium leadership, comprised of the Healthy Baby Network (HBN) and University of Rochester (UR), organized listening sessions (LS) between January and March 2020. Listening Sessions are a method increasingly used in community-based research to gather data from underrepresented populations about their views, experiences and ideas. LS, also referred to as Community Listening Sessions (Sifuentes et al., 2021), are led by trained members of participants’ community or group. LS are less structured than focus groups, allowing for more freedom of expression. Primary principles of LS include: a trained facilitator and a scribe that reflect participants’ community (e.g., ethnicity, language, gender identity); broad, unstructured open questions to guide but not restrict the conversation; an accessible venue in the community; and the discussion, identification and prioritizing of themes during and at the end of the session (often using a white board or flip chart). LS are often not audio-recorded to encourage uninhibited sharing, but also because participants participate in the “analysis” or identification of common themes from their stories. For the LS, the researchers drafted a guide based on existing literature, including protocol of processes and potential questions. Consortium members provided feedback, resulting in a focus on three open-ended questions to guide the LS: (1) What would you like to share with us today regarding your experiences during your pregnancy and delivery? (2) What aspects of your interactions/experiences during your pregnancy went well? (3) What advice would you give medical staff to help them better address the various issues you may have faced?

The specific objectives of the LS were to:

- (1) Actively listen to the ‘lived experiences’ of Black women in the Rochester community, including their stories, concerns, hopes, and ideas for change;
- (2) Acquire a better understanding of maternal health issues from the perspectives of Black women to inform future research;
- (3) Utilize active listening skills to ensure accurate information collection; and
- (4) Establish a welcoming environment that allowed for uninhibited discussions.

The LS were facilitated by 5 Black women from the consortium, who participated in a training session, followed by their own participation in a LS to standardize knowledge.

### Recruitment of Participants

Black women who had given birth within the last 5 years and resided in the Rochester area were recruited for the LS through flyers posted on social media accounts and hard copies. We used snowball sampling (Parker et al., 2019) to recruit additional participants. Participants signed up online, by phone or through friends. For each 2-h session, lunch and childcare were provided, and participants were given a \$30 stipend.

### Process

LS were conducted in easily-accessible community centers. Each LS consisted of at least one facilitator, one scribe, and no more than five participants. Scribes were responsible for typing or handwriting participant stories and ideas. At the recommendation of the Consortium, sessions were not recorded in order to further ensure full participation and confidentiality. Scribes took copious notes throughout the LS. As part of the LS method to ensure accuracy of ideas and thoughts expressed, at the conclusion of each session, the scribes shared with participants a summary of the key ideas and themes from the discussion and obtained feedback.

### Data Management and Analysis

Data from all LS were consolidated into one document. Three researchers conducted an initial consolidation of ideas and themes identified through participant debriefing during LS and through, coding key concepts separately, and then meeting to discuss differences. Once consensus was reached, the coders organized the themes and sub-themes, initially into three broad categories: Positive experiences, negative experiences, and recommendations. Categories and consolidated themes were presented to the Consortium for discussion and interpretation. Though all stakeholders' various perspectives provided clearer understanding of the bigger picture, the expertise of Black women members was essential for helping validate conclusions. Researchers revised the results accordingly.

Following initial review of the resulting themes, Consortium members decided on the need for a LS with Black fathers to obtain their perceptions of the mothers' experiences. The session was facilitated by a Black father who was also a licensed mental health counselor. The session was held at a local community center. Lunch, childcare and a \$30 stipend were provided. The men were asked to respond to the same three questions tailored to obtain their perspective on

the treatment and safety of their partners during the perinatal period. The scribe's notes were coded using the themes and categories from the women's LS, with new codes created as needed.

Another Consortium meeting served to review, validate and finalize the resulting themes and interpretation of findings. Members ranked the issues in order of importance and urgency to inform the team's next steps for future research projects.

