Centering Birthing Experiences of Women of Color: Protocol for a Qualitative Maternal Near Miss Study

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Abstract

Background: In the US, Black women are 3–4 times more likely to experience maternal near miss (MNM) or severe maternal morbidity (SMM) than non-Hispanic White women [1]. However, there is limited narrative-based investigation into Black and other marginalized women's maternal near miss experiences. Additionally, limited extant research on the impact of MNM and SMM on birthing women's family/support persons and healthcare providers precludes development of multilevel, patient-centered methods to eliminate these racial/ethnic disparities.

Objective: This paper presents the protocol for a study that aims to draw insights from the experiences of racially and socioeconomically diverse mothers with maternal near miss and/or severe maternal morbidity, their family/support persons (e.g., partners), and healthcare providers to inform legislation, clinical practice, and infrastructure for optimal social support.

Methods: Morehouse School of Medicine (MSM) will partner with health services and community-based organizations to promote inclusive participant recruitment for this multiphase study. In phase 1, we will conduct qualitative interviews will be conducted with birthing women (n ? 120) who have experience MNM and/or SMM. In phase 2, we will conduct qualitative interviews with the following groups: birthing women's partners/support persons (n ? 50); healthcare providers serving birthing women (n ? 50); and adults who lost their mothers to pregnancy related complications (n ? 50). In each phase, the total number of participants interviewed will be based on theoretical saturation, i.e., the point in iterative data collection and analysis when all important insights have been exhausted from the data already available.

Results: Recruitment for Phase 1 started in July 2021. As of March 2024, we have recruited 92 racially and socioeconomically diverse birthing women. Of those, 75% self-identified as Black or African American, 19% as Hispanic or Latina, and 9% as Native American or Alaska Native. Severe preeclampsia accounted for 46% of participants' pregnancy-related adverse experiences. Qualitative interviews grounded in narrative-based medicine are ongoing. Recruitment for Phase 2 will occur between July 2023 and July 2024. Study results will be published in peer-reviewed scientific journals.

Conclusions: The findings from this research will deepen understanding of how severe obstetric complications: (1) are experienced by birthing women; (2) perceived by their partners, support persons, health providers; and (3) impact the lives of bereaved family and community members.

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Keywords: maternal health disparities; maternal near miss; severe maternal morbidity; minority health; mental health; narrative-based medicine

Introduction

Maternal health encompasses the well-being of both mothers and their newborns during pregnancy, childbirth, and the postpartum period. Despite advancements in medical technology and healthcare systems, there remain persistent challenges with maternal mortality and morbidity. The Centers for Disease Control and Prevention (CDC) reports that the maternal mortality (MM) rate for the U.S. in 2021 was 32.9 deaths per 100,000 live births, compared with a rate of 23.8 in 2020 and 20.1 in 2019—statistics that suggest maternal mortality is increasing [2]. Likewise, severe maternal morbidity (SMM) is also on the rise in the U.S. [3]. SMM involves unforeseen birth outcomes that cause short-term and/or long-term health effects for birthing persons, including hemorrhage, cardiac arrest, organ failure, major surgery, and other life-threatening complications that require interventions [4]. Sadly, disparities in adverse pregnancy-related outcomes are widening. Research shows women of color experience disproportionate rates of MM and SMM in comparison to their non-Hispanic white counterparts [5–6]. This issue is perpetuated by racism embedded within the maternal healthcare infrastructure to the extent of which social determinants, such as higher income and education, no longer serve as protective factors for health [6–10].

The World Health Organization (WHO) contends that maternal near miss (MNM), defined as "a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of termination of pregnancy," is a more useful indicator for studying the evaluation and improvement of obstetric healthcare than MM [11]. To date, little is understood about the contributors to MNM, especially for women and birthing people of color. Public health's tendency to rely on medical records and statistics often renders those most affected by health disparities unseen, unheard, and unnoticed in the discourse [12]. As Silverio et al. [13] write, "it is not uncommon for quantitative approaches to be unable to detect the nuances of the experiences we seek to understand." Social context is needed to conceptualize the intricacies of health inequity as a means for developing effective and sustainable solutions [14]. Therefore, using a narrative-based medicine model, [15] this study centers women of color's lived experiences [16] with surviving life-threatening pregnancy complications. Additionally, we are collecting a multistakeholder perspective by interviewing healthcare providers and partners/support persons who have witnessed a maternal near miss experience and gathering narratives from adults who lost their birth mother due to maternal causes. Using this approach, we hope to obtain an understanding of these stakeholders' perceptions and the impact of their experiences. Our goal is to uplift participants' stories as data points for influencing maternal health legislation, clinical practice, and healthcare strategy.

