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## Perinatal care experiences among racially and ethnically diverse mothers whose infants required a NICU stay

Kimberly B. Glazer, PhD<sup>1,2</sup>, Shoshanna Sofaer, DrPH<sup>3,4</sup>, Amy Balbierz, MPH<sup>1,2</sup>, Eileen Wang, BA<sup>5</sup>, Elizabeth A. Howell, MD<sup>1,2,5,6</sup>

<sup>1</sup>Blavatnik Family Women's Health Institute, Icahn School of Medicine at Mount Sinai

<sup>2</sup>Department of Population Health Science & Policy, Icahn School of Medicine at Mount Sinai, New York, NY, USA

<sup>3</sup>American Institutes for Research, Washington, DC, USA

<sup>4</sup>Graduate School of Public Health and Health Policy, City University of New York, New York City, NY, USA

<sup>5</sup>Department of Medical Education, Icahn School of Medicine at Mount Sinai, New York, NY, USA

<sup>6</sup>Department of Obstetrics, Gynecology, and Reproductive Science, Icahn School of Medicine at Mount Sinai, New York, NY, USA

### Abstract

**Objective**—To learn how diverse mothers whose babies required a neonatal intensive care unit (NICU) stay evaluate their obstetric and neonatal care.

**Study Design**—We conducted three focus groups stratified by race/ethnicity (Black, Latina, White, and Asian women, n=20) who delivered infants at <32 weeks gestation or <1500 grams with a NICU stay. We asked women to assess perinatal care and applied classic qualitative analysis techniques to identify themes and make comparisons across groups.

**Results**—Predominant themes were similar across groups, including thoroughness and consistency of clinician communication, provider attentiveness, and barriers to closeness with infants. Care experiences were largely positive, but some suggested poorer communication and responsiveness toward Black and Latina mothers.

**Conclusion**—Feeling consulted and included in infant care is critical for mothers of high-risk neonates. Further in-depth research is needed to remediate differences in hospital culture and quality that contribute to disparities in neonatal care and outcomes.

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Corresponding author: Kimberly B. Glazer, PhD, MPH, Department of Population Health Science & Policy, Icahn School of Medicine at Mount Sinai, One Gustave L. Levy Place, New York, NY 10029, 212-468-2189 | [kimberly.glazer@mountsinai.org](mailto:kimberly.glazer@mountsinai.org).

Author Contributions

SS, AB, EW, and EH contributed to study design, instrument development, data collection, and data analysis. KG assisted with data analysis and drafted the manuscript. All authors edited the full manuscript.

Conflict of Interest

The authors have no competing financial interests related to the work described.

## INTRODUCTION

Racial and ethnic gaps in infant survival are persistent in the United States with non-Latina Black infants dying at more than double the rate of non-Latina Whites, and elevated mortality rates for Puerto Rican infants (1). Rates of preterm birth (<37 weeks gestation) and low birthweight (<2500 grams), both strongly associated with perinatal morbidity and mortality, are higher among infants of Black and Latina compared to White mothers (2–4). Further, when delivered very preterm (<32 weeks), infants born to Black and Latina women have higher risks of severe morbidities including necrotizing enterocolitis, intraventricular hemorrhage, bronchopulmonary dysplasia, and retinopathy of prematurity than White infants of similar gestation (5). Very and extremely preterm (<28 weeks) deliveries are estimated to account for more than half of the Black-White infant mortality gap (4).

Maternal race/ethnicity is associated with perinatal outcomes independent of patient sociodemographic and clinical risk factors, implying that causes aside from individual characteristics drive disparities. In a prior study of births in New York City (NYC) hospitals, where our study was conducted, Black and Latina women were significantly more likely than White women to deliver in hospitals with the highest risk-adjusted rates of very preterm birth morbidity and mortality (6). Differences in hospital of birth explained roughly 40% of the Black-White disparity and 30% of the Latina-White disparity in adverse neonatal outcomes. These data quantify the potential for facility-level improvement in quality of obstetric and neonatal care, particularly in poor-performing hospitals, to mitigate racial and ethnic perinatal inequities (7). Further, there is a growing recognition of exposure to racism rather than “race” itself as an underlying source of health disparities (8), requiring identification and remediation of provider and institutional biases that perpetuate inequity in service delivery and outcomes (9).

Understanding variation in how Black and Latina women experience perinatal care compared to White or Asian women can inform quality improvement efforts. Existing qualitative literature has analyzed maternal narratives of preterm delivery and NICU admission outside of the US (10–20), and an emerging body of research in the US has documented segregation and discrimination in women of color’s experiences of obstetric and neonatal care (21–23). Our study objectives were to understand how a racially and ethnically diverse sample of mothers experienced high-risk obstetric and neonatal care, and whether or not there were differences in these experiences by race and ethnicity that may suggest reasons for variation in quality of care and outcomes.