### Ethical Considerations

This study was submitted to the University of Rochester Research Subject Review Board and determined to meet the federal and University criteria for exemption. Prior to each LS, participants were provided with the objectives of the LS, the questions, and were assured that their responses would be analyzed and presented in an aggregate manner.

## Results

A total of 44 Black mothers between the ages of 18 and 43 years old (mean age = 30) participated in 5 LS (Table 1). They had an average of 2 children (range = 0–7) and 2.7 pregnancies (1–9). Their level of schooling varied: 6% had some High School, 23% had received a High School Diploma or GED, 34% attended some College, 17% had a College degree, and 20% had a graduate level degree. All resided in Rochester, NY, representing 19 zip codes in the city, which comprises 40 total zip codes. Participants included 6 refugees from African countries.

### Experiences with Perinatal Care

Difficult pregnancy and delivery experiences were described using words like 'frightening,' 'painful delivery,' 'difficult pregnancy,' 'tension between family and doctor,' 'inexperienced (young mother),' 'not listened to,' 'not feeling heard,' 'no support,' 'mental health issues,' 'anxiety,' 'having to work.' Positive experiences during prenatal care and delivery were credited to 'amazing medical staff,' 'supportive nurse,' 'awesome midwife,' 'awesome Doula,' 'supportive husband,' for example. The key themes that emerged clustered into four groups: (1) Mother-Provider Communication; (2) Social Support; (3) Systemic Factors and (4) Maternal Emotional & Mental Health.

### Woman-Provider Communication

Communication with providers (i.e., clinicians, midwives, nurses), emerged as an important recurring theme, both positive and negative. Black women's positive experiences

**Table 1** Participant characteristics (N = 44)

Characteristic	N	%
Age (mean = 30)		
18–34	33	74
35–54	11	26
Education		
Some high school	3	6
High school/GED	10	23
Some college	15	34
College degree	7	17
Graduate degree	9	20
Occupation		
Staff	18	41
Professional/Executive	14	32
Other (stay-at-home-mom, student, unemployed)	12	27
	Range	Mean
Number of children	0–7	2.2
Number of pregnancies	1–9	2.6

primarily centered on preparedness to face the challenges of delivery by being well informed (e.g., through prenatal care and community programs) of the processes prior to delivery and what to expect. This preparedness helped facilitate interactions with providers. On the other hand, most women felt unprepared and therefore reported poor communication with providers. For example, women describing negative experiences identified their own lack of knowledge about what to expect and not being well informed: “For my second and third pregnancies I knew I was having a c-section so I knew what to expect.”

Those reporting positive experiences reported a great appreciation specifically towards physicians, nurses, midwives, Doulas and lactation consultants who clearly communicated clinical information, involved women in decision-making, and showed they cared through the support and encouragement they provided to the mothers.

The lactation consultant was extremely helpful and I was given the opportunity to ask questions. I felt empowered by the environment, by breastfeeding. The medical staff was attentive and knowledgeable. They allowed me to play music and videos. I was able to rent hospital grade breast pumps. [They] took the baby and allowed me to sleep and brought him back to get fed—they acknowledged that I did not want formula given to my baby through a bottle, so they cup fed him and also taught me how to cup feed when pumping.

Amazing midwives at [hospital] midwifery! I needed vaginal reconstruction because I was circumcised and

they were supportive and understanding of my situation and even found me a doctor that could do the reconstruction.

The midwife advocated for how I wanted [the birth] to happen.

I was glad I had nurses of color. They helped me stick to my birthing plan; they helped me move around when husband was asleep and let me eat.

In contrast, not feeling comfortable enough to relate to their providers and/or not being listened to negatively affected women’s experiences.

I was so miserable during delivery. It’s like the providers didn’t care. I felt like I was just a number.

They think they know everything and you don’t, even though it’s your body.

Women identified numerous negative experiences with clinical staff. Women described various instances of feeling discriminated against and wrong assumptions made about them because of the type of insurance they had (i.e., Medicaid), their race/skin color, being immigrants, and being Muslim. Women felt that clinicians with which they interacted possessed very little knowledge of their community and of the variety of cultures in the region.

