PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Pregnancy and postpartum experiences in Chicago neighborhoods with increased adverse maternal outcomes: A qualitative study

Madeline F. Perry, MD[1,2]
April Thompson[3]
Talibah Johnson[3]
Kirbi Range, MSc[3]
Jessica Steinberg, MD, MSc[1,2]
Lisa Masinter, MPH, MD[4]
Jena Wallander Gemkow, MPH, BSN, RN[4]
Andie Baker, AM[3]
Marquita W. Lewis-Thames, PhD, MPH, MS [5,6]

AFFILIATIONS

1. Northwestern University Feinberg School of Medicine, 420 E Superior St, Chicago, IL 60611, USA
2. Northwestern McGaw Division of Obstetrics and Gynecology, 250E Superior St, Chicago, IL 60611, USA
3. EverThrive Illinois, 1006 S Michigan Ave #200, Chicago, IL 60605, USA
4. Alliance Chicago, 225 W. Illinois Street, 5th Floor, Chicago, Illinois 60654, USA
5. Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, 625 N. Michigan Ave, Chicago, IL 60611, USA
6. Center for Community Health, Northwestern University Feinberg School of Medicine, 750 N. Lake Shore Drive, Chicago, IL 60611, USA

Corresponding Author: Name: Madeline Perry
Address: 250E Superior St, Chicago, IL 60611,
Email: mfrancesperry@gmail.com

Submitted 13 June 2023, revised 17 November, accepted 17 January 2024.

Perry, M.F., Thompson, A., Johnson, T., Range, K., Steinberg, J., Masinter, L., Wallander Gemkow, J., Baker, A., Lewis-Thames, M.W. (2024) Pregnancy and postpartum experiences in Chicago neighborhoods with increased adverse maternal outcomes: A qualitative study. *Progress in Community Health Partnerships*. (Forthcoming.)
24 April 2024.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

This work was presented as a poster (#1073) at the Society for Maternal Fetal Medicine 43rd Annual Pregnancy Meeting. Manuscript: 4126

Funding

Dr. Lewis-Thames was supported by a grant from the National Cancer Institute (K01CA262342), a Northwestern University Clinical and Translational Sciences Institute grant (NUCATS; UL1TR001422, PI:D'Aquilla), a Respiratory Health Association of Metropolitan Chicago grant (RHA2020-01), a National Institutes of Health's National Institute on Aging (P30AG059988), and funds from the Northwestern University Center for Community Health. The activities described here are also supported by a grant from Merck for Mothers, Merck's $500M global initiative to help create a world where no woman has to die while giving life, as part of the Safer Childbirth Cities initiative. The content of this submission is solely the responsibility of the grantee organization and does not represent the views of Merck or the VNA Foundation. Merck for Mothers is known as MSD for Mothers outside the United States and Canada. Dr. Madeline Perry was supported by a stipend from this funding disbursed by AllianceChicago as a Graduate Research Fellow.

Competing Interests

None of the authors have any conflicts of interest to disclose.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

ABSTRACT

Background: Black birthing people are three to four times more likely to die from pregnancy-related causes than White birthing people.

Objective: We aimed to better understand the pregnancy and postpartum experiences with healthcare, support, and maternal morbidity and mortality of Black pregnant and parenting people living in neighborhoods with increased rates of maternal morbidity and mortality (MMM) in Chicago, Illinois.

Methods: This was a rapid qualitative analysis in Chicago, Illinois based on principles of community-based participatory research. Community partners recruited Black pregnant and parenting individuals living in neighborhoods with higher rates of MMM. Four focus groups from February 2021 to October 2021 were led by community health workers and covered pregnancy and postpartum experiences. Transcripts were deductively and inductively coded by paired-analyst teams and thematically analyzed.

Results: This study included 31 participants from eight neighborhoods. Key themes related to pregnancy and the postpartum period included the: (1) a need for social and mental health support during and after pregnancy, (2) a preference for multiple sources of health information, (3) a need for strengthened connection with medical providers and healthcare systems, (4) a lack of clarity regarding MMM and the postpartum period, (5) a difference in language between patients and healthcare providers.

Conclusion: Further research and interventions are needed to evaluate how to best support pregnant and postpartum people, to implement patient-centered language when communicating about pregnancy and postpartum complications, and to demonstrate investment by healthcare workers in Black birthing people. Crucial to further research and interventions is communication

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

with and input from communities most affected by MMM.

KEYWORDS: pregnancy, postpartum, maternal morbidity and mortality, support

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

INTRODUCTION

In 2020, the national maternal mortality rate of Black birthing people was 2.9 times higher than that of White birthing people, describing a nationwide crisis.[1] Black birthing people are also more likely to experience comorbid conditions and pregnancy complications.[2] Racial disparities in maternal morbidity and mortality are complex, and may in part be driven by structural racism.[3] Maternal mortality is associated with structural determinants of health such as public insurance, no insurance, lower levels of education – however these alone do not explain disparities in maternal mortality.[3] Even when controlling for social determinants of health such as education level, insurance status, and medical comorbidities, Black birthing people still have increased pregnancy outcome, again demonstrating the likely role of structural racism in outcomes.[4-6]

While there is mounting evidence that draws associations between race, namely Black race, and prenatal health outcomes, race is not a biological determinant of health, rather a social construct.[15] It is well documented that, in the U.S., racial and ethnic minoritized groups from historically marginalized populations have structural and systematic barriers to accessing equitable earning and wealth-building opportunities (e.g., wage-earning gaps, increased denial of home loans).[16,17] Such barriers have complex and multilevel implications on the health outcomes and access to quality healthcare resources for minoritized groups.

