



**Women's Experiences with  
Severe Maternal Morbidity  
in New York City:  
A Qualitative Report**

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**Authors:**

Folake Eniola, MPH

Adina Nack, PhD

Paulomi Niles, PhD

Christine H. Morton, PhD

Hannah Searing, MA, MHS

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## ACRONYMS AND ABBREVIATIONS

HIPAA	Health Insurance Portability and Accountability Act of 1996
ICU	intensive care unit
MM	maternal mortality
NICU	neonatal intensive care unit
NYC	New York City
QA	quality assurance
QI	quality improvement
SMM	severe maternal morbidity
SOC	Supplemental Online Content
VBAC	vaginal birth after cesarean

## EXECUTIVE SUMMARY

Maternal mortality has decreased in New York City (NYC) since 2001, but unacceptable racial and ethnic disparities remain: During the period 2011–2015, Black non-Latina (Black) women<sup>a</sup> had an eight times greater risk of pregnancy-related death (or maternal death) than White non-Latina (White) women. Latinas and other women of color were also at much higher risk of maternal death compared with their White counterparts.

For each maternal death, approximately 100 women suffer from life-threatening complications—collectively referred to as severe maternal morbidity (SMM)—and the same racial/ethnic disparities are seen there as well, driven by the pervasive stress of racism. With the growing recognition that both clinical and community action were needed to prevent adverse maternal outcomes and reduce the associated racial/ethnic disparities in SMM, the NYC Department of Health and Mental Hygiene (NYC Health Department) developed a three-pronged approach to address SMM. In collaboration with the Fund for Public Health in New York City and with funding from Merck for Mothers, NYC Health Department implemented a project to: 1) improve the quality of maternity care at NYC hospitals; 2) learn about mothers’ needs and their experiences with SMM, and the ramifications of SMM on their lives, to inform action and further research; and 3) mobilize and inform communities about maternal health.

This publication details the results of a qualitative research study aimed at learning about mothers’ needs and experiences after an SMM event. Lessons learned can help with strategic planning for maternal health programs across New York City and other jurisdictions.

Key findings and lessons from this study include the following:

- The style of health care providers’ interactions with women and their families influenced women’s experience of, and recovery from, SMM.
- Generally, women preferred clinicians who utilized patient-centered interaction styles to develop mutually respectful partnerships.
- Some women reported perceptions of not being listened to or believed by health providers.
- Experiences of poor care led women to mistrust health care providers and facilities and influenced their decisions about whether and when to seek future, needed care.
- Women’s experiences of SMM were made more challenging by complex social and medical needs and stressors, including housing conditions and stability, financial insecurity, and the need to navigate multiple, uncoordinated care systems.

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<sup>a</sup> The authors acknowledge that not all birthing people identify as women. Throughout this report, the terminology of “women” and “mothers” is used for consistency with the data sources used and the literature cited.

- The consequences of SMM events extended into the postpartum period (also called the “Fourth Trimester”<sup>b</sup>), when women faced added challenges to full recovery. Social support was essential to effectively address women’s postpartum mental health needs following a complicated or traumatic birth experience, which included SMM events.

Selected key recommendations include the following:

- After an SMM event, women and their families need accessible health education and information so they can understand what happened, emotional support so they feel cared for, a plan for coordinated follow-up care, and resources for ongoing physical and mental health issues.
- An SMM event was physically and emotionally destabilizing for women and their families. Just as the medical care during the birth hospitalization should be patient-centered, equitable, and respectful, the discharge process needs to ensure an integrative, holistic assessment of women’s needs postpartum. These needs are shaped by their having faced life-threatening and frightening events during a time when they were also striving to care for a newborn.
- Medical, psychological, and public health professionals need to understand the complex experiences of SMM events from patients’ points of view, to better support women and families after an SMM event during the Fourth Trimester.
- Supportive options for women who have had an SMM event should include extended hospital stays, home visiting by trained nurses, postpartum doula services, comprehensive mental health services, and access to other resources/care to ensure healthy starts for babies, mothers, and their families.

Lessons for future research include:

- Severe maternal events are traumatic for everyone involved. Research about, and service provision for, people who have experienced these events should take a trauma-informed approach. By recognizing the widespread impacts of trauma and its complex intersections with reproductive experiences, future research can build on this study’s foundation of ideas for how to support potential paths of recovery that not only recognize the impacts of trauma, but also actively protect against retraumatization for all persons affected by the event.
- Most of the women in this study were less than six months postpartum when the interviews were conducted. The health and social impacts of experiencing a severe complication are ongoing and demand further examination.

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<sup>b</sup> The Fourth Trimester concept focuses on the critical 12-week transition period from pregnancy to parenting for women and their families and is gaining greater acceptance and momentum among maternity providers. As a new paradigm, the Fourth Trimester recommends that postpartum care should be an ongoing process, rather than a single encounter, with services and support tailored to each individual’s needs, to enable mothers’ recovery from the birth and nurture of their infants.

## BACKGROUND

Maternal health and well-being are critical public health concerns in NYC. Deaths related to pregnancy and childbirth have fallen in NYC, yet profound inequities remain: During the period 2011–2015, Black non-Latina (Black) women had an eight times greater risk of pregnancy-related death (or maternal death) than White non-Latina (White) women. Latinas and other women of color are also at much higher risk of maternal deaths when compared with their White counterparts.<sup>1</sup>

For each maternal death, approximately 100 women suffer from SMM, such as heavy bleeding, blood clots, kidney failure, stroke, or heart attack. SMM increased by 34% in NYC from 2008 to 2014 and affects approximately 2,500 to 3,000 NYC women each year.<sup>2</sup> Black women in NYC are about three times more likely to experience SMM compared with White women.

Research from a variety of disciplines demonstrates that the pervasive stress of racism (a system of interlocking structures at the societal, institutional, and interpersonal levels that confer privilege or disadvantage)<sup>3</sup> within communities of color, coupled with longstanding and intentional disinvestment in these communities (including redlining,<sup>4</sup> predatory housing policies,<sup>5</sup> and unequal funding for schools<sup>6</sup> and hospitals<sup>7</sup>) are the root causes of these and other health inequities. Activists from the sexual and reproductive justice movement (led by Black women since the 1990s) have pushed the health community to address persistent and profound disparities in maternal health and well-being. Members of the sexual and reproductive justice movement locally have helped to increase public understanding of this issue and have driven the NYC mass media to cover several high-profile maternal deaths. There is a growing recognition that both clinical and community action are needed to prevent maternal complications and deaths.

As part of a broader strategy to address this public health crisis, in 2017 the NYC Health Department, in collaboration with the Fund for Public Health in New York City, received a grant from Merck for Mothers to implement the Severe Maternal Morbidity Project. Between 2017 and 2020, this Project worked directly with clinical and community partners to improve maternal outcomes, promote health equity, and reduce racial/ethnic disparities in SMM in NYC.

To address SMM, the NYC Health Department has a three-pronged strategy to:

- Improve the quality of maternity care at hospitals
- Learn about mothers' needs and their experiences with SMM, and the ramifications of SMM on their lives, to inform action and future research
- Inform and support mobilization of communities around maternal health

When the SMM Project began, the consensus among Project leadership was that the communities most affected by this issue should guide the process of improving maternal health outcomes, specifically around life-threatening complications related to childbirth.

This publication is one of a three-part series covering the work of the SMM Project. It describes the results of qualitative research aimed at learning about mothers' needs and experiences with SMM. It details the steps taken to design, conceptualize, and execute a qualitative study of women's experiences with SMM, including the methods employed, staffing, and ethical considerations. Materials developed for use in carrying out this research are included in the Supplemental Online Content (SOC). This report also highlights findings from in-depth interviews, including implications for public health and maternal health care clinicians. This report is intended to help public health agencies and community-based organizations to integrate the voices of women impacted by SMM in planning for maternal health projects and programs across NYC and other jurisdictions.

## **PURPOSE AND OBJECTIVES**

The purpose of this qualitative study was to explore the perceptions and experiences of women who faced an SMM event while giving birth, as well as the physical, emotional, social, and financial consequences of the severe complication on their lives. Participants were recruited from collaborating hospitals and their adjacent communities. Details of the methodology for the study are in the SOC, pp. 3–5.

Key questions included:

- How did women experience pregnancy, childbirth, and the SMM event?
- What were women's perceptions of medical care during pregnancy and childbirth (e.g., quality, communication, and respectfulness), as well as their experiences related to implicit bias or racism, whether interpersonal, institutional, or societal?
- What were the emotional, physical, social, and financial consequences of the SMM event on women and/or their families?
- How did women experience the process of recovery and healing from the SMM event?



## METHODOLOGY

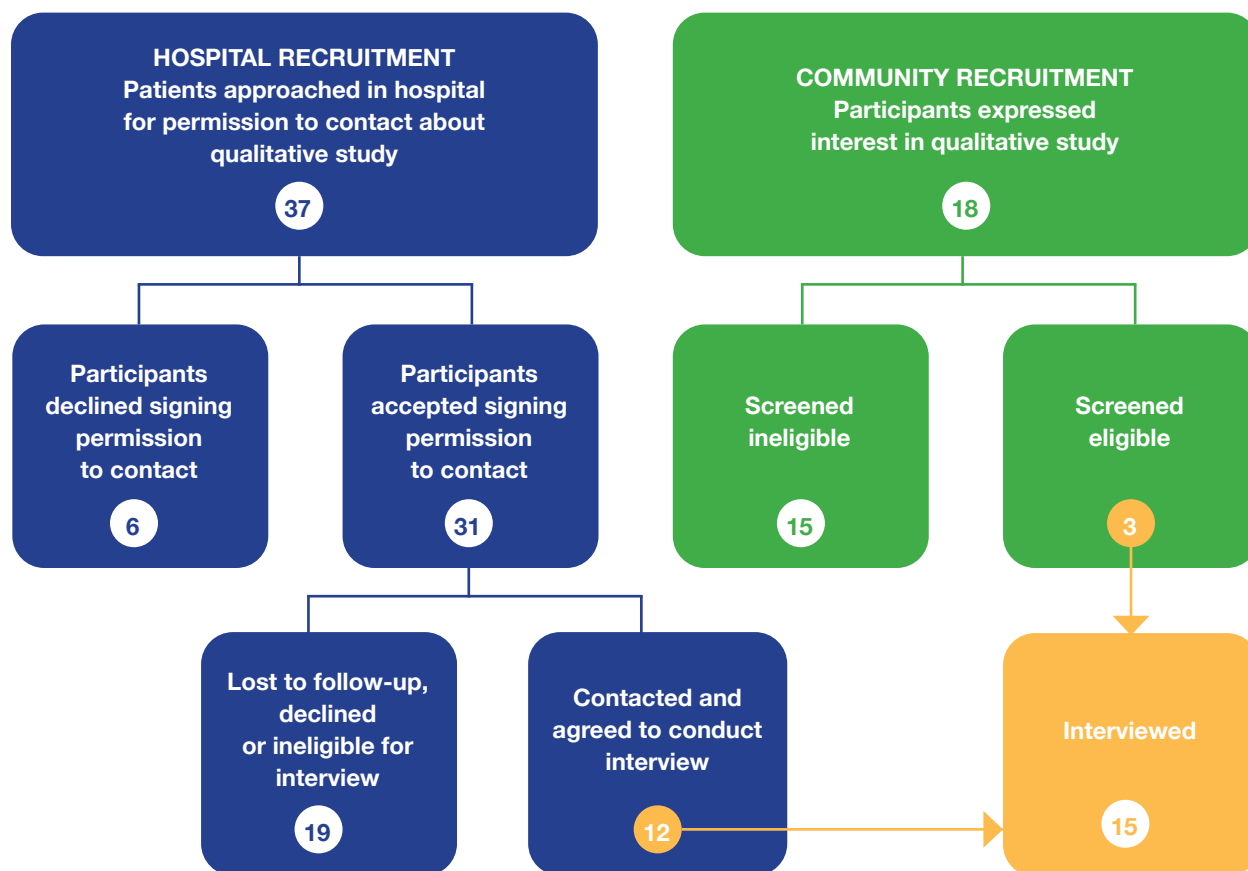
Researchers used a semi-structured guide to in-depth interviews with women selected from collaborating hospitals or their adjacent communities, based on eligibility criteria and recruitment strategies. The interview guide used in the study is shown on pp. 6–13 of the SOC.