The midwife suggested birth control; when I said I wasn’t interested, she said ‘you can’t just keep having babies.’ Another midwife came and told me that the comment wasn’t meant the way it was said.

I was moved to a room in the back, away from all the other mothers. Probably because I’m Muslim.

I saw that there were beautiful rooms down the hall but I got a ‘Medicaid room’ that was on the other end of the hospital.

They said my son had a congenital anomaly...they kept talking about abortion even though I kept telling them I didn’t want one...I finally switched to a Black provider who understood me and worked with me to start treating my son in utero. My son was able to be a catalyst for future babies with this condition. Now I educate the community about this syndrome.

I would peak at what they were writing about me—a lot of language said ‘non-compliant’ because I turned down things that I had researched and know I had the right to refuse. There are alternatives but those are not offered up. I felt criminalized for making choices for my own body.

They described undergoing procedures during delivery to which they had not consented, did not understand, or felt pressured to undergo (e.g., cesarean section, inducement of labor, epidurals). They felt decisions about their bodies and their babies were made without involving them, or while clearly going against their wishes.

I had a lot of bleeding during my labor. I felt faint. No one attended to this concern and I ended up fainting.

I wanted a water birth...had my birthing plan but he ignored it. I gave birth in the hospital.

I wanted a natural birth...I was given epidural without information or my consent.

I felt like they were pushing for me to have a C-section because I think they get money for it.

I had excessive bleeding afterwards and the medical staff wasn’t noticing; just kept redressing my wound. My mom noticed I was bleeding more than previous deliveries and kept insisting that something was wrong—they later discovered I had a torn uterus.

## Social Support

The women indicated positive experiences related to emotional and physical support they received from the fathers of their newborns, from friends and family members, and from various community organizations and programs (e.g., Centering pregnancy, Baby Love, Healthy Baby Network, Midwife programs, Doulas, Baby Safe Sleep Coalition). For example, a few mothers reported using the Centering Pregnancy support group. Support received included financial and material assistance from family members and programs supporting pregnant women and new mothers with baby supplies as well as assistance with rent payments and referrals to social assistance and prenatal care programs.

I used Baby Love—great support! They keep in contact with you up to a year after baby is born. They give out clothes, diapers, wipes, car seat, play pen... other baby needs provided too.

After my second pregnancy I did not feel sad, I felt enraged (from postpartum depression). The support from husband allowed me to take a step back when the rage built up.

I would have liked additional time off from work. It took a while for me to feel normal again.

Those who reported lack of support and engagement from the fathers of their infants recognized that it negatively affected their perinatal experiences. Additionally, women identified the lack of connection with peers under similar situations as rendering their pregnancies and birthing experiences more isolated, particularly for those with higher risk pregnancies. For example, the women discussed the need for social outlets or groups:

My [partner] was leaving every day to smoke weed and play video games at a friend’s house—because he was depressed from losing his job. He didn’t know how to cope.

I wish I was surrounded by other women who were going through the same thing because my family didn’t understand.

[We] haven’t really been able to talk about our birth stories—no one has ever been interested.

We need more groups on Facebook for Black moms—most of them are full of white moms and they often have problems, discussions that are hard to relate to. For example: ‘you have boy, it’ll be easy’ and it’s like, no, I have Black boys. It’s not going to be easy.

## Systemic Factors

Broader systemic issues described by the women included having rotating providers, which prevented them from building relationships, the lack of providers of color, and misinformation about available support (e.g., Doulas). Other challenging issues reported include work policies that were unsupportive of pregnant mothers, necessitating that the mothers work until the last minute of pregnancy despite potential complications. The fear of loss of wages was a stressful element of some of the mother’s perinatal experiences, especially for those who had partners not working or not providing financial assistance.

It’s like disjointed medical care at the same health-care organization; there was such a big difference in care between my first and second baby.

No Doula. I had a group of 13 midwives; every visit was with a new midwife so I couldn't get familiar with them. Not one Black face.