Methods

Study Design and Conceptual Framework

This study explores the burden of severe maternal morbidity using a narrative/storytelling approach recognizing birthing persons' experiences as legitimate sources of data. We utilized the Three Delays Model [17] to inform data collection and analysis. This model posits that severe maternal morbidity and mortality are largely the result of three critical delays: 1) Delayed decision to seek care—Barriers to making this critical decision include underestimation of the severity of the problem and its potential complications, poor understanding of danger signs and the potential scope of complications, cultural beliefs, customs, and attitudes (e.g., distrust) regarding seeking care, and lack of social supports, among others; 2) Delayed action/delay in reaching an appropriate site of care—Getting to care, by definition, requires adequate transportation. A notorious problem in the developing world, transportation is also a challenge in many U.S. states. Many states lack a sufficient number of perinatal providers; for example, half of Georgia's 159 counties lack a maternity provider [18]. Barriers like healthcare insurance enrollment and coverage, provider network limitations, as well as financial constraints can also be difficult to navigate. Further, lack of social support and/or lack of personal agency may hinder a woman's ability to act; 3) Delayed diagnoses and appropriate treatment once a facility is reached—Lack of facility resources (i.e., equipment, blood, drugs, etc.), a deficit of appropriately trained personnel, and systems that are poorly organized to manage obstetrical and medical emergencies are among the factors which can contribute to this delay.

Eligibility and Recruitment

To be eligible for the study, participants had to meet the following criteria: 1) self-identity as Black/African American, Indigenous, or Latinx; 2) over 18 years of age; 3) meet WHO near miss criteria, i.e., experience with severe postpartum hemorrhage, severe pre-eclampsia, eclampsia, sepsis/severe systemic infection, and ruptured uterus during pregnancy; and 4) can speak or read English. Recruitment occurred from July 2021 through April 2022. States originally chosen for recruitment included Georgia, Louisiana, New Jersey, and the DMV area (Washington D.C., Maryland, and Virginia) due to their high rates of maternal mortality. In September 2021, New York, Connecticut, South Carolina, and Mississippi were added to increase recruitment, followed by the addition of Alabama, Texas, and Oklahoma in December 2021. After numerous inquiries from birthing persons outside the previously included states, the study was expanded to include the entire U.S. in March 2022.

Purposive sampling was applied to this study. Birthing persons were identified through contacts with Morehouse School of Medicine (MSM) partner organizations, including our national community partner Reaching Our Sisters Everywhere (ROSE). ROSE was founded to address breastfeeding disparities in Black communities and works to normalize breastfeeding by providing resources and networking opportunities for individuals and communities. As a national expert, and in partnership with communities, ROSE builds equity in maternal and child health and in fatherhood initiatives through culturally appropriate training, education, advocacy, and support. This partnership served as an opportunity to combine our advocacy and support of the community. ROSE used their network to recruit participants and also assisted in conducting interviews. MSM and ROSE team members closely supported one another in debriefing some of the challenging and emotionally charged conversations held with participants about their MNM experiences [13]. Optum, the health services business of UnitedHealth Group, contributed a grant and volunteered their time to raise awareness and recruit and interview individuals for the study through the Optum Social Responsibility Pro Bono Program. Optum team members utilized technology platforms to recruit a large number of participants. Screening criteria were the same across all tools, and participants were cross-referenced against past and scheduled participants to avoid duplication of data.

In Phase 2, healthcare providers must meet the following criteria: a) Self-identify as a physician, nurse practitioner, physician assistant, midwife, pediatrician, psychologist, or doula; b) over 50% of their patient population identifies as a racial or ethnic minority; and c) work primarily in community-based settings. Support persons/partners will be considered eligible if they are identified by a birthing person as a support person; this can include fathers, partners, family members, peers, or friends. For adults whose mother died due to maternal causes, the death must have occurred within one year of their birth.

Data Collection

All internal and external team members were required to complete the basic Collaborative Institutional Training Initiative (CITI) course, and all CITI certificates were submitted and approved by the MSM Institutional Review Board. Team members were also trained in research interviewing techniques, including how to ask additional questions that may be relevant to each specific interview. Prior to interviews, participants completed a screening survey to verify their eligibility. Participants also completed a voluntary survey collecting sociodemographic data in addition to data surrounding the structural determinants that may have contributed to their MNM experience. These factors include age, parity, marital status, place of residence, education level, income, neighborhood characteristics, food insecurity, etc. Scheduling for interviews took place over email or messages via the technology platforms provided by Optum. Interviews were conducted virtually over the Zoom platform and typically lasted between one and two hours.