### SAMPLING

The total sample consisted of 15 participants with completed interviews who were recruited via two sampling strategies (hospital and community recruitment), as outlined below.

Figure A shows that overall, 55 eligible women were identified through hospital and community recruitment; of these, 37 were identified via hospital recruitment, and 31 (89%) agreed to be contacted about the study. Upon successful contact via a follow-up call 1–2 months following discharge, 12 women agreed to be interviewed and completed the interview. From the community recruitment, 18 potential participants contacted Project team members; after being screening for eligibility, three met the inclusion criteria and completed their interviews.

**Figure A. Qualitative Study Hospital and Community Recruitment Flowchart**



Participants were recruited and interviewed between November 2018 and February 2020. The first group of respondents were recruited at participating hospitals after they were identified using medical records as having had a severe complication during the birth hospitalization. The SOC (pp. 14–16) provides examples of the forms used to recruit hospital patients. Scripts used to contact potential participants are included in the SOC (pp. 17–19).

It became apparent over time, however, that the intended sample size could not be attained solely through hospital recruitment. Halfway through the Project, a convenience sampling approach was added: Project team members placed recruitment flyers at locations most likely frequented by new mothers in communities located near hospitals (SOC, pp. 20–23). Individuals who self-identified and expressed interest in the study were screened to determine their eligibility (SOC, pp. 24–25), and they were subsequently contacted to schedule an in-depth interview. This interview took place within two weeks of the initial contact and screening call, at a quiet, private location chosen by the participant. The SOC explains the recruitment processes in more detail and provides a list of the types of sites from which participants were recruited (pp. 26–27).

## **ETHICAL CONSIDERATIONS**

Institutional Review Board approval of the study protocol was obtained from the NYC Health Department and each participating hospital. Informed consent forms were tailored to each recruitment strategy (SOC, pp. 28–35). Incentives were provided to all participants at the conclusion of the interview (or at the time the participant chose to withdraw from the study). Participants' compensation included a round-trip MetroCard (current value of \$5.50) and a \$50 Visa® gift card.

## **DISTRESS PROTOCOL AND ADDITIONAL RESOURCES**

Given the sensitive nature of the questions, the Project team acknowledged that participants might experience emotional discomfort or strong feelings during or after the interview. Therefore, the Project team, interviewers, and consultants undertook specialized training through an eight-hour NYC Health Department Adult Mental Health First Aid course.<sup>6</sup> Additionally, a licensed social worker on the team developed a distress protocol in case any respondents experienced some form of psychological distress during an interview due to remembering the events that they were asked about (SOC, pp. 36–42). The psychological distress may include normal reactions such as anger, frustration/impatience, and sadness. This protocol is a guideline to help interviewers (SMM Project staff interviewing respondents) identify potentially distressed respondents, to provide the assistance respondents may need, and to standardize the SMM Project team's response to these potential situations. The social worker was available during all interviews to triage and provide guidance on issues that might

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<sup>6</sup>This training can be accessed at: <https://mhfa.cityofnewyork.us/>.

arise; afterward, the same team member was available to debrief the interviewers, as needed. All participants received a list of accessible, supportive, community-based mental health and clinical resources at the completion of their interview SOC (pp. 43–52).

## **INTERVIEWER TRAINING**

All three interviewers were self-identified women of color with experience in supporting pregnant and parenting people as doulas, childbirth educators, and other social services professionals. Two were Spanish speakers, to accommodate participants who preferred completing the interview in Spanish. All interviewers received training on qualitative research data methods, mental health first aid, research ethics (e.g., data integrity and confidentiality), how to conduct interviews on sensitive topics, and how to manage confidential data (SOC, pp. 53–76). All members of the Project team were required to be certified in human subject research through the Collaborative Institutional Training Initiative (CITI).

## **STUDY LIMITATIONS**

Because of the recruitment challenges described above, the sample included just half of the number of participants who were sought for the study. Although the smaller sample limits the generalizability of study findings, it was sufficient to support the aims of theory-building and point to core ways in which women’s experiences of SMM can inform quality of care improvements. By relying on self-reported data from participants, the “patient’s point of view” is centered in the analysis, giving researchers and policymakers insight into the complex ways in which SMM impacts not only physical health but also mental health, social relationships, and the ability to return to prenatal roles (both paid and unpaid labor) and to provide care to newborns.

The timing of the study in relation to giving birth likely shaped the range and scope of data collected. These interviews, conducted within 3–6 months postdelivery, reflect the women’s immediate and short-term perceptions of SMM experiences. A follow-up study with these participants or a larger study of different participants conducted at least one year after an SMM would likely better capture the breadth and depth of long-term impacts on women’s health and well-being.

## **ANALYTIC APPROACH**

All data were securely stored on a password-protected server, to protect participants’ confidentiality. The interviews were audio-recorded and transcribed (and translated from Spanish to English, if needed). Transcripts were stripped of all identifiers and reviewed by a member of the Project team for quality and fidelity to the audio recording. Final deidentified

transcripts were uploaded to Dedoose® data management software, version 8.3.16 (SocioCultural Research Consultants, LLC, Manhattan Beach, California) for analysis.

The data (interview transcripts) were collaboratively coded and analyzed following a thematic analysis approach,<sup>8</sup> drawing on coding methods for grounded theory.<sup>9</sup> The research analysis centered participants' experiences to anchor interpretations, strengthen theoretical rigor, and minimize potential individual researcher biases. In the final analyses, the researchers considered whether the narrative themes were congruent with theories around social stigma, reproductive equity, and quality of care.<sup>10</sup> The analysis of the data was based on the principles of grounded theory<sup>11</sup> and used constant comparative methods<sup>9</sup> to adjust analytic categories to theoretical concepts as they emerged. The overarching coding categories looked at different stages in the SMM experience: the prenatal period, childbirth, the spiral into acute SMM, the recovery from SMM, and adaptations to other postpartum challenges. The data were then reexamined with a focus on the medical, social, and psychological aspects of the participants' SMM-relevant experiences with significant others, health care clinicians, employers, etc.

## FINDINGS

### PARTICIPANT CHARACTERISTICS

The 15 women who participated ranged in age from 27 to 40 years old. Participants were asked to self-identify their race/ethnicity: eight identified themselves as Black (five of whom were non-Hispanic), five as Hispanic/Latina, one as White non-Hispanic, and one as Asian/Pacific Islander. Seven of the women were married or living with a partner, while eight were single or not living with a partner. English was the preferred language spoken at home for six women, Spanish for two, bilingual English and Spanish for three, and languages other than English or Spanish for four. Nine of the interviewees did not experience any changes in their living situations from the time they received prenatal care through the time of the interview, while six moved during pregnancy or in the postpartum period. Five of the participants experienced housing instability while pregnant or during the postpartum period. Eleven were employed prior to giving birth—with eight working in health care or a health-related field—and 10 utilized Medicaid.

### CLINICAL CHARACTERISTICS

Six women reported giving birth at less than 36 weeks' gestation (preterm). Five were pregnant with their first baby. Ten of the women did not have labor induced. Ten had a cesarean<sup>d</sup> birth, six primary and four repeats. Four women had vaginal births and one had a vaginal birth after a cesarean (VBAC). Primary SMM diagnoses among the sample included hemorrhage (defined

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<sup>d</sup> Incision through a pregnant woman's abdominal wall and uterus for extraction of the fetus.

as a loss of a large amount of blood in a short period, either externally or internally) (n=6) and placental issues (placenta previa or placental abruption<sup>e</sup>) that led to hemorrhage. Other diagnoses included pulmonary embolism<sup>f</sup> and chronic anemia. Eight women were transferred to the intensive care unit (ICU) soon after giving birth, with five of them reporting a stay of 1–2 days.

## REPRODUCTIVE HEALTH CHARACTERISTICS

Women were asked general questions about their reproductive health, including current and future reproductive health choices. Women discussed whether the pregnancy was planned, whether they had seen a health care provider before becoming pregnant, and whether their recent birth experience had an impact on their decisions to have another child. A slight majority of women reported that they had planned their pregnancies. Eleven reported not having seen a health care provider in the months prior to becoming pregnant, and six reported that this SMM experience affected their future reproductive choices.

## WOMEN'S EXPERIENCES

### Maternity Care

Maternal health care encounters are interactions among individuals that take place within contexts shaped by structural policies, professional norms, social statuses (insurance type, education), personal identities (race, immigrant status, language), and cultural constructions of roles (e.g., patient, woman, mother, physician, midwife, nurse, etc.). While usually framed around the idea of a private, interpersonal relationship, such interactions are also structured patterns produced and supported by policies, procedures, and norms within organizations and systems.<sup>10</sup>

Historically, Black women and women of color have experienced worse maternal and neonatal outcomes within U.S. health care settings. Women's accounts of their SMM experiences need to be analyzed within the broader structures fostering and perpetuating racist and patriarchal practices.<sup>10,12</sup> Understanding that these social determinants of health (i.e., the social and economic conditions that influence health outcomes) and socioeconomic stressors result from structural and systemic racism helps to focus an equity lens on the issue.<sup>13</sup> Studies have pointed to mistreatment of women of color in maternal care settings, resulting in women of color having higher rates of SMM and mortality.<sup>14</sup>

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<sup>e</sup> Placenta previa occurs during pregnancy when the placenta, the organ that allows interchange between the fetus and the mother, is abnormally placed and partially or totally covers the cervix, the opening to the uterus. Placental abruption, which occurs when the placenta detaches from the uterine wall, is a life-threatening complication for women and infants.