I had heard of Doulas but didn't know they were free—I thought they were for rich people.

I interviewed a white Doula—two of them. I didn't like them. It would have stretched my pocket but could afford it; but didn't feel right. My image of a person of support would be a grandma, not a perky/yoga-type.

It got difficult to constantly be on my feet and my job told me they could not use me in my current condition—I ended up taking a lot of PTO—they eventually gave me a desk job.

I was out of work for months leading to delivery because being on my feet was making me dilate early.

I was stitched up while still working but ended up having to leave the job.

### Maternal Emotional & Mental Health

Participating women explained that, in addition to negative experiences with providers' poor communication and discriminatory behaviors, their own limited knowledge of health policies and clinical procedures caused additional mental distress during pregnancy and delivery. For example, one mother explained how her provider ignored her mental health conditions and did not refer or provide treatment. This untreated depression led her to isolate herself from family and friends, which made pregnancy and delivery more challenging. Additionally, those who reported lack of paternal or social support found it even more difficult to cope with these challenges.

I had an undiagnosed psychosis—hallucinations (Was later diagnosed with postpartum depression).

I had post-partum depression. I started 'talk therapy' the therapist did not take my concerns and feelings seriously; so, I stopped talk therapy and started taking medication.

I accidentally attacked my [partner] after being stressed; he called the police on me. I was just holding so much in. I'm trying to get by and do the best for my child.

### Input from Black Fathers

The LS with 5 Black fathers echoed the women's experiences. Positive experiences appeared to be based on possessing "good" health insurance, being involved in the birthing process, and having kind and responsive clinical staff. Similarly to many of the women, the fathers reported being made to feel unimportant in the process, not being informed

of procedures, and feeling a sense of racism, judgment, or lack of respect from providers.

I felt ignored in the process. I was treated like a 'plus-one'.

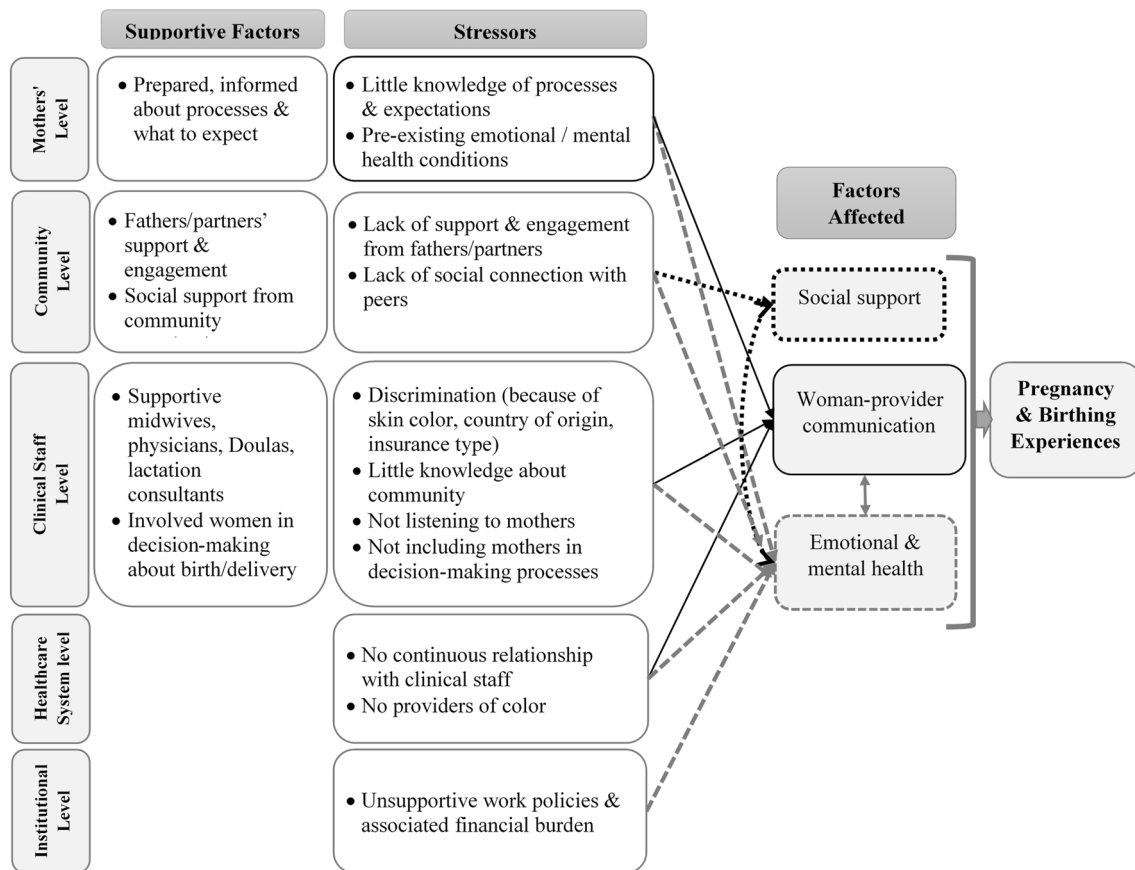
It was like [the medical staff] was being secretive... giving us vague responses.