Folders containing information about interviews and data analysis, including recruitment tracking, team interviewer availability, interview scheduling, and progress, were securely stored in an encrypted online drive. Access was restricted to certified team members via password. Regular bi-weekly meetings were set up for the internal team, along with separate bi-weekly working sessions held with the funder.

Consent for interview facilitation and recording and transcription of interviews in addition to the demographic information were all collected via REDCap. After determining that mental health effects were a common theme during several interviews, the consent form was modified in the event that emergency professionals needed to be contacted. The adjusted language stated: “This certificate does not stop Morehouse School of Medicine from giving out information to prevent harm to you or others.” Any participants that mentioned suicidal ideation were also sent a Patient Safety Plan Template. This template, completed by individuals in their own time, collects warning signs, coping strategies, crisis contacts, and other material for participants to reference as needed [19].

As aforementioned, this study utilizes the power of storytelling, particularly narrative-based medicine (NBM), which applies the narratives of patients or participants to medical practice [15]. We sought to understand participants’ interactions with health providers, perceptions of quality of care, the circumstances of their “near miss,” social support received, and their lived experiences prior to becoming pregnant. The interview guide was informed by the Three Delays Model and the International Consortium for Health Outcomes Measurement (ICHOM) Set of Patient-Centered Outcome Measures for Pregnancy and Childbirth. These measures, including survival, morbidity, patient-reported health and wellbeing, and patient satisfaction with care, were developed for providers to assess to improve patients' health outcomes and well-being [20]. In total, the interview guide contained 12 main questions and 13 probing questions.

For example, one key question of the interview guide employed the Three Delays Model:

> *"How was the process when you arrived at the hospital and how was your complication resolved? Take me through this part. What was said to you? Did you know what was going on? What was communication like? How did you feel at that moment?*
>
> I. *Who/what were obstacles or facilitators to timely care?*
> II. *What was the wait time for care?*
> III. *Reasons for any delays*
> IV. *Perceptions of quality of care"*

Furthermore, most of the interviews was spent answering the "near-miss" question:

> *"Tell me about your birth experience. Tell me the story, all the way from beginning to end, describe the setting, who was involved, do you have any pictures you would like to share, please address important timelines…"*

After the completion of interviews, each participant received an email with a $100 virtual gift card as compensation. Acknowledging that re-living traumatic experiences may have an effect, all participants received a detailed list of mental health resources located in their indicated state of residence.

Data Analysis

After interviews were transcribed, transcripts were uploaded into Dedoose, a web-based qualitative data analysis program developed by researchers at University of California, Los Angeles [21]. A qualitative analysis training session was conducted and recorded for all team members involved in the process. Our team used an open coding approach in which the codes identified emerged from the data itself, also known as inductive coding [22–23]. Once codes were found, they were classified under larger themes to establish a codebook. Research team members met periodically to refine and collate codes. Each coded transcript was reviewed by another team member to ensure consistency of code application. Data analysis began in May 2022 and was completed in March 2023.

Results

This study was funded in 2021, and recruitment for Phase 1 started in July 2021. As of March 2024, we have recruited 92 racially and socioeconomically diverse birthing persons for Phase 1. Of those, 75% of self-identified as Black or African American, 19% as Hispanic or Latina, and 9% as Native American or Alaska Native (Table 1). Given the relatively low representation of some racial/ethnic groups, we will tailor ongoing recruitment efforts for Phase 2 to improve inclusivity.

Table 1: Participant Demographics (n = 92)

Variable	n (%)
Race and Ethnicity	
Black or African American	69 (75%)
Hispanic or Latino/Latina	17 (19%)
Native American, Alaska Native	8 (9%)
Asian	4 (4%)
Other	4 (4%)
Middle Eastern	1 (1%)
Indian	1 (1%)
Hawaiian or Other Pacific Islander	0 (0%)
White	0 (0%)

Severe preeclampsia accounted for 46% of participants' pregnancy-related adverse experiences (Table 2). Qualitative interviews grounded in narrative-based medicine are ongoing.

Table 2: Pregnancy-Related Complications (n = 92)

Which pregnancy-related complication did you experience?	
Variable	**n (%)**
Severe pre-eclampsia	42 (46%)
Severe postpartum hemorrhage	24 (26%)
Other	19 (20%)
Eclampsia	3 (3%)
Ruptured uterus	2 (2%)
Sepsis/severe systemic infection	1 (1%)

Recruitment for Phase 2 is scheduled to occur between July 2023 to July 2024. Findings from each phase will be published in peer-reviewed scientific journals.