<sup>f</sup> Pulmonary embolism is a life-threatening event that happens when a blood clot gets caught in one of the arteries going from the heart to the lungs, blocking normal blood flow.

Women’s accounts of their interactions with clinicians demonstrate the ways in which they not only sought to manage challenges but also made sense of—and assigned meaning to—having survived and starting to recover from SMMs. In this study, each woman described interactions with clinicians (i.e., physicians, midwives, advanced practice nurses, and other health care professionals, such as nurses and therapists) when recounting key events before, during, and after childbirth. Each woman’s descriptions of, and reactions to, their clinicians’ verbal communication (word choice and tone) and nonverbal communication (facial expression, ways of initiating physical contact with patient, etc.) with them during health care interactions were coded.

### **Clinician Interaction Styles**

In comparing and contrasting interaction descriptions across study participants, three clinical interaction styles that have previously been defined in the literature were identified: a) the biomedical model, in which women are viewed and treated as patients, cases, or diseases, and interactions are short and clinically focused, with technical jargon used;<sup>15</sup> b) the moral surveillance model, defined as an interaction style in which clinicians communicate negative judgments about patients’ characters (e.g., their morality, intelligence, or responsibility) during medical encounters that leave patients feeling judged, discredited, or discounted by the clinicians’ words or actions;<sup>16</sup> and c) the patient-centered model, defined by the Institute of Medicine (IOM) as providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.<sup>17</sup> By the study participants’ accounts, their experiences of health care during prenatal care, birth hospitalization, and postpartum recovery from SMMs were shaped by these three distinct styles.

### **Biomedical Model**

The biomedical model of clinician-patient interactions is characterized by the clinician’s treatment of the patient’s body in a scientific or neutral way. In this model, clinicians engage in what has been described as a “paternalistic” relationship, often noted for its top-down style, in which clinicians report health information to patients and then prescribe a plan for action without input from the patient. The implicit or explicit expectation is for the patient to show respect for the clinician’s expertise by complying with it. There is rarely a dialogue in the biomedical model, and patients are not encouraged to ask questions, express their views, or communicate their needs. In this model, clinical care can be viewed as meeting high “quality” care, when defined narrowly as clinical outcomes.

However, such depersonalizing and emotionally distanced behaviors by clinicians can have negative consequences for patients' health and well-being. Of the 15 participants, all but one described interacting with clinicians who did not provide clear enough information about their physical health (diagnosis, prognosis, treatment plans) and did not make them feel comfortable asking questions, requesting needed medical attention, or expressing mental health needs.

For example, one woman reported that she was offered health services in a manner and at a time that was not only inconvenient but also contraindicated by her recovery needs. She described that hospital routines and clinician schedules determined when she would be seen, rather than her health condition. In particular, although she wanted to breastfeed, she viewed the lactation and mental health consultations she received as invasive during her recovery from a severe hemorrhage, and she felt that the nurses did not take her intense pain into account while providing these routine consults:

*I was being seen by so many people.... One woman came in at 11:00 p.m., and I was in such pain, and that woman was practically forcing me to pump... They should be more considerate.... I told one person that I couldn't talk, and they showed up for the consultation anyway. It was a psychologist. They're invading your space, and in the moment, it's not necessary. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)<sup>9</sup>*

In another example, a woman recounted that her doctor did not explain that her bowel had been perforated during her repeat cesarean, and this left her with doubt about the quality of her care and the likelihood of recovering her health:

*Basically [the provider] just told me I lost a lot of blood. He didn't even go into detail of what was going on. He just told me... that my uterus had stopped pumping [contracting], so he had to reopen me. [Interviewer: Did that make sense to you?] No, it did not. You didn't know that my uterus wasn't pumping before you closed me?" (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

Another woman heard information about her SMM diagnosis for the first time while surrounded by clinicians discussing the plan for performing surgery, in which the doctor referred to her not by name, but by her diagnosis:

*He said, "Okay, so we have a placenta abruption patient. We're going to perform a C-section on her." They started saying scientific words, doctor's words, that I didn't understand. The whole time I was listening to them, but I didn't understand, but I'm praying, like, "God, please help me, help my child. Make sure everything is fine." (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

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<sup>9</sup> In the presentation of findings from this study, each woman is identified by a case number and three descriptors: her self-identified race/ethnicity, her delivery mode, and her primary SMM diagnosis.

The clinician's use of jargon and unwillingness to include the patient as a participant in this conversation left her going into surgery fearing for her and her newborn's lives. Another woman reported that no one explained to her what was happening:

*Even though there are trained doctors, and trained nurses, I think they need to address people like human beings.... You ask them questions; you can't get a straight answer. They're trying to give you some terms they know you don't understand. Every time they talk to you, you have to be Googling. What if I couldn't read? (Woman #14, Black Hispanic, primary cesarean, preeclampsia<sup>h</sup>).*

Women in this study described how they wanted their partners or loved ones who were with them in the hospital to be given information about their condition. However, several reported that their significant others were often ignored by clinicians. For instance, one woman started crying as she recalled:

*They rushed me to the surgery room, and I didn't know nothing until the next day. I think when I went into the surgery room, I think [my sister] was already outside.... She [my sister] told me that, as she was waiting there, there was a lot of doctors going in, but no one told her what's going on. (Woman #5, Hispanic, repeat cesarean, postpartum hemorrhage)*

Women reported that when their partners or support persons were not given information or updates, they became fearful and traumatized. Some women described feeling frustration when family members were given information before they themselves knew what had happened.

One woman reported that her partner had been in the hallway on the phone organizing child care when she began to hemorrhage. He heard her screaming and later heard hospital staff, "yelling 'blood transfusion—we need the blood bank!'" She described debriefing with her partner while recovering and telling him, "I saw myself die. I saw the white light. I was screaming." She then recalled how he verified her memory:

*He said, "Yeah, I heard you screaming. Nobody told me anything. They kept walking past me. They kept walking past me, and nobody told me anything. It wasn't 'til I heard you screaming, and I started talking about legal actions that they went and told me that something took place, that your uterus stopped pumping." (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

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<sup>h</sup> Preeclampsia refers to the development of high blood pressure with protein in the urine or significant swelling, or both, due to pregnancy or the influence of a recent pregnancy; it usually occurs after the 20th week of gestation, but it may develop before this time or postpartum.



One woman pushed back against an institutional decision to discharge her after an antepartum hospitalization when she was at 30 weeks' gestation. She knew she was at risk of bleeding and preterm birth and was terrified to be at home alone.

*They didn't send me home, because I refused to go home. The next day I was still bleeding heavy, because to me, it was heavy. To them, heavy is one pad soaked in an hour... I was bleeding a lot with blood clots, so no, I didn't feel safe at home. I explained, "Listen, you're going to send me home, and I don't feel safe, what if something happens? Then you guys are going to be responsible." (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

That participant succeeded in advocating for a longer stay in the hospital. *"The nurse manager told me the next day that the best thing I did was refuse to go home."* The next day she experienced a placental abruption—a life-threatening condition. She was still in the hospital with access to prompt treatment, and she and her baby lived. If she had been home, the outcome might have been different.

### **Moral Surveillance Model**

Pregnancy is a time of health surveillance: Clinicians gather data about women's characteristics and behaviors prenatally and during and after childbirth to enable them to monitor the health status of the mother and the newborn. Women's behaviors and decisions during pregnancy are often highly scrutinized and judged by many in society, including health care personnel.<sup>18,19</sup> This is particularly true for Black women and others whose choices and behaviors may be viewed through the lens of structural racism.<sup>20</sup> The term "moral surveillance" was coined to describe a clinician-patient interaction style characterized by clinicians going beyond the biomedical norms of paternalism, use of medical jargon, and assumed compliance from patients.<sup>16</sup> In particular, moral surveillance interactions include clinicians' consistently failing to effectively communicate about health issues with their patients and explicitly or implicitly communicating their negative judgments of their patients. This interaction style often reflects a clinician's own biases, including racism, classism, and sexism.<sup>16</sup> One-third of the participants in this study reported experiences indicative of this type of interaction.

Five of the women interviewed reported feeling that clinicians treated them as if they were either unintelligent, irresponsible, dishonest, or unreliable (i.e., not able to accurately report experiences of symptoms). These interactions left women feeling deeply disrespected and not inclined to trust these clinicians to prioritize their health and well-being. Some women experienced this type of disrespectful care from the moment they arrived in triage. One woman's choice of adjectives when describing her first nurse illustrates how the nurse communicated meaning through her words, tone, and actions:

*She didn't even introduce herself. She was just like, "Just lay on the bed." That was actually the same nurse that, when I grabbed her arm to hold when they [were] going to put the IV in my arm, she was rude. She was very nasty to me. (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

A woman who began hemorrhaging at home, several weeks before her due date, described a nurse who insisted on seeing pictures of the blood loss in her home bathroom before her family cleaned up:

*They wanted to see how heavy I was bleeding, because I feel like my words weren't enough. I don't know if they thought I was lying about the golf ball-sized blood clot, but they wanted to see it physically. I showed them the picture, and they still didn't know what was wrong with me. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

The same woman reported that another nurse did not believe that she knew her blood pressure measurement. Later, when admitted for birth hospitalization, she described negative interactions after epidural anesthesia was unsuccessful. Her doctor later framed the need for general anesthesia as in some way being her fault:

*The last thing I remember was the doctor doing a cold test to make sure that I was numb completely from the epidural. She put [ice] on my stomach, and I said I felt it. She put it on my legs, and I said I felt it. She put it everywhere, and I felt everything. She looked at me like she couldn't believe that I was feeling everything.... I felt like she was upset that she had to put me to sleep. She was like, "Ah, okay, hon, we're going to have to put you to sleep because you're feeling everything." I felt relieved because I wasn't going to feel what I'm feeling, but then I felt scared because I didn't know if I was going to wake up or if my baby was going to be fine. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

Due to the emergent nature of the situation and the need for general anesthesia, there was no time to adjust the epidural, but there was likely an opportunity to educate and reassure a patient that the clinicians would do everything possible for her and the baby.