It doesn't feel like we [were] treated with the same respect that a couple of another race would have gotten.

### Discussion

As a result of the LS with Black women, multi-level factors emerged as influencing Black women's experiences with providers during their pregnancy and delivery. Their perceptions of their experiences were affected by the factors at the individual, interpersonal, clinical/healthcare and systemic levels (Fig. 1). For example, knowledge of processes and expectations of the woman (individual level), provider discriminatory behavior (clinical/healthcare level) and the system of rotating clinicians (healthcare system level) all contributed to poor patient-provider communication, leaving the women to feel unsupported, uninvolved in their own care. *Woman-provider communication was the most important factor influencing the maternal experience*, as determined by participating mothers and Consortium members. Closer examination of the women's interactions with providers indicate that maternal health literacy, provider discriminatory attitudes and behaviors played important roles. Women with positive experience indicated their own knowledge of pregnancy and birthing processes as helpful, while those with difficult experiences reported feeling lost because of their own lack of understanding of the processes.

Health literacy, defined as the "the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions," (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010; Ratzan & Parker, 2000) has indeed been identified as influencing how birthing persons communicate with their providers (Lupattelli et al., 2014; Taheri et al., 2020). Often women's lack of knowledge is emphasized as the core of the communication problem, but studies indicate that clinicians tend to overestimate their communication skills, even in encounters when patients view the communication exchange as inadequate (Maskrey, 2019). This suggests that clinicians may be unaware of communication blind spots that could affect the quality of their clinical encounters. Observational studies outside of the perinatal period suggest that clinicians often use medical terminology, miss affective cues and signs that the patient is no longer following, and



**Fig. 1** A multi-level representation of supportive factors and stressors associated with Black women's experiences with perinatal health care

block opportunities for patients to address their concerns (Back et al., 2019).

Providers' communication style and skills also guide interaction with patients. Studies have demonstrated gender biases, finding that women in general do not feel heard or involved in medical decision-making processes (Fiks et al., 2011; Keefe et al., 2016). For Black women, cultural differences and racism create additional layers that exacerbate or supersede gender bias. Multiple layers of racism and discriminatory practices in healthcare were perpetuated throughout American history, from the treatment of slaves, to the recent crisis in SMM/MM, to current racial disparities in COVID-19 outcomes (Dorn et al., 2020). Racial bias may manifest as communication behaviors such as poor eye contact and closed posture (Pathak, 2020). Numerous studies indicate that Black patients experience worse communication with providers than do Whites, evident in less rapport-building, listening, shared decision-making, information sharing, and positive affect (Attanasio & Kozhimanil, 2015; Derrington et al., 2018).