Previous qualitative studies have evaluated aspects of pregnancy and postpartum experiences for Black birthing people. These studies generally include people recently pregnant or postpartum and often focus on people who have had an adverse pregnancy outcomes.[7-9] Existing research has demonstrated that Black pregnant individuals experience more stress than other racial and ethnic groups, stress from isolation, and a lack of support and resources.[10] A

desire for more social support has been frequently described among Black birthing people.[7,11,12] Qualitative research evaluating maternal morbidity and mortality again often describes the experiences of people who have personally experienced maternal morbidity and mortality. Black and Latina people who have experienced severe maternal morbidity have described disorganized care, a lack of communication or attentiveness of providers.[9] Collectively, this research has brought much needed attention to the experiences of Black birthing people. Yet, these studies elicited the perspectives of people with known adverse pregnancy outcomes, such as maternal morbidity and adverse neonatal outcomes such as preterm birth. [7-9] It's worth noting that the studies mentioned fail to fully utilize a community-based participatory research approach that involves community members in the research process and incorporates their perspectives. Given that we're discussing structural inequalities at the community level, it's important to shift the power dynamics from the researchers to the community itself, as this aligns with the principles of health equity and helps to preserve the authenticity of the community's voice.[13,14] As maternal morbidity and mortality is heavily concentrated in the Black population, we aimed to highlight community perspective of certain aspects of the pregnancy and postpartum period in neighborhoods with increased rates of maternal morbidity and mortality - rather than specifically including people with known adverse pregnancy outcomes or people recently pregnant or postpartum.

Specifically, the aim of this study was to assess the experiences and perceptions of three aspects of the pregnancy and postpartum period among Black birthing people from neighborhoods in Chicago, Illinois with high rates of maternal morbidity and mortality: experiences utilizing healthcare, sources of support, and perceptions of maternal morbidity and

mortality. We utilized a community-based participatory model to perform focus groups with community-dwelling Black pregnant or parenting people.

METHODS

Setting

This research was led through an academic-community partnership between AllianceChicago and EverThrive Illinois (community partners) and Northwestern University Feinberg School of Medicine (academic partner). All partners were located in Chicago, IL. Similar to nationwide trends, in Chicago, maternal morbidity and mortality is highest in Black birthing people who are nearly three times more likely to experience morbidity and six times more likely to die than White birthing people during the pregnancy and postpartum period.[15] Neighborhoods in the South and West side of Chicago have higher rates of maternal morbidity and mortality.[15]

Community Partners

AllianceChicago and EverThrive Illinois are non-profit community-based organizations that serve Chicago's west- and south-side neighborhoods. AllianceChicago is a national health center-controlled network of federally qualified health centers (FQHCs) whose mission is to improve personal, community, and public health through collaboration with FQHC leadership, clinicians, and staff.

EverThrive Illinois is a statewide organization working to achieve health equity and reproductive justice through community driven partnerships, policy action and systems change. Central to their mission is the engagement and leadership of community health workers from the communities in which they work, who provide evidence-based health information and resources on topics such as the immunizations, postpartum warning signs and connecting to primary care.

In 2019, AllianceChicago and EverThrive IL formed the Chicago Collaborative for Maternal Health (CCMH), a joint initiative aimed to decrease maternal morbidity and mortality in Chicago by building awareness in communities and fostering collaboration between health providers, social services, and government to implement change.[16] CCMH's activities included quality improvement in obstetric outpatient clinics, community engagement to build awareness about maternal morbidity and mortality, and political advocacy to improve maternal health.

Research team and reflexivity

To facilitate trustworthiness—the likelihood of results, with similar participant, in a similar context—we used a triangulated approach which included members of the community also conducted the interviews and coded the interviews.[17,18] Community health workers (AT, TJ) conducted the focus groups and identified as Black, Community health workers (AT, TJ, KR) were trained in conducting rapid qualitative analysis techniques by the Northwestern University academic partners (MP, MWLT). Participants may have been familiar with interviewers through prior community outreach as the community health workers had worked with partner organizations for a range of 3 to 18 years. MWLT is a community -engaged health disparities researcher with an expertise in qualitative research. MP has experience with health disparities research and has performed qualitative research in the past. To maximize community engagement, neither MWLT or MP were present during the focus group sessions. Coding and analysis were performed by AT, TJ, and KR (MSc), all of whom work for community partner Everthrive IL as community health workers. Coding and analysis were performed by AT, TJ, and KR (MSc), all of whom work for community partner Everthrive IL as community health workers.

Conceptual Model

This research was developed from a partnership with community-based partners in Chicago, using principles of community-based participatory research (CBPR).[19-21] CBPR is a methodology based on a genuine partnership and co-learning between community and academic partners, including capacity building, pursuing knowledge that benefits all partners, and a long-term commitment to reduce disparities.[19,22] CBPR engages community stakeholders longitudinally throughout the research process and has been used to address disparities in maternal health, and specifically inequities in Black maternal health, within the United States.[23,24] The study's Principal Investigator was from AllianceChicago (LM). The study design was co-developed by community and academic partners. Community partners secured funding for the research, developed the study design, recruited participants, co-developed interview guides, collected data, co-analyzed the data, and co-disseminated the findings. Academic partners consulted on the qualitative study design, co-developed the interview guides, co-analyzed the data, and co-disseminated the findings. This study received approval from the Institutional Review Board at the Chicago Department of Public Health (#20-09).