In another example, a woman described a nurse who became angry with her as she expressed pain. This resulted in negative impacts on her health:

*There was one nurse, she yelled at me because I grabbed her arm to hold my pain. She's like, "Don't do that." I just didn't want her in the room. When she was in the room, my whole tension just came up. I would get more contractions and everything more when she was in the room." (Woman #11, Black non-Hispanic, primary cesarean, preeclampsia/sepsis<sup>1</sup>)*

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<sup>1</sup> Sepsis is a potentially life-threatening condition caused by the body's response to an infection.

This interaction style resulted in unnecessary stress for women whose health conditions were already fragile. In a few cases, women described clinicians as using sarcasm and inappropriate humor to mock them and/or express disapproval of their birthing outcomes. For example, Woman #14 (Black Hispanic, primary cesarean, preeclampsia) told the interviewer how she remembered hearing the doctor performing her cesarean saying, “*Oh, congratulations on your preemie*” in a sarcastic tone. She remembered that medical students in the room were talking and laughing, as if it were her fault that her first baby was born prematurely.

One woman, herself a perinatal nurse, reported that the physician performed a manual extraction to remove placental fragments from her uterus to manage her hemorrhage, a very painful procedure. In postpartum recovery, she reported feeling stigmatized as “drug seeking” when she requested stronger pain medications. She said:

*I had to ask for OxyContin. The nurses were very hesitant to give it to me because I had a vaginal birth. I'm trying to explain to them I didn't have a regular vaginal birth. I had traumatic birth.... You know what I mean? I'm not drug seeking. I just want to be comfortable enough to care for my child and be comfortable because it's not fun being in pain.* (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)

She was only able to obtain effective pain medication after she contacted a physician who knew her professionally and trusted her self-assessment. Her observation illustrated how maternity unit culture affects patient experience:

*That was very interesting because, usually, the research says, if the provider or the contact is of another race, they're hesitant to prescribe pain meds, but these were all black nurses, and they knew I was a nurse. Even then, me asking for stronger pain meds, they were uncomfortable, which is very weird because, where I work, we're all about pain control.* (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)

Another woman, who sought care for unexplained bleeding prior to pregnancy, had been told by her physician that she could not conceive and should have a hysterectomy.<sup>j</sup> Before she was due to have this procedure, she discovered that she was pregnant. She then made the decision to change providers, which she accomplished with help from the insurance company:

*I felt uncomfortable from the beginning, obviously, because if someone tells you that you can't have any more children, and then you get pregnant, you can't trust those people. I just went ahead and made the change at the second appointment during my pregnancy. They're monthly appointments, so I think I made the change in July, and by August, I had my new doctor.* (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)

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<sup>j</sup> Hysterectomy is the surgical removal of the uterus; unless otherwise specified, it usually denotes complete removal of the uterus (corpus and cervix).

In the aftermath of her recovery, Woman #8 felt “insufferable pain” and said her nurse “didn’t want to hear it.” As her pain intensified, her blood pressure increased to dangerous levels, and the nurse consulted with an ICU specialist, who corrected the placement of the tube that was causing her pain. After thinking it over, she filed an official complaint.

*In the end, I did make a complaint. She’s a nurse, and I understand her job, but she has to understand that, when a patient complains, it’s because they’re in pain. At the end of that situation, a resident, a Colombian woman who spoke Spanish, came to me. She was very nice, and we were able to connect. I explained the situation; she understood and said, “Do you want me to remove her?” I don’t know exactly what her position was, but she was able to manage all of the nurses there. She removed her from my service. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Woman #2 also referenced her professional status and knowledge when she expressed dissatisfaction and criticism about the care she received. “*I am not the typical patient. Not only am I nurse, I’m also an OB [obstetric] nurse, so I understand the language. I understand the medications. I understand the indications.*” She knew the warning signs that indicate a call or visit to her provider. Yet, when she observed irregular and potentially worrisome blood loss at home postpartum, she was reluctant to return to the hospital:

*It [the bleeding] was very heavy. I knew I was supposed to go back, but I didn’t want to go back. As long I wasn’t hemorrhaging, I was not going back.... I just watched it. It took a long time for my bleeding to stop, and I passed a clot at home, which meant technically I should’ve gone back to [Facility name], but I did not. (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)*

As a nurse and fourth-time mother, Woman #2 knew that her postpartum bleeding was a warning sign and that “technically” she met the criteria to seek medical care. Instead, she decided to stay home because she did not want to return to a hospital where she had been mistreated. Later, as she considered her contraceptive plan, she questioned her overall confidence in the health care system:

*I didn’t go back there for my six-week check-up. I went back to my GYN [gynecologist]. I was supposed to get a tubal [ligation<sup>k</sup>]. I don’t want them to do a tubal on me. I have not set foot back there. This whole incident, it has made me more hesitant to get a tubal, because I’ve been researching.... It’s made me even more hesitant now with health care.... I will figure out some way not to get pregnant because I’m not getting pregnant again. I still have pain. I’m still uncomfortable. (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)*

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<sup>k</sup> Tubal ligation is a surgical procedure for female sterilization that involves severing and tying the fallopian tubes.

## Patient-Centered Model

The patient-centered model of interaction is grounded in a biomedical approach but improves upon it by considering the patient as a whole person in the clinical interaction (i.e., the physical, social, and psychological ramifications of the health event). A quality patient-centered interaction style in childbirth should be grounded in principles of respectful care, such as those outlined in the *NYC Standards for Respectful Care at Birth*,<sup>1</sup> and the International Childbirth Initiative: 12 Steps to Respectful MotherBaby-Family Maternity Care.<sup>21</sup>

In contrast to the feelings of disrespect, disregard, and disconnection associated with moral surveillance and biomedical models, the study participants described interactions with patient-centered clinicians as respectful, leaving them feeling well cared for as they received individualized care. This personalization of care included clinicians asking about patients' feelings and facilitating their active involvement in decision-making. These positive experiences often began during prenatal care, with one woman explaining what she most valued about her provider's prenatal care:

*I liked the fact that I didn't waste a lot of time at the appointment, she would see me when I arrived.... I liked that she was very direct with me.... She treated me in a friendly way. You know how with gynecologists, when one has to take off their clothes, sometimes you can feel shy. However, she tries not to make you feel like that. She explains the situation and puts your health first.... I felt very comfortable. It didn't feel like a burden to go to the gynecologist.... it was cool. (Woman #13, Hispanic, repeat cesarean, placenta previa/hemorrhage)*

Another woman who also reported satisfaction with her doctor recounted that she felt her provider saw her as a person and gave her quality, personalized care:

*She's an excellent professional. She would listen to you. She doesn't commercialize her patients. She's not interested in asking about your insurance. She's interested in looking out for your health and making sure you're okay. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Women also described interactions where they felt heard, understood, and comfortable discussing treatment options. In one example, a woman reported that her doctor assessed the fetus to weigh the costs of prematurity against the cost of her health from worsening preeclampsia. This woman described how her strong reaction against surgical delivery held fast even as she affirmed her trust in her doctor. However, because her doctor also took the woman's needs and concerns into account, they were able to delay the cesarean birth, resulting in a better outcome for both the woman and her baby. She recounted:

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<sup>1</sup> <https://www1.nyc.gov/assets/doh/downloads/pdf/ms/respectful-care-birth-brochure.pdf>.

*She [the doctor] made me turn on my right side, turn on my left side, get on all fours and turn back on my back. She couldn't find the baby's heartbeat. She wanted to do an emergency C-section.... I'm only 31 weeks. I cried, and she was, like, "I've been here with you since you found out you was pregnant. Have I ever steered you wrong?" I said, "No." She said, "But I'm going to try something else." They gave me a magnesium shot, and another shot, and his heart rate came back up. She was able to keep him in for another week. (Woman #11, Black non-Hispanic, primary cesarean, preeclampsia/sepsis)*

The woman who had praised her clinician for not commercializing patients also remembered that, while in the hospital recovering from SMM, the nurses had told her how lucky she was to have the “best” doctor. They explained how their trust in her doctor had helped them in providing more patient-centered care for her:

*The nurses weren't saying that anyone else would have neglected me, but with her—when I started having headaches, they called her.... The nurses saw that I was doing so poorly, and they didn't know what to do. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

This illustrates how a patient's perception of her provider can be maintained or transformed by how other clinicians view that provider. In the case of patient-centered care, this same woman recalled her doctor's extra care:

*My doctor got to the hospital at 9:00 p.m., outside of visitors' hours, and she left at 12:30 a.m. She didn't go home until she had made me better.... That really means a lot. She never looked at me the wrong way. I was dying, and she always arrived smiling, so that I wouldn't feel what was happening. "Hi, [woman's name]. Hi darling! Good morning, my love." You know, she was always affectionate with me, always kissing me and hugging me. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Other women also reported experiencing compassionate care at critical moments. One reported that her entire health care team mobilized to respond to her hemorrhage and were “running getting everything ready, literally running, speed walking. Then they got all together in a circle, surrounding me.” She remembered that her partner had not been able to get to the hospital yet, and she was alone with her fears until a nurse offered a humanizing touch:

*She was running back and forth, but every time she comes close to me, she sees me crying and she tells me, "You're going to be okay. Everything's going to be okay." She goes running back and forth doing whatever she has to do, and then she comes right back to me and she tells me the same thing. She told me that three times. She was the only person that made me feel comfortable, because she was the only one that told me that everything's going to be okay. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

Two other women also reported remembering nurses as the source of their greatest comfort, especially during painful procedures:

*The one nurse that I had, I'll never forget her, her name is [removed]. She stayed with me through the whole thing. She let me lean on her shoulder while they gave me the needle. She was like my mama in the hospital. (Woman #11, Black/non-Hispanic, primary cesarean, preeclampsia/sepsis)*

*It was one nurse that she was really nice to me. She knew that I was uncomfortable with getting a catheter in. She knew I was afraid of needles. She went as far as getting some numbing cream so I wouldn't feel the needle. She made me feel comfortable. (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

In another example of patient-centered care, Woman #3 reported that her nurse came to the hospital on her day off to visit her and shared a picture that they had taken together during her postpartum recovery period. She said:

*[Nurse's name], she cried for me. Literally, I've seen her cry because she couldn't believe that she was finding that I made it [did not die]. I was in the ICU after they took my tubes off my mouth, and she came on her day off with her regular clothes, all the way from her home on her day off, to come see me to send me that picture, that video that I showed you, and she cried. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

The findings of this study among a predominantly Black and Hispanic population point to the importance of women's perceptions of their interactions with clinicians and the care they received during and after the SMM event. The analysis identified negative experiences, usually in maternity care interactions that included moral surveillance or biomedical approaches. While women in this study did not explicitly connect their negative clinical experiences with racial/ethnic bias or discrimination, other research has consistently documented that the same historical inequities that limit access to resources (including health insurance, access to quality care, and health education) also manifest among women experiencing SMM events. Mistrust or expectations of poor care affected women's decisions about whether and when to seek medical care. In these situations, women weighed the uncertain benefits of returning for needed care against certain and burdensome costs, such as the time and expense required for a trip to the hospital, conflicting caregiving and work commitments, or poor-quality care.<sup>21</sup> Care that is rooted in bias toward certain racial/ethnic groups and people with certain comorbidities, insurance carriers, and other demographic and clinical characteristics can negatively affect care, outcomes, and patient experiences.