Quality of patient-clinician communication for Black women is important, especially during pregnancy when monitoring maternal emotional state, behaviors and physical

status are critical for optimal outcomes. Clinicians not listening to Black mothers can result in dismissal of concerns, missed warning signs and delayed diagnosis. One survey found that 40% of African American women experience communication challenges during prenatal care (Howell, 2018). Breakdowns in communication can contribute to delays in the prompt identification of medical conditions and diagnoses leading to poor outcomes (Ibrahim et al., 2019). In light of the persisting racial disparities in pregnancy outcomes, our study findings highlight the need for improving maternal literacy as well as provider training on communication skills. Many national, state and local organizations and programs aim to help improve health literacy, as indicated by some of the participants in our study. These programs often target specific sub-populations such as adolescent mothers or those with great socioeconomic need. However, women from our study emphasized the need to expand the reach to Black women in general, regardless of their socioeconomic reality. This is supported by national data indicating that Black women of higher education and income also suffer from worse pregnancy outcomes than their white counterparts (Braveman et al., 2015). Future interventions to



improve health literacy should then include women of all economic backgrounds.

## Limitations and Strengths

We note several limitations in this exploratory study. First, the design and small sample size do not allow for comparisons of participants' experiences by sub-groups such as immigrant/refugee status or type of insurance, for example. Nonetheless, results provide an in-depth look at local Black women's common experiences. Secondly, the recruitment of Black women was a challenge, considering the existing distrust of researchers and past negative experiences with clinicians. Consortium members who were Black mothers helped to bridge that trust gap during recruitment as well as during the LS, which they led. Third, selection bias could be present in terms of women self-selecting to participate who may exhibit stronger perceptions and/or more unfavorable experiences with perinatal care. Finally, the emergence of COVID-19 required the Consortium to hold virtual meetings via Zoom. Because the group was already established, this change did not negatively affect the work of the Consortium. Members with no Internet access were able to participate via telephone, insuring the continued engagement of all. Fortunately, the pandemic did not affect data collection because LS were completed prior to social distancing restrictions.

The primary strengths of this study are in the community-engaged aspects and full participation of multiple stakeholders, and the use of LS methods to ensure participants openly discuss their experiences and are included in the identification of key factors emerging from their stories. Throughout the process, we grounded the planning and actions of the consortium in the voices of Black women. The LS were run exclusively by Black mothers; the LS approach (vs. individual interviews or Focus Groups) created an environment that led to greater disclosure. The focus on a single community which could be considered a limitation is a potential strength as local context specifics or gaps could be identified for potential intervention.

The motivation for and task of the Consortium were to address SMM/MM. In true community-engaged process, members indicated the need first to understand the experiences of Black birthing persons in order to identify specific factors to address in their future work towards reducing SMM/MM among Black women. Based on the key themes identified by the women during the LS, communication between women and providers emerged as an important aspect that affected their experiences and led to both positive interaction and outcomes, or created a negative experience that affected them emotionally and physically. In their planning for future research and program implementation, the Consortium prioritized the improvement of mother-provider

interaction and communication in order to ultimately affect medical birth outcomes.

Although some research findings indicate a linkage between continuity in antenatal and intrapartum care and favorable birth outcomes (Keefe et al., 2016), our early review of the literature did not yield findings related to continuity and racial equity. As our community-engaged model required the findings be driven by birthing women themselves, we allowed them to drive the narrative. Although the women in this study did not identify continuity of care provider as a key factor, we acknowledge this area could warrant further study.

## Conclusions and Health Equity Implications

Mother-provider interaction is a key factor affecting Black mothers' experiences with perinatal care. Specifically, maternal health literacy and racial discrimination in maternity care practices influenced interactions with providers. Interventions to address racial disparities in pregnancy outcomes would be well served to examine and intervene with improved patient-provider communication, through maternal health literacy and provider training in implicit racial bias and cross-cultural communications skills. Persisting racial disparities in pregnancy outcomes in the Black community in Rochester, NY, as in the U.S. in general, indicate the need for a better understanding of the experiences of Black women specifically during the perinatal period in order to inform practice, research and interventions.

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## Declarations

**Conflict of interest** No competing financial interests exist.

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