Participant Description

We recruited our study population using purposive sampling. Community health workers (AT, TJ, MD) approached women in neighborhoods in the South and Westside of Chicago. Women in target neighborhoods were approached on the street by community health workers to complete a survey about maternal health and if interested were invited to join a focus group about pregnancy and postpartum experiences. Information about focus groups was also advertised with community flyers, disseminated during EverThrive IL community canvassing, and posted on the EverThrive IL Website. Eligible participants resided in South and West side communities, were pregnant or parenting, and at least 18 years. There were no exclusion criteria.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Number of participants who declined participation in study was not recorded. Participants were verbally consented for participation in focus groups.

Focus Group Question Guide

Where do you get health information?
Do you have a healthcare provider?
What are health issues pregnant people in your community face?
How are people in your community supported during pregnancy?
How are people in your community supported after pregnancy?
What does self care mean?
Have your heard of maternal morbidity and mortality?
Is maternal morbidity and mortality an issue?

Figure 1. Abbreviated questions used in focus group question guide.

Interview Guide Development and Data Collection

Interview guides were developed by EverThrive IL and reviewed by the Principal Investigator and research collaborator at AllianceChicago. The interview guide probed eligible participants regarding sources of health information, availability and access to supports for pregnant and postpartum people, perceived stress related to pregnancy and postpartum care, self-care needs, and maternal morbidity and mortality knowledge (Figure 1).

Focus groups were conducted from February 2021 to October 2021. All focus groups were conducted via Zoom and included six to eight participants. Each focus group was facilitated by two community health workers from EverThrive IL (TJ, AJ). The interview guide was adapted after the first interview to narrow the focus of questions asked (Figure 1). Subsequent

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

focus groups followed the adapted interview guide. All focus groups were audio-recorded and approximately 60 minutes long. Audio recordings were transcribed by a Temi (2023) with quality control performed by the EverThrive IL research collaborator (AB). Transcripts were not returned to participants for comment or correction. All project stakeholders were offered $45 gift cards for their participation in this study. Community health workers were compensated as part of their typical wages.

Analysis

Community Health Workers were trained to deductively code and analyze the data by a qualitative expert and trainer (MWLT, MP) to conduct rapid analysis data management.[11] Rapid analysis is a method of qualitative research that has been shown to decrease the time required for qualitative analysis, without sacrificing quality.[25,26] This methodology is primarily deductive and explanatory, seeking to answer a specific question.[26,27] All transcripts were double coded by two analysts – the qualitative trainer and primary author (MP) and one of the three community health workers (AT, TJ, KR). MWLT occasionally joined consensus meetings with MP, KR, TJ and AT to contribute to the robust discussion about potential themes. Analysts completed coding template by assigning text to agreed upon codes and inductively coded when necessary. The qualitative expert (MWLT) and qualitative trainer (MP) resolved any coding disagreements. Once all transcripts were coded, analysts used thematic analysis techniques to group and summarize the codes into relevant themes.

Word processor was used to facilitate analysis and all transcripts were securely stored on a password protected shared drive. Study participants did not provide feedback on the findings.

Note on Language

In this study use the terminology "women" and "maternal morbidity and mortality." We recognize that gender is a construct and that people of all genders have the capacity to be pregnant and postpartum. We adopt the language used by participants, academic terminology (such as maternal morbidity and mortality) and use inclusive language when possible. Additionally, we discuss race and ethnicity in this paper. We acknowledge that race is a social construct. Unless otherwise specificized, White and Black race refers to people who identify as non-Hispanic. Therefore, we use terms such as "Black birthing person" rather than "non-Hispanic Black birthing person."

RESULTS

Participants included 31 pregnant and parenting people. Ages of participants ranged from 23 to 57; median age was 33. Participants lived in the following neighborhoods on the South and Westside of Chicago: Austin, West Garfield Park, East Garfield Park, Lawndale, Bellwood, Englewood, Chatham, Beverly. All participants identified as Black or African American.

Participant focus groups revealed five major themes regarding their experiences with support, healthcare, and maternal morbidity and mortality during the pregnancy and postpartum period: (1) need for interpersonal and mental health support during and after pregnancy, (2) preference for multiple sources of health information, (3) need for strengthened connection with medical providers and healthcare systems, (4) lack of clarity regarding maternal morbidity and mortality and the postpartum period, (5) differences in language and associated gaps in understanding. Table 1 provides exemplar quotes thar represent each theme and corresponding subthemes.

Need for interpersonal and mental health support during and after pregnancy

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Participants described the need for additional support during the pregnancy and postpartum periods. Largely, the support that was lacking was interpersonal or social support. Only a minority of pregnancy-related conditions described by participants were medical comorbidities and complications, and overwhelmingly health related issues discussed were related to psychological and mental health.

Interpersonal support

Participants described a need for more support from their family, friends, and community both during and after pregnancy. Participants most frequently described a need for emotional or social support, financial assistance, people to trust, and people to rely on for help.

> "A lot of people don't have the support of family, like others…just having somebody there to talk to about your situation" (Transcript 1, Speaker 1)

At times participants acknowledged that a lack of trust in others limited their ability to utilize social support:

> "…[Black people who are pregnant] really don't trust anyone or they don't really feel like they have anyone that they could talk to about what they're going through." (Transcript 3, Speaker 4)

Moreover, one participant thought that "we've normalized being a strong Black woman…if you ask for help, you're looked at as weak or you're not looked at as the norm" (Transcript 2, Speaker 7).

Mental health support

Participants described challenges with mental health, namely the lack of social support for depression, postpartum depression, stress, and anxiety.