## Key Findings

- How clinicians interact with women and their families can profoundly impact women's experience of, and recovery from, SMM.
- Women prefer clinicians who adopt patient-centered, respectful styles of interaction and develop a mutually respectful partnership.
- Not being listened to, or believed, was a widely reported experience by the participants in this study, the majority of whom self-identified as Black and Hispanic women.
- In the aftermath of an SMM event, experiences of disrespectful care and moral surveillance left women feeling traumatized, physically and emotionally.

## Postpartum Recovery

Physical and psychological recovery are central for recent parents adapting to the addition of a new family member, alongside the normal physiological postpartum transition.<sup>22</sup> The period of recovery also presents common challenges for new mothers, such as acute sleep impairment, physical discomfort or pain, and emotional fluctuations.

After an SMM, recovery is further complicated by the need to heal from significant physical and emotional trauma. The Fourth Trimester concept highlights the critical 12-week transition period from pregnancy to parenting for women and their families and is gaining greater acceptance and momentum for optimizing postpartum care.<sup>23</sup> Not only should postpartum visits focus on the woman's physical, social, and psychological well-being, but women with pregnancies complicated by preterm birth, gestational diabetes, or hypertensive disorders of pregnancy should be counseled that these disorders are associated with a higher lifetime risk of maternal cardiometabolic disease.<sup>23</sup>

## Challenges to Self-Care and Resumption of Prenatal Roles

The mothers in this study described a postpartum period shaped by their SMM event. In addition to physical complications, women with medical and socioeconomic vulnerabilities experienced barriers to traveling safely and conveniently to work or to medical appointments. Women with underlying health concerns and unmet socioeconomic needs, such as safe housing, financial resources, and social support, struggled to recover from their traumatic deliveries.

Three themes were identified from analyses of women's experiences during their postpartum transition after leaving the hospital: *physical recovery*, *caring for newborns*, and *emotional healing*. Overlying these three themes were two factors: the type of care provided by clinicians (patient-centered versus biomedical and moral surveillance) and the level of support needed (but not always provided) from family and friends and from social service organizations.



## Physical Recovery

Some women experienced ongoing pain and medical complications from the SMM event that posed additional challenges in their recoveries. For example, one woman was discharged home with an IV in place to deliver antibiotics:

*On top of after [Baby Name] was born, then they diagnosed me with preeclampsia. Then I wound up getting—I think e-coli in my urine. I had to come home with the IV in my arm, I had to do that for, like, seven days. (Woman #11, Black non-Hispanic, primary cesarean, preeclampsia/sepsis)*

Another woman gave herself injections twice daily after being discharged from the hospital:

*I have to take medication every night. When I came home, I had to take two different blood thinners. I have to do the one with the syringe, poke myself with it morning, evening, and I have to take the medication at the same time. It wasn't easy.... You see yourself being poked with a needle.... I wish I'm over it. (Woman #1, Black non-Hispanic, primary cesarean, pulmonary embolism)*

For some women, their postpartum healing required multiple visits to one or more clinicians. One woman described that immediately after being discharged, she was told that her bandages needed to be changed twice a day. A visiting nurse came once a day, after the woman made a morning trip to the hospital:

*I would go to the hospital every morning and then in the afternoon the visiting nurse would come. Because by the time they changed it at, like, 11 o'clock, the visiting nurse would come, like, 5 o'clock in the evening, and it will be full and need to clean again. They changed it from twice a day to only twice per week, so I would go to the gynecologist on Tuesdays and Thursdays and the visiting nurse would come Monday, Wednesdays, and Fridays. (Woman #14, Black Hispanic, primary cesarean, preeclampsia)*

Major disruptions to recovery occurred among three women who had to be readmitted to the hospital postpartum. For example, one woman who gave birth by cesarean to her fourth child reported pelvic pain prior to being discharged, and her doctors assured her that it would be fine once she was up and walking around. She recalled:

*A week later, I ended back in the hospital because I had a uterine infection and became septic within the same night of being admitted for that. Because they said my uterus wasn't contracting properly after I gave birth to release everything. It was holding everything in and that's why I got a uterine infection, but I don't see it that way. I'm telling you about this pain. You should've looked at it even more. (Woman #4, Black Hispanic, repeat cesarean, preeclampsia/postpartum hemorrhage/sepsis)*

When readmitted, she was not only diagnosed with sepsis from the newly diagnosed infection, but also with postpartum preeclampsia.

These examples illustrate some of the individual-level burdens and public health costs of patients receiving care from clinicians who utilized biomedical and moral surveillance interaction models. Patients may be less comfortable asking questions and getting clarifications about their SMM diagnoses or treatment plans if they have received disrespectful or poor-quality care. In all births, but particularly after an SMM, women's pain needs to be carefully assessed and treated as a critical vital sign. Unresolved pain can indicate a serious underlying problem and can lead to worse outcomes for women,<sup>24</sup> including readmission.

### Caring for Newborns

In addition to coping with the pain and loss of abilities associated with postpartum complications, women noted how the SMM posed specific challenges to bonding with and caring for their newborns. Returning home increased some mothers' responsibilities. One woman spoke about the challenge of being a multitasking, working, home-schooling mother of three older children amid pain and dysfunctional uterine bleeding:

*I still have pain. I still have cramping where it feels like I'm getting my period.... It's very uncomfortable. I went to my OB. I was supposed to get an ultrasound. I haven't been able to go. I should've went, I know. It's hard. I have four children, and I homeschool, and I work. It's very hard to get out for me. (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)*

Many women struggled in the early weeks postpartum to accomplish basic household tasks. Some needed to buy new beds that were comfortable and easy to access due to ongoing pain from surgical incisions. For some, the timing of discharge felt too soon, and they felt unable to care for their newborns:

*Throughout the week that I came home, I couldn't walk.... My feet, they got so swollen. It was very painful. I wish I would have stayed [in the hospital] a little bit longer because when they brought me home, how am I going to—I can't even walk. How am I going to take care of her? (Woman #1, Black non-Hispanic, primary cesarean, pulmonary embolism)*

For seven women whose babies required care in the neonatal intensive care unit (NICU), they often found it challenging to breastfeed. In one case, Woman #3, who was dedicated to providing her baby with breastmilk while in the NICU, experienced considerable stress after she was discharged from the hospital. Her struggles to pump at regular intervals, find transportation, and go to the hospital were at odds with her physical recovery needs:

*It was just hard because I was pumping every day to see her... I would take milk, give it to her, and then come back home. I used to do the same thing every single day for a whole month. I told them that I wasn't going to pump at 3 in the morning because my daughter's not home, and I need all the sleep right now while she's in the NICU so that I can be prepared so when the time that she comes home, so yeah. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

She was one of the three women readmitted for postpartum hemorrhage, and she regretted being unable to continue breastfeeding once her baby came home from the NICU:

*[My baby] came home a month later... Oh my god, it was a relief. I had her with me. Eventually I stopped breastfeeding. Not that I stopped: I wasn't getting milk in my breast, and I feel like it was because she was in the NICU for a whole month. You need that skin-to-skin connection for your milk to get better, to improve. I wasn't getting that skin-to-skin connection. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

Other women reported a lack of social support; they talked about the intersecting challenges they had to face on their own during the postpartum period:

*One night, I called my mom around 11:30 p.m., just crying and feeling totally helpless, because I was having a nervous breakdown. I couldn't figure out how to handle the situation. The more rest I got, the better it was for me and my recovery, but I couldn't recover, because I had to take care of her. I didn't have anyone to help me. There were many days when I wouldn't even sleep for an hour. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Women's needs for additional support to care for their newborn while physically recovering from an SMM complicates the concept of the Fourth Trimester: SMM patients have distinct needs during their first 12 weeks postpartum.

### **Emotional Healing**

In addition to physical recovery challenges, women talked about how they coped with difficult emotions and memories about the SMM. One woman described the impact of her unexpected and difficult pregnancy and birth for herself and her partner:

*I was happy to have the baby finally with me in the house, but two weeks passed and I was feeling depressed, because I would think about everything I went through those two months in the hospital. There was a time that me and [my husband] would lay in bed while [our baby] is sleeping next to us...in her bassinet, and we would just stare.... He's traumatized, and I'm traumatized. He's traumatized at things that he's seen with his eyes that I couldn't see, because either I was too drugged up, or I was asleep that*

*whole time, or I was in the ICU and I wasn't aware of a lot of things going on. There're times that I still think about it. It gets better, but I still think about it, like, "Damn, this really happened to me." I'm still traumatized. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

Despite describing symptoms that may fit the criteria of post-traumatic stress disorder, she did not disclose feeling depressed in the postpartum period. Woman #3's postpartum mindset was likely shaped by her experiences during prenatal care when she believed that she was mistakenly labeled "depressed" and then incorrectly referred to a social worker.

*...When I went to my OB/GYN and they asked me how I'm feeling from 1 to 5. The reason why I put 1, and that's why I'm scared, I think that's why, I put 1, that I feel little to no interest of doing anything, was because it was my first trimester and I didn't want to do anything. I was sick, so they saw it as I was depressed and I needed mental help. That's how I got a social worker. That's why I don't want to tell anybody how I feel. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage).*

That experience left her feeling "scared" to report her true emotional and mental health reactions to surviving a traumatic birth, even when she and her partner needed postpartum support.

Too often, mental health referrals are not part of SMM discharge processes. One woman, herself a perinatal nurse, acknowledged that health care is overly focused on patients' physical health, with minimal regard for their emotional needs. Her use of the word trauma is also notable.

*We [speaking as an obstetric nurse] have a lot of moms who do have traumatic births, and we don't have anything. When they come up, we don't really address the trauma. We do address, "I know you had heavy bleeding. Watch your bleeding if your bleeding's heavy." We don't address their emotional well-being around the trauma. (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)*

Loneliness was another key emotion expressed by many of the women: One woman described postpartum as a time when "one feels alone, one feels depressed":

*Support is the most important thing in this process. If a woman has her husband at her side, I think that person should support her. The family too, they should try to call. If they can't go, ask how they are, how they feel. A call, some encouragement.... When relatives call you, visit you.... They come and make my food.... The family, mainly, should try to stay united during that time, so that the person doesn't have to worry and that she doesn't have serious postpartum problems. During postpartum, one feels alone, one feels depressed, but if the family is there with the couple, everything will be easier. (Woman #13, Hispanic, repeat cesarean, placenta previa/hemorrhage)*

In this way, she viewed social support as “the most important thing” in postpartum recovery. Common challenges of the postpartum period may be compounded for women with limited resources and/or social support. Traumatic birthing experiences and multifaceted consequences of surviving an SMM event often influence women’s future engagement with health care.