Discussion

Sharing narratives from women of color who have experienced a MNM and/or SMM not only provides an opportunity to amplify the voices of those who have been historically silenced; but also, the evidence needed to advance maternal health justice. These perspectives are imperative in guiding the development of health priorities, policy, and strategies that drive optimal experiences for *all* birthing people. Some of our recommendations include equitable and respectful healthcare training, workforce diversification promotion, and health system disparity dashboards. Gathering stories from additional stakeholders will allow us to use their perspectives to refine our recommendations.

Strengths and Limitations

Initially, the interviews conducted were determined to be experiences of SMM and MNM. Utilizing the WHO near-miss approach, the screener survey was edited to include questions regarding critical interventions [11]. Participants were asked which critical interventions were performed to save their life, including cesarean section, blood transfusion, and intensive care unit (ICU) admission. After implementing these changes, the following interviews were determined to be experiences of MNM. All SMM interviews were noted as such, and they were organized separately from the MNM interviews. Additionally, we noted many completed screener surveys were fraudulent. There was an influx of emails, in both the internal email account and our funder’s email account, that were spam and/or fraudulent. To combat this issue, we incorporated a reCAPTCHA into our survey. Campbell et al. [24] explain that humans and advanced bots can successfully avoid these mechanisms; this was consistent with our findings, given that reCAPTCHA did not seem to reduce the number of fraudulent screeners completed.

Future Directions

At this time, the study has expanded to include partners and support persons of those who have experienced a maternal near miss, healthcare providers who have witnessed a maternal near miss, and adult children who lost their mother due to maternal causes. Garnering a multi-stakeholder perspective about MNM, SMM, and maternal deaths will allow us to examine the impact that severe obstetric complications may have on family members, survivors, and healthcare providers.

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Author Contributions:

Natalie Hernandez-Green: Principal Investigator, conceptualization, project administration, supervision, writing (review and editing)
Kaitlyn Hernandez-Spalding: Coordinating submission, Writing (review and editing)
Oluyemi Farinu: Supervision, Writing (review and editing)
Lasha Clarke: Supervision, Writing (review and editing)
Tamiah Lewis: Writing (review and editing)
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Ashley Molleti: Writing (review and editing)
Sherry Maxy: Writing (review and editing)
Elaine Preimesberger: Writing (review and editing)
Bilikis Oladimeji: Writing (review and editing)

Data Availability

Data are not yet publicly available. The authors will make the data available upon request to the corresponding author once the study is completed.

Conflicts of Interest

None declared.

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Abbreviations

MNM: Maternal Near Miss

SMM: Severe Maternal Morbidity

NBM: Narrative-based Medicine

WHO: World Health Organization

CDC: Centers for Disease Control and Prevention

MSM: Morehouse School of Medicine

ROSE: Reaching Our Sisters Everywhere Inc.