> "[A close friend] fell into depression and she didn't get the support that she needed. Not a lot from her friends and I'm, and I'm guilty of that as well. Um, I don't think that we supported her the, the way that we should." (Transcript 4, Speaker 5).

To overcome and deal with stress, depression and other mental health conditions, participants described the importance of self-care:

> "Personally think [self-care is] very, important and a lot of people don't realize that when you're stressed mentally, that stress can actually make you physically sick…especially Black women, when you're mothers and you're caretakers, you always put yourself on the back burner because there's always someone else who's needing something from you…" (Transcript 4, Speaker 5)

Preference for multiple sources of health information

Participants described numerous sources of health information and frequently noted using multiple sources of health information concomitantly, including family, people who have been pregnant, the internet, and medical providers.

Sources of information that are not medical providers

Participants relied on family members, in particular mothers and elders, for health information. They explained that they preferred to seek information from people who had lived experiences of pregnancy, postpartum and other health challenges:

> "[I would talk to] my mom…my family about previous experience[s] when they was pregnant…you know how did that go" (Transcript 3, Speaker 3)

Moreover, residents describe utilizing resources in their communities such as "community centers" and "churches" for trustworthy pregnancy-related information (Transcripts 4, Speaker

5). Other community resources identified were the publicly funded programs such as the Women Infants Children Program (WIC) or Healthy Start. Along with these external resources, participants also relied on their ability to research their questions:

> "I Google everything [to] figure out what's, what's going on." (Transcript 3, Speaker 1)

Medical providers as sources of information

Healthcare providers were a reliable source of health information for some participants. At clinics where both medical providers work and social services are provided, participants reported:

> "…if you're having a rough pregnancy dealing, maybe housing issues or…just mental issues that you need support, you know, the doctor is there, they refer you and you always have a case management" (Transcript 1, Speaker 6).

However, other participants "don't trust the doctors" (Transcript 3, Speaker 6), and were concerned that "the doctor doesn't always have your best interest…in mind" (Transcript 4, Speaker 2).

Need for strengthened connection with medical providers and health care systems

Participants commented on a lack of investment by medical providers caring for Black pregnant and postpartum people, an inability to trust healthcare providers, and the challenges of accessing medical services.

Perception of lack of investment by medical providers

Participants commonly reported that medical practitioners provided limited attention to their health concerns, thus contributing to a feeling that healthcare providers were not genuinely committed to their health.

> "I did not feel like my healthcare provider had my best interest in mind. I…felt like they was basically just telling me what they wanted me to do. What, what would be more profitable for them as opposed to actually listening to my concern." (Transcript 3, Speaker 1)

Furthermore, along with feeling that providers were not invested in their care, participants were also concerned that medical providers were not accounting for their social determinants of health.

> "They not really seeing what our, our environment…has to play in it. What our, you know, what our stress levels, what our life at home has to do with anything. They just basically, um, diagnosing us off of textbook definitions." (Transcript 3, Speaker 1)

Failure of providers to build trust with patients

Participants reported experiences where medical providers were unable to garner trust from their patients. This lack of trust sometimes stemmed from acute events, such as changing a due date.

> "I feel like a lot of the stuff that the doctors were telling me [wasn't right], like they couldn't even get my due date." (Transcript 4, Speaker 2)

The lack of trust also expanded to broader perception that medical providers cannot be trusted to care for Black birthing people.

> "I feel like most of us feel like we're supposed to trust our doctors, but, um, I don't feel like the doctor is always necessarily gonna tell you the best thing for you." (Transcript 3, Speaker 1)

Challenges accessing medical services

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Participants commented on how trusted and accessible medical services were not readily available. Concerns included insufficient access to trusted medical providers in local neighborhoods, a lack of appointments that accommodate work schedules, and an inability to access high-quality care when publicly insured. In referring to her doctor, one participant noted:

> "I guess she just got tired with the situation with healthcare. And when I last heard from her in April, she said she wasn't going to practice anymore. She needed a break." (Transcript 2)

Additionally, participants were concerned that being publicly insured diminished the quality of care they received and limited their autonomy to choose their provider. Relatedly, a participant described their experience with public insurance as "if you have a public aid card, you're going to go to wherever they send you" (Transcript 2, Speaker 1). Public insurance also limited access to resources, as described by one participant:

> "I feel like Black women, especially depending on the insurance, they don't even get told about options that they have after pregnancy. Like, you know, doulas and midwifes." (Transcript 4, Speaker 3)

Lack of clarity regarding maternal morbidity and mortality and the postpartum period

Participants described numerous experiences with maternal morbidity and mortality, including complications with cesarean sections, hemorrhages, pre-eclampsia, and cardiac function. In reflecting on pregnancy complications, one participant reflects on how she knows of people who have died in the pregnancy or postpartum period:

> "Just like everybody else. I know someone, I haven't lost a family member or friend thankfully, but it's always someone that we knew that someone else knew…" (Transcript 2, Speaker 4)

Participants were often unclear about the etiology or sequalae of pregnancy-related complications.

> "And then she called me to immediately, she had to get a C-section. And when I talked to her that she was fine and everything went good. And then like the next day they called me and tell me that she was like, something happened with her heart and whatever. So she was like on a machine for like several days…So I don't know, like, she don't really know what happened either to her…" (Transcript 2, Speaker 3)

When discussing the postpartum period, many participants equated postpartum to postpartum depression, rather than describing the scope of this period after delivery:

"When I say postpartum care, what was the first thing that popped in your mind?" (Facilitator)

"Depression" (Speaker unknown, Transcript 1)

Explanations that participants received about the postpartum period were limited, sometimes consisting of "something that's like on a pamphlet." Participants also felt that community understanding of the importance of the postpartum period was limited, reporting that people who had given birth felt pressure to "handle" the postpartum period independently.