### **Key Findings**

- Women who survived an SMM needed additional medical and social support during their postpartum recoveries and could benefit from referrals to physical and mental health professionals with specific expertise in helping women recover from birth trauma and/or managing unexpected pain, disability, and/or dysfunction while trying to care for their newborns.
- Women with intersecting vulnerabilities, such as underlying health conditions, unstable housing, insecure finances, and few social supports, experienced additional destabilization after SMM events.
- SMM events may be traumatic to others around the mother, often because of what they experienced during the event, in addition to the trauma to the woman herself. Family and friends often need support as well.

### **Making Sense of SMM Experiences**

Each interview for this study concluded by the interviewers asking the participant the following: “As we conclude our interview today, what advice do you have for me about how I can improve the interview experience?” All replied that they could not think of a way to improve the interview, and over 70% of the women interviewed articulated how healing the experience had been for them.

The multifaceted negative impacts of SMM often delayed or prevented the participants from taking care of their newborns full-time, which left the women feeling disappointed, ashamed, or even stigmatized. The interviewers provided a safe space in which each woman could privately share her SMM experiences with an empathetic listener. The study’s call for participation validated these women by treating their experiences as meaningful, and the small amount of compensation they received and the numerous sincere expressions of gratitude for their openness helped them reframe their experience of illness as one that signified courage and would have a positive impact on other women. By confidentially sharing the details of their struggles with nonjudgmental interviewers who valued their input, these women managed their stigma via therapeutic disclosure.<sup>25</sup>

Several women clarified that their interview had been the first time they told their full SMM story to another person:

*You're the first person that I ever said everything that happened to me. I know I didn't cry... but I've cried so much that no tears are going to come out right now at all.... It is not easy at all, at all. Thank you. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

Another woman, who worked in the hospital where she gave birth, also felt the interview had been helpful:

*It's also a way for me to talk things through.... When I worked in the hospital, those memories start flashing back to me.... I am bothered by this experience, but I couldn't keep talking to my family because everyone's already helping me with the child care. I actually appreciate someone [who] could let me talk about things that happened. (Woman #10, Asian, vaginal birth, placental inflammation/sepsis)*

Prior to this last question about improving the interview, all participants were asked for their advice about others who might benefit from their SMM insights. Many of the participants in this study were motivated to contribute to a project focused on improving maternal health outcomes and improving SMM experiences for others.

### **Advice for Pregnant Women and Family/Significant Others**

This analysis identified three themes from among the participants' advice to pregnant women and their families. The first theme, Take care of your health, refers to the importance of physical self-care for those who are pregnant, birthing, or recovering from childbirth.

**Take care of your health.** Several mentioned the importance of regular health check-ups:

*The first thing I would say is for them to not neglect themselves. They shouldn't neglect their appointments, their check-ups, or their medication. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

They understood how their social roles of being caretaker to babies and children often competed for their time and energy to invest in self-care:

*Trust me, you need to go to the doctor to do [a] check-up more often.... Don't stop going to the doctor, because we have kids, and we really don't think about ourselves.... We need to think about ourselves first to be able to take care of them. (Woman #5, Hispanic, repeat cesarean, postpartum hemorrhage)*

Some also emphasized the importance of paying attention to one's body and going to a clinician when you feel ill or are in pain:

*For women that are pregnant, if they have a situation where they don't feel right, they should go and tell their doctor everything they want to say. If there is something that is*

*bothering them, don't wait until the last minute. (Woman #13, Hispanic, repeat cesarean, placenta previa/hemorrhage)*

*Don't sit down if you're in pain.... Any signs and symptoms of anything, seek help, professional help. (Woman #14, Black Hispanic, primary cesarean, preeclampsia).*

One woman also noted self-awareness of postpartum changes and encouraged others to seek help if their healing and recovery process is not going well:

*...after every pregnancy, after you give birth, your body changes just a little.... As you age, your body, hormones, and all that changes as well. Just stay in tune with your body, and if there's something that's not normal... tell the doctor and tell them that you want them to check this.... Check yourself. Don't be afraid to go to the doctor. (Woman #4, Black Hispanic, repeat cesarean, preeclampsia/postpartum hemorrhage/sepsis)*

To underscore how significant others or family members can help women take care of themselves, one woman noted what can happen if they fail to provide support:

*Families should support them, try to go with them to their medical appointments so that the family member can be informed. Don't leave them alone.... Help them to monitor the situation.... I would have wanted to have someone by my side saying, "You have to go. Go to your appointment, because you don't feel well. See what the doctor says. Tell him that your feet are swollen and that you can't walk, you know?" (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Several participants warned against resuming normal levels of work or other activity too soon after an SMM and advised others to take time to fully recover:

*Take care of yourself. Don't overdo it, not even at your job. It's not worth it.... Just leave that job, because you're putting your whole pregnancy at risk.... It was my job, I was doing too much. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)*

*Recovery-wise, take the time that's needed.... When you have a C-section, you do heal outside a lot quicker than you do inside. The more C-sections you have, the longer you might need.... If you need the time off, then you should take it. (Woman #7, multiracial, repeat cesarean, chronic anemia)*

Women in this study had traumatic, painful birth and postpartum experiences that resulted in many having a profound appreciation for their own health and well-being. Many recognized that their ability to effectively care for their children was more difficult due to the physical healing required during recovery.

**Preparedness.** A second theme identified in advice given to pregnant women and their families involved being prepared to be one's own advocate (or making sure a significant other was advocating for you) and learning what to expect postpartum in terms of how SMM impacts physical recovery, breastfeeding, and mental health. Women emphasized importance of understanding what is happening before and during medical care. For example, one advised:

*Before you go in to have the procedure, do your research. Do research so that you know what you're getting yourself into.* (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)

Another pointed out that assertively asking questions was key to maintaining an understanding of one's own condition during the rapidly changing circumstances that are common in SMMs:

*Sometimes they don't like when you ask them questions, but ask questions if you're not sure.... They're not going to know what's wrong with you.... Sometimes you ask and they do nothing about it, but you have to be vocal about some things, but don't get too rude, because you won't get no attention at all. You have to be polite.... Use wisdom, and ask questions.* (Woman #14, Black Hispanic, primary cesarean, preeclampsia)

Unfortunately, advice focused on self-education often led women to blame themselves for one or more aspects of their SMM:

*I learned also that anything could happen to you.... I would never think that this would happen to me, and it did.... The whole time I was pregnant I felt like I was healthy and this would never happen to me ever, and it did, and worse.* (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage)

This type of retrospective regret was most commonly expressed by women who had felt their pregnancy had been “healthy” and “low risk” until their labor/delivery transformed into a SMM. When their birth hospitalizations became traumatic medical experiences, many found themselves unexpectedly unconscious or otherwise having an altered mental state due to medication effects. For these reasons, several realized the importance of having someone by their side throughout the hospital stay:

*I'll advise an individual to ensure that they have someone around them who they can trust, someone who will be their eyes and ears when they can't manage.... Whenever you get medications and stuff, they will make you drowsy, so it's good to have someone around you. They have to be assertive, as to what is going on around you, because at the end of the day, it's like they're going to have your back whenever you can't have your own back.* (Woman #14, Black Hispanic, primary cesarean, preeclampsia)

Being proactive about getting information or changing providers is another form of self-advocacy. One woman explained how being your own advocate may affect outcomes:



*Women have to pay attention to everything that happens to them, and communicate everything they're feeling to their doctor as it happens. Women shouldn't ignore anything, because anything you ignore could lead to other consequences. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage/hypertension)*

Being prepared in the postpartum period involved understanding more about the realities of SMM recovery, breastfeeding, and infant care. One of the study participants, a perinatal nurse, summarized the situation:

*A lot of moms are induced now, and they are not educated on what can happen.... A lot of moms are not [even] prepared for a normal newborn. These newborns make a lot of adults cry.... That affects breastfeeding. Why do we have the breastfeeding ways we have? Because moms are not prepared. (Woman #2, Black non-Hispanic, VBAC, postpartum hemorrhage)*

**Trauma Recovery.** In addition to the intensity of the physical pain and recovery, women were still in the process of coming to terms with what happened. The third theme, trauma recovery, captures the continuing work of healing from the trauma of the experience.

*My partner goes to work in the night... leaves me with her. She only sleeps for an hour or so... then you're up feeding and you start thinking back, it makes you sad.... Then I look on her, it makes me smile, so you always have mixed emotions.... I'm still processing a lot of stuff. I'm still getting to know who I am as a mother. I'm still trying to figure it out. (Woman #14, Black Hispanic, primary cesarean, preeclampsia)*

Some women acknowledged the irony of giving advice during this interview that they themselves were not following:

*It's hard to give them advice like this when I'm not taking it myself, because I know that they feel the same way I do. Talk to someone about how you feel.... Know that you're not alone.... There's other people like you that are going through the same thing you're going through.... If you have someone to talk to, talk to them, because keeping things inside of you is not good, because one day you'll explode. (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage).*

The acknowledgment of the potential benefits of seeking mental health care, paired with a woman's own reflection on her inability to seek this care, points to likely sociocultural stigma regarding mental illness:

*...cherish life because that's scary. You experience that near-death experience.... Go to therapy if needed. [Interviewer: Mm-hmm. Is that something you've done?] I can go. I just haven't gone, for some odd reason. I don't know why. I do believe that I should go to therapy. (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

Many of the women interviewed gave birth less than six months prior to the interview. Some were still processing events and feelings, while others emphasized the importance of focusing on recovering and getting better. Those women referred to faith, including, “*Just have faith and keep yourself occupied – do things that make you happy*” (Woman #3, Hispanic, primary cesarean, placental abruption/hemorrhage). Other women specifically referenced God:

*...don't overthink what happened, because it's not going to change what happened.... Focus on yourself to recover, on the baby, and things will get better. The human has this great ability to recover. God gave us this huge miracle of recovery, and I'm thankful.*  
(Woman #12, White/non-Hispanic, primary cesarean, perineal injury/hemorrhage)

The reliance on faith and religion to process events surrounding the birth reflects women who felt it was not helpful to recall or discuss scary or unpleasant aspects of SMM; rather, they emphasized the importance of accepting what happened and recovering as completely as one can.