CITI: Collaborative Institutional Training Initiative

US: United States

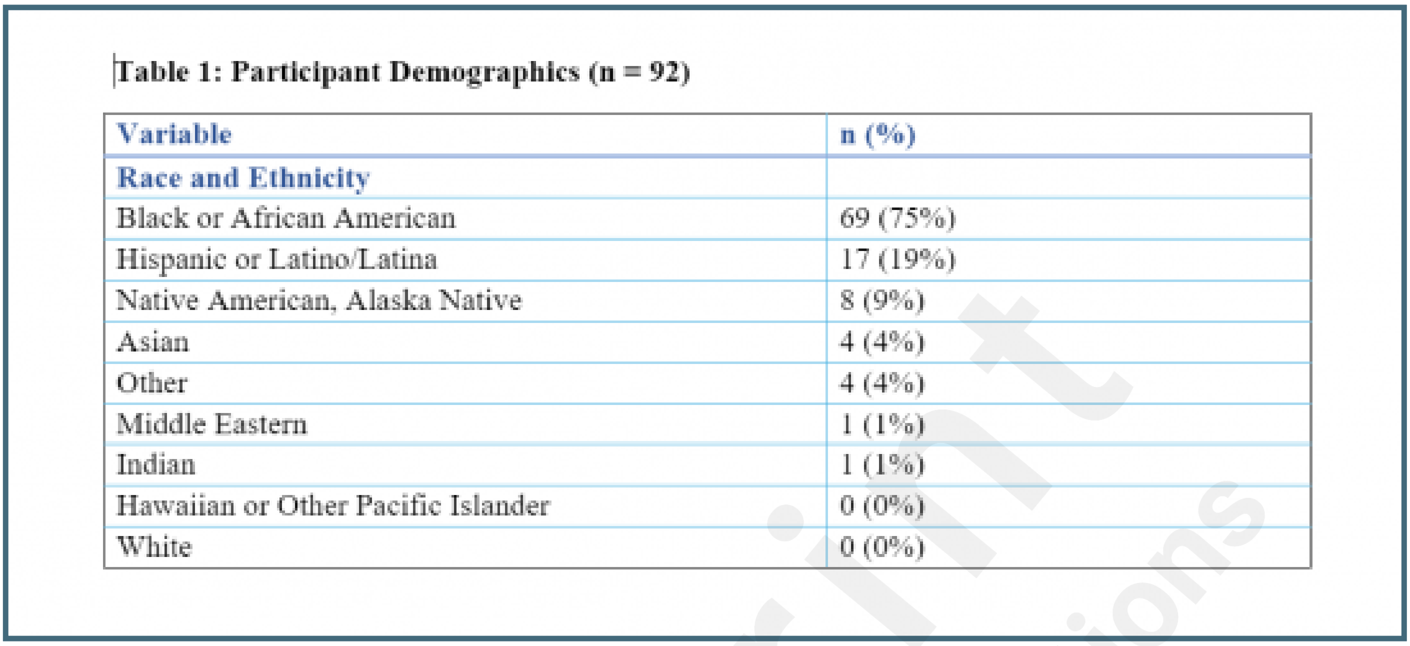
QoL: Quality of Life

ICU: Intensive Care Unit

Supplementary Files

Figures

Participant Demographics (n=92).



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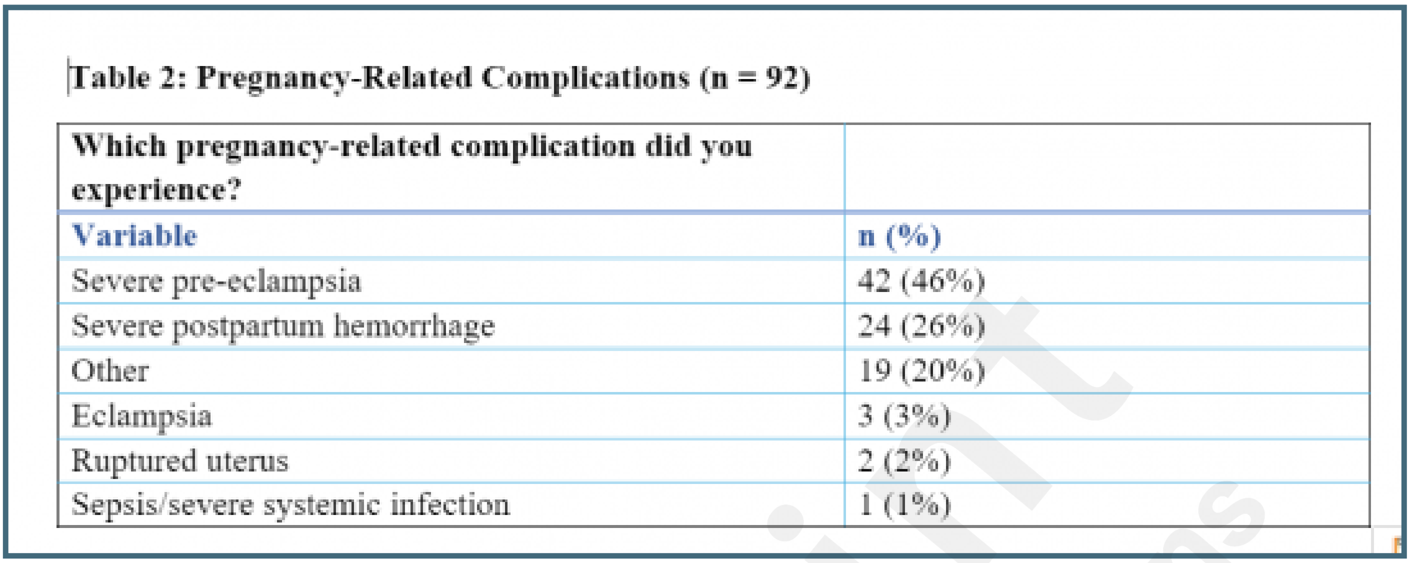
Pregnancy-Related Complications (n=92).



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