> "I feel like our community doesn't understand postpartum…You know, you have a baby, you go back home, you deal with it and you keep it moving." (Transcript 2, Speaker 5)

Differences in language and associated gaps in understanding

Participants acknowledged discordant language between patients and medical providers was used to describe pregnancy complications and the postpartum period. Discordant language

was a barrier to understanding the postpartum period and maternal morbidity and mortality as it limited the ability of patients and providers to easily communicate. For example, respondents used the word "setback" to describe medical complications - "when you think about [a] setback [it] could be somebody having, you know, issues with their blood pressure being too high." (Transcript 1, Speaker 6). Participants were concerned that using this non-medical jargon may be confusing to medical providers because they're not putting "medical terms to it."

Few participants were familiar with or used the term "maternal morbidity and mortality." Multiple participants had not heard of these terms or thought they were not relevant to their communities though they expressed lived experiences of adverse maternal outcomes. Others associated maternal mortality with postpartum people harming their neonates. When discussing how to broaden people's awareness of these terms, participants recommended using more direct language such as "has this person died from this or that happened" (Transcript 1, Speaker 1).

DISCUSSION

We conducted four focus groups to explore experiences with support, healthcare access and services and maternal morbidity and mortality during the pregnancy and postpartum period of Black birthing people living in neighborhoods in Chicago with high rates of maternal morbidity and mortality. Five main themes were identified through our thematic analysis:(1) need for interpersonal and mental health support during and after pregnancy, (2) preference for multiple sources of health information, (3) need for strengthened connection with medical providers and healthcare systems, (4) lack of clarity regarding maternal morbidity and mortality and the postpartum period, (5) differences in language and associated gaps in understanding. This study adds to the existing literature exploring the roots of inequities in pregnancy,

childbirth, and maternal morbidity and mortality specifically for Black women—a population burdened by excessive maternal mortality rates and severe morbidity. [2,28-31]

In this study, participants described a need for more social support both during and after pregnancy. For pregnant people, social support is inversely associated with depressive symptoms and perceived stress.[32] People who do not have social support feel more isolated.[23] Maternal stress is associated with adverse pregnancy outcomes such as preeclampsia, preterm birth and smaller newborns.[33] Social support can act as a buffer, protecting people who are pregnant from adverse social situations.[8] Moreover, when healthcare providers are a source of support, they can encourage engagement with medical care, which may help to improve outcomes.[34]

Our participants described utilizing numerous sources for health information simultaneously. Other qualitative studies describe similar information gathering strategies including information-seeking via social networks, primarily through pregnant or formally pregnant family members.[35,36] Multiple health information resources help pregnant people develop their own consensus opinion.[37] While social networks can be helpful health information resources, they can also facilitate misinformation and medical distrust. To promote the spread of healthful accurate postpartum and pregnancy information through social networks, education delivered during prenatal visits or by community should include outreach to pregnant peoples' social networks as well in language that is easily understood.[36]

Participants' reflections on the perceived lack of investment by medical providers, failure of medical providers to build trust and challenges in accessing medical services demonstrate a sentiment of being undervalued. Existing studies highlight decreased trust of medical providers among Black populations[38,39] and the perception they are not acknowledged by healthcare workers.[40] Breakdowns in communication not only can contribute to these feelings of being

undervalued, but also can result in patient morbidity.[23] Improved communication on behalf of medical providers may start to address the perceived lack of trust and investment.[23,41]

While participants had exposure to maternal morbidity and mortality through their social networks or personal experiences, the etiology of many pregnancy complications were often unexplained or unclear. Communication and language could have a role in how information about a pregnancy complication was conveyed and understood. Although we did not measure health literacy, low health literacy has implications on understanding and pregnancy complications and maternal morbity and mortality.[42,43] Language discordance— when a patient and healthcare provider lack an understanding of the same language—may be exacerbating a patient's understanding of pregnancy medical complications. Existing research demonstrates differences in language between healthcare providers and patients and that this difference can result in decreased understanding, however this research is limited among pregnant and postpartum patients.[39,44]

Through this research, we identify potential next steps to address current maternal health inequities. Further research should evaluate mechanisms to increase the social support of pregnant and postpartum people. This could include centering pregnancy,[45] counseling programs including people who are pregnant and/or their partners,[46] and studying the collective services, gaps, and opportunities for improvements among the community-based organizations in an entire city.[47,48] Additionally, we identified communication and the lack there-of to be central to patient – provider relationship and the understanding of health conditions and complications. In our population, family and friends were important to disseminating and processing health information. Efforts to improve communication and health literacy in other communities may

benefit from evaluating the influence of social networks in communication for their target population.[36,37]

This study is strengthened by its community based participatory approach which we believe is critical to engage the voices of populations often marginalized and misrepresented in medical research. Leaders of the community-based organization managing this study have a history working with predominately Black neighborhoods in Chicago, and their alliance with the represented communities likely improved recruitment and transparency regarding maternal morbidity and mortality. Yet, our study is not without limitations. Generalizations about this study's findings should be limited to understanding the pregnancy and birthing experiences of Black pregnant people living large Midwest urban centers. Neighborhood structure, access to resources, available medical care, and historical context of the neighborhoods our participants lived in understandably varies from other people experiencing maternal morbidity and mortality in the United States. Moreover, we relied on a small number of community health workers to identify people potentially interested in participating in our focus groups, which could introduce bias and oversample people already engaged with community health organizations. Finally, while our analytic plan was guided and supervised by an expert qualitative researcher (MLT) and double coded by trained researcher (MP) the analysis may be influenced by the researchers' own experiences and interpretations resulting a researcher bias.