### **Advice for Clinicians Providing Health Care to SMM Patients**

This analysis identified three themes from the advice women had for clinicians who provide prenatal, labor and delivery, and postpartum care. In some ways, these areas of advice paralleled the women’s experiences of, and resistance to, different clinician-patient interaction styles.

**Continuity of Care.** Many women saw several clinicians during their pregnancy, birth, and postpartum care. One recalled that she “didn’t really feel good” about having multiple providers:

*...during pregnancy you want to go to the same provider, she knows what's going on, and you feel safe. I didn't really feel good seeing different ones each time. Then I have to tell the whole story.* (Woman #12, White/non-Hispanic, primary cesarean, perineal injury/hemorrhage)

When admitted to the ICU, she found the discontinuity of care unsettling:

*There were different nurses every night. I think one of the bad experiences, too, is the discontinuity of care during my stay. Every day, someone new would show up. I even stopped counting how many doctors came.* (Woman #12, White/non-Hispanic, primary cesarean, perineal injury/hemorrhage)

A second woman echoed the problems of having to see different doctors and having to repeat her story:

*I didn't care if I saw one or the other, because that's the worst thing. You have to tell them your story.... It's a gynecologist today, and a resident tomorrow. The resident has never seen you, so you have to repeat the story.... That's terrible.* (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage)

In this case, the advice is for clinicians to make sure to engage in “deep” or active listening and detailed notetaking so that the patient does not have to retell—and relive—her traumatic SMM story. When clinicians do not review the patient medical history prior to an interaction, women felt that key details were not included in notes from their last appointment and worried that this reflected poor quality care.

One caveat to the continuity of care concerns cases where negative interactions necessitate a change. For example, when one woman set up her postpartum visits, she “specifically” requested a single provider, but this request was not honored:

*After the baby was born, I asked specifically to have a single provider. I don't care which one, but I want some consistency with each visit. [But,] I didn't want to see the one who delivered me, and had all of these complications, because each time I would see her, I would remember all the trauma.* (Woman #12, White non-Hispanic, primary cesarean, perineal injury/hemorrhage)

Her story illustrated how SMM patients can be retraumatized by seeing the same provider involved in the SMM event, especially because she felt that the provider's delay in calling a consultant had contributed to her injuries. Women with such trauma may avoid future interactions with health care clinicians as an act of self-protection to avoid retraumatization. This avoidance may result in unintended negative health consequences.

**Respectful and Clear Communication.** The second area of advice centered on clinicians doing a better job at communicating clearly and respectfully with patients. In particular, women advised clinicians who practiced within the biomedical model to avoid using medical jargon:

*I have to be googling; I have to be searching... to find out what was that word again?... I always have to be writing down stuff to try and remember what terminology that they have been using.... “What was wrong with my arm?” “Oh no, I can't tell you what was wrong.”... “Will this heal inside of me? It's going to cause some long-term effect.”* (Woman #14, Black Hispanic, primary cesarean, preeclampsia)

Woman #14 advised clinicians to give clear answers that do not require translation into everyday language. Similarly, another woman gave advice on how to ensure shared decision-making:

*No matter what the situation, communicate. Tell [women] everything.... Don't leave out anything. Don't take options away from them. When they ask you, be honest. (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

Reflecting on recovering from surgery, one participant remembered how betrayed she felt when she learned that clinicians gave detailed information about her medical condition to her mother before sharing it with her or with her newborn's father.

*They shared, with my mom, things that they didn't even share with me or my daughters' father.... When my daughters' father, who is my proxy, asked what was going on, you don't share that with him? But, my mom, who is not on anything on my medical record, you shared that with her?... I'm glad that they shared that with my mom, but I'm also upset. "You broke HIPAA"<sup>m</sup>.... You [weren't] supposed to discuss that with anybody. You [weren't] even supposed to discuss anything with my child's father unless you saw that he was my proxy on my chart." (Woman #6, Black Hispanic, repeat cesarean, postpartum hemorrhage)*

This example illustrates how the women's recommendations for ethical communication focused on the issues often covered by doctor-patient confidentiality and HIPAA. In addition, the women advised clinicians to own up to any missteps in treatment or errors in diagnosis and to open a dialogue with patients who are showing signs of distress:

*Some patients are scared to ask or they don't know how to ask.... Try to get them to talk if they look like they're uncomfortable, because body language, nonverbal language, it says a lot... especially when they're in pain, speak to them, listen to them, run more tests, exams.... Listen when a patient is saying, "I'm in pain, I'm in pain," of whatever part of their body. Check it. Don't overlook it. Listen to the patient. (Woman #4, Black Hispanic, repeat cesarean, preeclampsia/postpartum hemorrhage/sepsis)*

Women understood that childbirth can "naturally" take a turn for the worse or that mistakes can happen. Their experiences informed their advice for clinicians to make sure that women felt comfortable disclosing their symptoms, because that information could help clinicians provide timely and appropriate treatment, refer them to specialists, or connect women with a new clinician if a second opinion was desired.

All the above advice to clinicians is anchored in a health care version of the golden rule: Treat patients as you would want to be treated. Women wanted prenatal care providers to be

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<sup>m</sup> The Health Insurance Portability and Accountability Act of 1996 (HIPAA) required the Secretary of the U.S. Department of Health and Human Services (HHS) to develop regulations protecting the privacy and security of certain health information.

respectful of their feelings, time, and pain. Those who rotated through large group practices often were seen by clinicians who did not know them or their history. One participant advised clinicians to follow social greeting protocols:

*I hate when they just walk by. They're your doctors. They will stand right in your eye and not even say "Hi."* (Woman #15, Black non-Hispanic, repeat cesarean, postpartum hemorrhage)

Women preferred clinicians who demonstrated care and concern for them as in a holistic manner:

*When I would go to my doctor, I usually bring my kids with me.... She'll ask them how's school doing.... It just makes you feel better when they're more open with you, and it's not just strictly, "This is what you're here for, so okay".... When they have an open level of communication, then you feel more comfortable, and you're more open to say certain things.... You'll feel more comfortable talking to them about personal issues.* (Woman #7, multiracial, repeat cesarean, chronic anemia)

This woman exemplified the sentiment expressed by many women—they wanted their doctors to interact with them as unique individuals, and feeling connected made women more willing to openly communicate about sensitive health issues.

When it came to long waiting times, women wished clinicians realized they were often missing work, dealing with transportation schedules, and/or inconveniencing family or paid caretakers to watch over their newborn or their older children. For example, one pointed out:

*Time is money, but I don't see that. They think people don't have things to do. They think, when they come to the hospital, you can pass all day for no reason. You don't have anything to do at home.* (Woman #9, Hispanic, vaginal delivery, preeclampsia)

Another woman also advised clinicians to be on time:

*Just pay attention to your patient. Stop letting them waiting for hours and hours and hours. We're pregnant out here. We don't want to sit in one crowded room.... I ain't got no extra time. I'm pregnant. I want to go home, or lay down.... I was working at that time, too.* (Woman #15, Black non-Hispanic, repeat cesarean, postpartum hemorrhage)

Overall, the women want clinicians to know that long waits felt disrespectful, because patients were likely to feel they were being treated as though their time and energy was unimportant during a particularly vulnerable period in their lives.

Women also urged clinicians to recognize their implicit biases and avoid communicating explicit biases. The woman in the following quote encouraged clinicians to be especially

respectful of undocumented patients, who were likely to feel less powerful in health care interactions:

*They can help people, if you have papers or not, to see doctors, because nobody can play with people's lives. Can be you or your mom or whatever person in your family. I think people—they are supposed to respect each other. (Woman #9, Hispanic, vaginal delivery, preeclampsia)*

Another woman cautioned clinicians to let go of assumptions about women's reproductive plans:

*Don't think that, just because you're a patient, you don't have any knowledge about what's going on. Don't think that you don't want immigrants to get pregnant, because you don't want them to keep having children. (Woman #8, Hispanic, primary cesarean, postpartum hemorrhage).*

Reflecting on positive interactions, one woman related:

*We need to really respect them.... When someone works in health care, sometimes they have health problems of their own, they still go to work to help others and it's not just about money, it's their vocation to do things for others... to run when there's an emergency. We have to respect those people, because it's not easy.... If those people, the doctors, hadn't helped me quickly, I would not be here telling you this. That's why we need to value and respect them a lot. (Woman #13, Hispanic, repeat cesarean, placenta previa/hemorrhage)*

## Key Findings

- Disclosure can be therapeutic and can help individuals manage feelings of stigmatization resulting from experiencing an SMM.
- Being an active participant in one's own health care has many advantages, such as learning self-care practices, accessing health care, and ensuring individuals have access to information about pregnancy, delivery, and postpartum recovery, especially related to SMM.
- Women who experience SMM need specialized advice and support in getting mental health care for themselves and, when needed, for their significant others.
- Ensuring continuity of care helps patients feel “known” by their clinician, which increases patients' trust in, and comfort with, sharing sensitive health issues that arise in pregnancy.
- Clinicians who communicate in ways that their patients understand show that they care about patients participating in their own health care.
- Clinicians who provide respectful care—especially by actively listening to patients—are more likely to be perceived by their patients as trustworthy.

## RECOMMENDATIONS

This study underscores opportunities for public health institutions and community-based organizations to provide support to women throughout their pregnancy and birthing experience, and postpartum recovery. Women who experience SMM events and their families are especially in need of support during in the postpartum period.

### IMPROVE THE QUALITY OF MATERNITY CARE AT HOSPITALS

- After an SMM event, women and their families need accessible health education and information to understand what happened, emotional support to feel cared for, a plan for coordinated follow-up care, and resources for ongoing physical and mental health issues.<sup>26</sup>
- Providers should adopt and sustain a patient-centered model of interaction, support shared decision making, and improve patients' understanding of treatment plans. Particularly for women who experience SMM, the patient-centered care model can facilitate effective patient-clinician communication, sincere mutual respect, and increased trust in health care.
- System capacity and infrastructure need to be built to support ongoing training of clinicians and other relevant team members to acknowledge, investigate, and address women's needs in the context of their unique existing social, cultural, and structural resources.

### SUPPORT FAMILIES AND SIGNIFICANT OTHERS IN SUPPORTING WOMEN

Women consistently spoke of the valued and important roles played by those in their support circles, especially during their birth hospitalizations and postpartum recoveries.

- Health care providers need to educate everyone. When families or significant others of women who had SMM events are not educated on the possible courses of labor and postpartum, they are ill-prepared for the realities of taking care of a newborn while also supporting the mother's physical and emotional recovery.
- Clinicians should prioritize patient-centered care and make time for and encourage questions from women and their significant others.
- Social safety nets are needed for when women's support systems are constrained by factors such as limited financial opportunities or separation by distance. Social isolation during the postpartum period can have dire consequences for women in terms of their ability to access health care, secure safe, trustworthy child care, or balance work and child care responsibilities.

- Women who experience SMMs would benefit from coordinated, comprehensive follow-up postpartum care from a multidisciplinary team of care providers.
  - For women with underlying health conditions, their postpartum care should be coordinated with primary care or specialist providers.
  - Wrap-around services for women recovering from SMM events can include integrated postpartum teams comprising mental health care professionals, public health visiting nurses, and community-based, culture-matched doula services, to address their comprehensive care needs.
  - Perinatal community health workers can also provide external support to the entire family unit.

### **PROMOTE HEALTH EQUITY VIA PUBLIC HEALTH AGENCIES AND COMMUNITY HEALTH PROGRAMS**

Engagement with health care systems is not the only point of support needed by many participants in this study. Health care engagement serves as a conduit through which pregnant and parenting people are offered connections to other critical services.

- Publicly invest in a full continuum of care for every SMM patient with supportive, therapeutic, and preventive care services. Recovery from SMM is challenging, but underlying health concerns and unmet socioeconomic needs, such as safe housing, financial resources, and social support, created a cascade of negative consequences for women.
- Borough-based social support hubs co-located in or alongside the hospital could offer child care services to women to facilitate their attendance at follow-up appointments and to provide assistance to women who may be applying for other forms of essential subsidized support (the Supplemental Nutrition Assistance Program [SNAP] or housing and employment assistance).
- Telehealth/phone-based services also offer a viable, low-cost option to support the continued engagement of women who have suffered an SMM event during the postpartum transition period.



## CONCLUSIONS AND DIRECTIONS FOR FUTURE RESEARCH

Given that almost half of all SMM and maternal mortality events are preventable, there is an urgent need for maternity settings to take intentional steps to center women of color in clinical quality improvement efforts.<sup>27</sup> Policy makers, health care organizations, and clinicians have opportunities to ensure that maternity care for those with SMM experiences is comprehensive, respectful, and trauma-informed. As the study findings show, this type of care would include careful assessment of women's mental, social, cultural, and financial needs and would provide quality and coordinated clinical care to women who present with social and medical risk during pregnancy and postpartum.

In addition, this study supports the expansion of maternity care teams to include midwives, doulas, health educators, mental health professionals, and other specialists, as needed. Integrated midwifery care is known to improve maternity care outcomes and patient satisfaction. Doulas can provide prenatal and childbirth support, while health educators can strengthen postpartum care by providing SMM-specific information to support each woman's recovery trajectory. Maternity clinicians frequently refer SMM patients for postpartum mental health care to help them process traumatic birthing experiences.

An SMM event causes ripple effects through all the lives involved. The health and social impacts of experiencing a severe complication are ongoing and deserve further examination. Emerging from the findings of this study is the need for a trauma-informed framework and community-based action research methodology to:

- recognize the widespread impact of trauma;
- consider potential paths of recovery;
- recognize signs and symptoms of trauma as they arise in the research; and
- actively resist retraumatization by creating physical settings and interpersonal processes that support safety for researchers and public research participants.<sup>28</sup>

A Guide to Women's Experience with Severe Maternal Morbidity in New York City: A Qualitative Report Supplemental Online Content (SOC) can be found at [www1.nyc.gov/site/doh/data/data-sets/severe-maternal-morbidity-surveillance.page](http://www1.nyc.gov/site/doh/data/data-sets/severe-maternal-morbidity-surveillance.page) and consists of the following materials:

- Detailed Methodology
- Interview Guide
- Permission to Contact Form (Hospital Recruitment)
- Scheduling Call Script
- Community Recruitment Flyer (English Version)
- Recruitment Flyer (Spanish Version)
- Community Participant Screener
- Community Recruitment Sites
- Informed Consent Form (Hospital Recruitment)
- Informed Consent Form (Community Recruitment)
- Distress Protocol Sample
- Resource Guide Sample
- Sample Training Content
- Bibliography

## REFERENCES

1. New York City Department of Health and Mental Hygiene (NYC Health Department). 2020. *Pregnancy-Associated Mortality: New York City, 2011–2015*. New York. <https://www1.nyc.gov/assets/doh/downloads/pdf/ms/pregnancy-associated-mortality-report-2011-2015.pdf>.
2. NYC Health Department. 2016. *Severe Maternal Morbidity in New York City, 2008–2012*. New York. <https://www1.nyc.gov/assets/doh/downloads/pdf/data/maternal-morbidity-report-08-12.pdf>.
3. Jones, C. P. 2000. Levels of racism: A theoretic framework and a gardener's tale, *American Journal of Public Health* 90(8):1212–1215.
4. Krieger, N., Van Wye, G., Huynh, M., et al. 2020. Structural racism, historical redlining, and risk of preterm birth in New York City, 2013–2017. *American Journal of Public Health*.110(7):1046–1053.
5. Mendez, D. D., Hogan, V. K., and Culhane, J. 2011. Institutional racism and pregnancy health: Using Home Mortgage Disclosure Act data to develop an index for mortgage discrimination at the community level. *Public Health Reports* 126(Suppl. 3):102–114.
6. Shen, M. 2018. The association between the end of court-ordered school desegregation and preterm births among Black women. *PLoS One*. 13(8):13(8):e0201372.
7. Howell, E. A., Egorova, N. N., Balbierz, A., et al. 2016. Site of delivery contribution to black-white severe maternal morbidity disparity. *American Journal of Obstetrics and Gynecology*. 215(2):143–152.
8. Braun, V., and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2):77–101.
9. Strauss, A., and Corbin, J. 1998. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 2nd ed.* Thousand Oaks, CA: Sage Publications.
10. Altman, M. R., Oseguera, T., McLemore, M. R., et al. 2019. Information and power: women of color's experiences interacting with health care providers in pregnancy and birth. *Social Science and Medicine*. 238:112491, doi:10.1016/j.socscimed.2019.112491.
11. Charmaz, K. 2006. *Constructing Grounded Theory*. Thousand Oaks, CA: Sage Publications.

12. Scott, K. A., Britton, L., and McLemore, M. R. 2019. The ethics of perinatal care for black women: dismantling the structural racism in “mother blame” narratives. *Journal of Perinatal and Neonatal Nursing*. 33(2):108–115. doi: 10.1097/JPN.0000000000000394.
13. Bailey, Z. D., Krieger, N., Agénor, M., et al. 2017. Structural racism and health inequities in the USA: evidence and interventions. *Lancet* 389(10077):1453–1463, doi:10.1016/S0140-6736(17)30569-X.
14. Howell, E. A. Reducing disparities in severe maternal morbidity and mortality. 2018. *Clinical Obstetrics and Gynecology* 61(2):387–399. doi:10.1097/GRF.0000000000000349.
15. Stewart, M., Brown, J. B., Weston, W. W., and McWhinney, I. R. 1995. *Patient-Centered Medicine: Transforming the Clinical Approach*. Thousand Oaks, CA: Sage Publications.
16. Nack, A. 2008. From the patient’s point of view: practitioner interaction styles in the treatment of women with chronic STD, in Jacobs Kronenfield, J. (ed.), *Care for Major Health Problems and Population Health Concerns: Impacts on Patients, Providers and Policy. Research in the Sociology of Health Care*, Vol. 26, Bingley, UK: Emerald Group Publishing Limited, pp. 95–122. doi:10.1016/S0275-4959(08)26005-9.
17. Institute of Medicine. 2001. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press.
18. Morton, C. H., Henley, M. M., Seacrist, M., and Roth, L. M. 2018. Bearing witness: United States and Canadian maternity support workers’ observations of disrespectful care in childbirth. *Birth*. 45(6):263–274. doi: 10.1111/birt.12373.
19. Rubashkin, N., and Minckas, N. 2018. How should trainees respond in situations of obstetric violence? *AMA Journal of Ethics* 20(1):283–246, doi: 10.1001/journalofethics.2018.20.3.ecas2-1803.
20. Chambers, B. D., Arabia, S. E., Arega, H. A., et al. 2020. Exposures to structural racism and racial discrimination among pregnant and early post-partum Black women living in Oakland, California. *Stress and Health*, 36(2):213–219. doi: 10.1002/smi.2922 (2020).
21. Lalonde, A., Herschderfer, K., Pascali-Bonaro, D., et al. 2019. The International Childbirth Initiative: 12 steps to safe and respectful MotherBaby-Family maternity care. *International Journal of Gynaecology and Obstetrics*, 146(1):65–73, doi: 10.1002/ijgo.12844.
22. Martell, L. K. 2001. Heading toward the new normal: a contemporary postpartum experience, *Journal of Obstetric, Gynecologic and Neonatal Nursing* 30(5):496–506, doi: 10.1111/j.1552-6909.2001.tb01569.x.
23. American College of Obstetricians and Gynecologists (ACOG). 2018. ACOG Committee Opinion No. 736: Optimizing Postpartum Care. *Obstetrics and Gynecology*. 131, e140–e150, doi:10.1097/AOG.0000000000002633.
24. Morton, C. H., Seacrist, M. J., VanOtterloo, L. R., and Main, E. K. 2019. Quality improvement opportunities identified through case review of pregnancy-related deaths from preeclampsia/eclampsia, *Journal of Obstetric, Gynecologic and Neonatal Nursing* 48(3):275–287, doi: 10.1016/j.jogn.2019.02.008 (2019).
25. Herman, N. J. 1993. Return to sender: reintegrative stigma-management strategies of ex-psychiatric patients, *Journal of Contemporary Ethnography* 22(3):295–330, doi: 10.1177/089124193022003002.
26. Council on Patient Safety in Women’s Health Care. 2016. *Patient safety bundle: Support after a severe maternal event*. <https://safehealthcareforeverywoman.org/patient-safety-bundles/support-after-a-severe-maternal-event-supported-by-aim/>.
27. Eichelberger, K. Y., Doll, K., Ekpo, G. E., and Zerden, M. L. 2016. Black Lives Matter: claiming a space for evidence-based outrage in obstetrics and gynecology. *American Journal of Public Health*. 106(10):1771–1772, doi:10.2105/AJPH.2016.303313.
28. Substance Abuse and Mental Health Services Administration (SAMHSA). 2014. *SAMHSA’s Concept of Trauma and Guidance for a Trauma-Informed Approach*. HHS Publication No. (SMA) 14-4884. Rockville, MD: SAMHSA. <https://store.samhsa.gov/product/SAMHSA-s-Concept-of-Trauma-and-Guidance-for-a-Trauma-Informed-Approach/SMA14-4884>.