Conclusion

Overall, this research adds existing literature on experiences with support, healthcare access and services, and maternal morbidity and mortality in a Black birthing people living in neighborhoods with higher rates of maternal morbidity and mortality. Main themes included a need for interpersonal and mental health support during and after pregnancy, preference for

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

multiple sources of health information, need for strengthened connection with medical providers and healthcare systems, lack of clarity regarding maternal morbidity and mortality and the postpartum period, and differences in language and associated gaps in understanding. Elevating the voices of minoritized communities at the center of the maternal health crises in the United States is a crucial step in considering effective solutions to eliminate disparities.

Reference List

1. Hoyert DL. Maternal mortality rates in the United States, 2020. 2022.
2. Howell EA. Reducing Disparities in Severe Maternal Morbidity and Mortality. Clin Obstet Gynecol 2018;61(2):387-399. (In eng). DOI: 10.1097/grf.0000000000000349.
3. Wang E, Glazer KB, Howell EA, Janevic TM. Social Determinants of Pregnancy-Related Mortality and Morbidity in the United States: A Systematic Review. Obstet Gynecol 2020;135(4):896-915. (In eng). DOI: 10.1097/aog.0000000000003762.
4. Fang J, Madhavan S, Alderman MH. Maternal mortality in New York City: excess mortality of black women. Journal of urban health : bulletin of the New York Academy of Medicine 2000;77(4):735-44. (In eng). DOI: 10.1007/bf02344034.
5. Berg CJ, Chang J, Callaghan WM, Whitehead SJ. Pregnancy-related mortality in the United States, 1991-1997. Obstet Gynecol 2003;101(2):289-96. (In eng). DOI: 10.1016/s0029-7844(02)02587-5.
6. Harper MA, Espeland MA, Dugan E, Meyer R, Lane K, Williams S. Racial disparity in pregnancy-related mortality following a live birth outcome. Ann Epidemiol 2004;14(4):274-9. (In eng). DOI: 10.1016/s1047-2797(03)00128-5.
7. McLemore MR, Altman MR, Cooper N, Williams S, Rand L, Franck L. Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. Soc Sci Med 2018;201:127-135. (In eng). DOI: 10.1016/j.socscimed.2018.02.013.
8. Eapen DJ, Wambach K, Domian EW. A Qualitative Description of Pregnancy-Related Social Support Experiences of Low-Income Women with Low Birth Weight Infants in the Midwestern United States. Matern Child Health J 2019;23(11):1473-1481. (In eng). DOI: 10.1007/s10995-019-02789-2.
9. Wang E, Glazer KB, Sofaer S, Balbierz A, Howell EA. Racial and Ethnic Disparities in Severe Maternal Morbidity: A Qualitative Study of Women's Experiences of Peripartum Care. Womens Health Issues 2021;31(1):75-81. (In eng). DOI: 10.1016/j.whi.2020.09.002.
10. Koenig MD, Crooks N, Burton T, et al. Structural Violence and Stress Experiences of Young Pregnant Black People. J Racial Ethn Health Disparities 2023 (In eng). DOI: 10.1007/s40615-023-01661-y.
11. Smith KL, Shipchandler F, Kudumu M, Davies-Balch S, Leonard SA. "Ignored and Invisible": Perspectives from Black Women, Clinicians, and Community-Based Organizations for Reducing Preterm Birth. Matern Child Health J 2022;26(4):726-735. (In eng). DOI: 10.1007/s10995-021-03367-1.
12. Collins CC, Brown PL, Rice H, et al. Experiences of Black women during pregnancy: The meaning of perinatal support. Am J Orthopsychiatry 2021;91(5):589-597. (In eng). DOI: 10.1037/ort0000557.
13. Duran B, Oetzel J, Magarati M, et al. Toward Health Equity: A National Study of Promising Practices in Community-Based Participatory Research. Prog Community Health Partnersh 2019;13(4):337-352. (In eng). DOI: 10.1353/cpr.2019.0067.

14. Suarez-Balcazar Y, Francisco VT, Rubén Chávez N. Applying Community-Based Participatory Approaches to Addressing Health Disparities and Promoting Health Equity. Am J Community Psychol 2020;66(3-4):217-221. (In eng). DOI: 10.1002/ajcp.12487.
15. Health CDoP. CDPH Data Report: Maternal Morbidity & Mortality In Chicago. City of Chicago 2019.
16. Chicago Collaborative for Maternal Health. (https://www.chicagomaternalhealth.org/).
17. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. Am J Occup Ther 1991;45(3):214-22. (In eng). DOI: 10.5014/ajot.45.3.214.
18. Tobin GA, Begley CM. Methodological rigour within a qualitative framework. J Adv Nurs 2004;48(4):388-96. (In eng). DOI: 10.1111/j.1365-2648.2004.03207.x.
19. Israel B, Eng E, Schulz A, Parker E. Methods in Community-Based Participatory Research for Health. San Francisco, CA: Jossey-Bass, 2005.
20. Israel BA, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. Health Educ Q 1994;21(2):149-70. (In eng). DOI: 10.1177/109019819402100203.
21. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health 1998;19:173-202. (In eng). DOI: 10.1146/annurev.publhealth.19.1.173.
22. Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. Health Promot Pract 2006;7(3):312-23. (In eng). DOI: 10.1177/1524839906289376.
23. Alio AP, Dillion T, Hartman S, et al. A Community Collaborative for the Exploration of Local Factors Affecting Black Mothers' Experiences with Perinatal Care. Matern Child Health J 2022;26(4):751-760. (In eng). DOI: 10.1007/s10995-022-03422-5.
24. Muzik M, Kirk R, Alfafara E, Jonika J, Waddell R. Teenage mothers of black and minority ethnic origin want access to a range of mental and physical health support: a participatory research approach. Health Expect 2016;19(2):403-15. (In eng). DOI: 10.1111/hex.12364.
25. Taylor B, Henshall C, Kenyon S, Litchfield I, Greenfield S. Can rapid approaches to qualitative analysis deliver timely, valid findings to clinical leaders? A mixed methods study comparing rapid and thematic analysis. BMJ Open 2018;8(10):e019993. DOI: 10.1136/bmjopen-2017-019993.
26. Hamilton AB. Qualitative Methods in Rapid TurnAround Health Services Research VA HSRD Cyberseminar Series: Spotlight on Women's Health2013.
27. Hamilton AB, Finley EP. Qualitative methods in implementation research: An introduction. Psychiatry Res 2019;280:112516. (In eng). DOI: 10.1016/j.psychres.2019.112516.
28. Creanga AA, Bateman BT, Kuklina EV, Callaghan WM. Racial and ethnic disparities in severe maternal morbidity: a multistate analysis, 2008-2010. Am J Obstet Gynecol 2014;210(5):435.e1-8. (In eng). DOI: 10.1016/j.ajog.2013.11.039.

29. Prevention CfDCa. Severe Maternal Morbidity in the United States. (https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html#anchor_trends).
30. Prevention CfDCa. Pregnancy Mortality Surveillance System. 2022 (https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm).
31. Freaney PM, Harrington K, Molsberry R, et al. Temporal Trends in Adverse Pregnancy Outcomes in Birthing Individuals Aged 15 to 44 Years in the United States, 2007 to 2019. J Am Heart Assoc 2022:e025050. (In eng). DOI: 10.1161/jaha.121.025050.
32. Hawkins M, Misra D, Zhang L, Price M, Dailey R, Giurgescu C. Family involvement in pregnancy and psychological health among pregnant Black women. Arch Psychiatr Nurs 2021;35(1):42-48. (In eng). DOI: 10.1016/j.apnu.2020.09.012.
33. Traylor CS, Johnson JD, Kimmel MC, Manuck TA. Effects of psychological stress on adverse pregnancy outcomes and nonpharmacologic approaches for reduction: an expert review. Am J Obstet Gynecol MFM 2020;2(4):100229. (In eng). DOI: 10.1016/j.ajogmf.2020.100229.
34. Mehra R, Boyd LM, Magriples U, Kershaw TS, Ickovics JR, Keene DE. Black Pregnant Women "Get the Most Judgment": A Qualitative Study of the Experiences of Black Women at the Intersection of Race, Gender, and Pregnancy. Womens Health Issues 2020;30(6):484-492. (In eng). DOI: 10.1016/j.whi.2020.08.001.
35. Lewallen LP. Healthy behaviors and sources of health information among low-income pregnant women. Public Health Nurs 2004;21(3):200-6. (In eng). DOI: 10.1111/j.0737-1209.2004.021302.x.
36. Song H, Cramer EM, McRoy S, May A. Information needs, seeking behaviors, and support among low-income expectant women. Women Health 2013;53(8):824-42. (In eng). DOI: 10.1080/03630242.2013.831019.
37. Moon RY, Mathews A, Oden R, Carlin R. A Qualitative Analysis of How Mothers' Social Networks Are Established and Used to Make Infant Care Decisions. Clin Pediatr (Phila) 2019;58(9):985-992. (In eng). DOI: 10.1177/0009922819845332.
38. Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. Public Health Rep 2003;118(4):358-65. (In eng). DOI: 10.1093/phr/118.4.358.
39. Doescher MP, Saver BG, Franks P, Fiscella K. Racial and ethnic disparities in perceptions of physician style and trust. Arch Fam Med 2000;9(10):1156-63. (In eng). DOI: 10.1001/archfami.9.10.1156.
40. Roder-DeWan S, Baril N, Belanoff CM, Declercq ER, Langer A. Being Known: A Grounded Theory Study of the Meaning of Quality Maternity Care to People of Color in Boston. J Midwifery Womens Health 2021;66(4):452-458. (In eng). DOI: 10.1111/jmwh.13240.
41. Canty L. The lived experience of severe maternal morbidity among Black women. Nurs Inq 2022;29(1):e12466. (In eng). DOI: 10.1111/nin.12466.
42. Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. Fam Med 2002;34(5):383-9. (In eng).

43. Yee LM, Kamel LA, Quader Z, et al. Characterizing Literacy and Cognitive Function during Pregnancy and Postpartum. Am J Perinatol 2017;34(9):927-934. (In eng). DOI: 10.1055/s-0037-1601307.
44. Mollen CJ, Fernando M, Hayes KL, Barg FK. Pregnancy, contraception and emergency contraception: the language of urban adolescent young women. J Pediatr Adolesc Gynecol 2012;25(4):238-40. (In eng). DOI: 10.1016/j.jpag.2011.11.006.
45. Chae SY, Chae MH, Kandula S, Winter RO. Promoting improved social support and quality of life with the CenteringPregnancy(®) group model of prenatal care. Arch Womens Ment Health 2017;20(1):209-220. (In eng). DOI: 10.1007/s00737-016-0698-1.
46. Sharifipour F, Javadnoori M, Behboodi Moghadam Z, Najafian M, Cheraghian B, Abbaspoor Z. Interventions to improve social support among postpartum mothers: A systematic review. Health Promot Perspect 2022;12(2):141-150. (In eng). DOI: 10.34172/hpp.2022.18.
47. Molina RL, DiMeo A, Graham L, Galvin G, Shah N, Langer A. Racial/Ethnic Inequities in Pregnancy-Related Social Support: Design Workshops With Community-Based Organizations in Greater Boston. J Public Health Manag Pract 2022;28(Suppl 1):S66-s69. (In eng). DOI: 10.1097/phh.0000000000001438.
48. West R, DiMeo A, Langer A, Shah N, Molina RL. Addressing Racial/Ethnic Inequities in Maternal Health Through Community-Based Social Support Services: A Mixed Methods Study. Matern Child Health J 2022;26(4):708-718. (In eng). DOI: 10.1007/s10995-021-03363-5.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Theme	Subtheme	Exemplary Quotes
Need for interpersonal and mental health support during and after pregnancy		
	Interpersonal support	One of the main problems within our community is we don't necessarily...have a strong support system while we're pregnant…we really don't know who to talk to or who we could depend on because we really, most of the time we really only have ourselves A lot of people don't have the support of family…just having somebody there to talk to about your situation …[Black people who are pregnant] really don't trust anyone or they don't really feel like they have anyone that they could talk to about what they're going through. Like, you know, people really don't trust anyone… Everybody just for they self.
	Mental health support	She fell into depression and she didn't get the support that she needed. Not a lot from her friends and I'm, and I'm guilty of that as well. Um, I don't think that we supported her the, the way that we should. Personally think [self-care is] very, important and a lot of people don't realize that when you're stressed mentally, that stress can actually make you physically sick as well…especially Black women, when you're mothers and your caretakers, you always put yourself on the back burner because there's always someone else who's needing something from you. But you do have to take that time to realize that you are important as well…" Because that stress is real. Stress will slow you down the stressful stuff and it will kill you. I feel like people are just very ignorant to people with postpartum depression, or they're not really paying attention to a mother and her cries for help
Preference for multiple sources of health information		
	Non-medical sources of information	[I would talk to] my mom…my family about previous experience[s] when they was pregnant…you know how did that go I Google everything [to] figure out what's, what's going on. …the elders of my family, but I'm big on research and stuff. So I'll research everything.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

		It's usually a combination. Just trying to figure it out. I see what's going on the web. I research, I do my own due diligence and then I come up with my own synopsis.
	Medical providers as sources of information	If you're having a rough pregnancy dealing, maybe housing issues or, um, just mental issues that you need support, you know, the doctor is there, they refer you and you always have a case management, a case manager at the doctor's office and they give you a referral
Need for strengthened connection with medical providers		
	Perceived lack of investment by providers	I did not feel like my healthcare provider had my best interest in mind. I, I felt like they was basically just telling me what they wanted me to do. What, what would be more profitable for them as opposed to actually listening to my concerns and telling me what I felt was best and working and compromising and working with me to figure out what was best for my specific situation. I feel that Black women in general, when we go to the doctor to talk about concerns that we have…I don't think that we are taken seriously. And I think when we become pregnant, um, the same thing happens. And it, I, in my experience with both of my sisters, it continued throughout their delivery to the point to which everyone ended up in the ICU or NICU for, in my opinion, preventable reasons. They not really seeing what our, our environment…has to play in it. What our, you know, what our stress levels, what our life at home has to do with anything. They just basically, um, diagnosing us off of textbook definitions.
	Failure of providers to build trust with patients	I feel like a lot of the stuff that the doctors were telling me [wasn't right], like they couldn't even get my due date I feel like most of us feel like we're supposed to trust our doctors, but, um, I don't feel like the doctor is always necessarily gonna tell you the best thing for you
	Challenging access to medical services	I guess she just got tired with the situation with healthcare. And when I last heard from her in April, she said she wasn't going to practice anymore. She needed a break. I feel like Black women, especially depending on the insurance, they don't even get told about options that they have after pregnancy. Like, you know, doulas and midwifes. It depends on your insurance, it's like some doctors, um, they have to talk and listen to you and if you really don't get good insurance, then they really don't listen to you.

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Lack of clarity regarding maternal morbidity and mortality and the postpartum period	Just like everybody else. I know someone, I haven't lost a family member or friend thankfully, but it's always someone that we knew that someone else knew… And then she called me to immediately, she had to get a C-section. And when I talked to her that she was fine and everything went good. And then like the next day they called me and tell me that she was like, something happened with her heart and whatever. So she was like on a machine for like several days…So I don't know, like, she don't really know what happened either to her… I feel like our community doesn't understand postpartum…You know, you have a baby, you go back home, you deal with it and you keep it moving.
Differences in language and associated gaps in understanding	When you think about [a] setback [it] could be somebody having, you know, issues with their blood pressure being too high We had these adverse health outcomes… after we have our children, we liked dang, well, I had a setback because… they're not putting the, the medical terms to it …I haven't heard of maternal mortality. I dunno what that is. What is it? As part of maternal mortality. And I feel like, I think I, what it is with the mother, you know, going through the postpartum and they essentially kill their baby. I think that's right?

Table 1: Exemplary quotes

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.