## METHODS

We used a qualitative approach to elicit rich description in women’s own words. Focus groups allowed study participants to express their opinions freely among others with similar experiences (24). An academic medical center Institutional Review Board approved the study.

## Participant Selection and Recruitment

This study used a purposive, convenience sample drawn from deliveries in an NYC academic medical center over a two-year period. Inclusion criteria were: (1) live birth between June 2016-June 2018 and (2) very preterm (VPT) or very low birthweight (<1500 grams) (VLBW) delivery with a minimum five-day neonatal intensive care unit (NICU).

The research team accessed hospital medical records to identify women who appeared eligible for the study and contacted women by telephone to screen further for eligibility and interest. In addition, recruitment flyers advertising the focus groups were posted in hospital-affiliated clinics and surrounding community organizations serving pregnant or postpartum women.

## Data Collection

We conducted three focus groups with four to eight mothers in each group (n=20). We stratified focus groups by three self-identified categories of race or ethnicity: Black (FG1), Latina (FG2), and White or Asian (FG3). We obtained written informed consent from participants, who also completed an anonymous demographic questionnaire at the start of each session. One of two moderators experienced in qualitative research methods led each focus group. Focus groups were approximately 120 minutes long, conducted in English, professionally recorded and transcribed verbatim. Researchers who identified as women of color moderated the focus groups with Black and Latina women. Moderators used the same semi-structured guide with open-ended questions across all groups. Topics included choice of prenatal care provider and delivery hospital; experiences of pregnancy, childbirth, neonatal complications; quality of interactions with health care providers; and perceived discrimination. To supplement the tapes, research team members took notes on verbal expressions, body language, group dynamics, and discussion content.

## Data Analysis

Data were analyzed using standard qualitative analysis methods (25) and NVivo V.12 qualitative software. Three research team members (EW, SS, KG) read all transcripts. EW inductively developed a codebook based on themes that emerged during data collection and close reading of transcripts. The full research team reviewed and revised the codebook after all focus groups. EW and KG independently applied codes line by line to the transcripts, and updated and added codes as analysis continued. The final codebook included primary codes for overarching themes and subcodes for more nuanced indexing of data within the primary codes (25). In a second cycle of analysis, themes that emerged from the first cycle of coding were grouped into pattern codes, which integrate themes according to higher-level categories, relationships, or constructs (25). EW and KG collaborated to compare coding, describe commonalities and differences across focus group transcripts and field notes, and highlight illustrative quotes.

## RESULTS

The study population was 40% Black (n=8), 40% White or Asian (n=8), and 20% Latina (n=4). Two-thirds (n=8 of 12) of Black and Latina participants had Medicaid coverage,

while all White and Asian women were privately insured. Additional sociodemographics are presented in Table 1.

### Commonalities in the patient experience across racial and ethnic groups

**Negative emotions in pregnancy and childbirth**—Pregnancy and childbirth were stressful events that many women described as “traumatic,” “scary,” or “rough.” To explain the shock of her very preterm delivery, one woman said: “The birth experience was honestly surreal. I was like no, this isn’t happening yet, I’m not ready, I’m gonna make it longer. It took me a couple days to really process what had happened” [FG3]. In many cases, such as when pregnancy progressed normally until the sudden onset of labor or need for delivery intervention, the lack of opportunity to adjust childbirth expectations caused considerable stress. Another woman said,

“The whole experience to me was traumatizing. I didn’t have a condition before I knew I would be giving [birth] at 31 weeks and 2 days. Basically, I was admitted one day, the next day I had to give birth. So, I was extremely scared, I didn’t anticipate that.” [FG3]

Mothers said that they felt powerless over their bodies, which detracted from pregnancy and initial motherhood experiences: “Trying to be happy about having a child—it’s also very nerve-wracking, because I didn’t know at what point I wouldn’t be able to sustain a pregnancy” [FG3]. However, while some mothers described disappointment in not being able to carry their pregnancy to term, they also noted accepting the need to relinquish control and “trusting the professionals” [FG1].

**Adjusting to mothering in the NICU**—NICU admission entailed multiple interruptions of the mothering role. Specifically, women experienced sudden and protracted separation from their infant, physical barriers to closeness (incubators, lines, monitors, etc.), challenges establishing and sustaining breastfeeding, and mother-child interaction heavily mediated by health care providers.

The physical mother-child separation typically began with transfer to the NICU right after delivery, which contrasted sharply with women’s expectations of birth: “My baby came out, and I didn’t even get to see him. They took him immediately, because he was just so small” [FG1]. One mother noted that she was ill prepared for the emotional toll of postnatal separation despite having anticipated a NICU stay:

“The thing that was the toughest that I think about a lot was...that separation moment...I knew that I would be delivering early, and I told my husband ‘I want you to go to the NICU, and I’ll recover myself,’ and I don’t think I really realized how hard that would be” [FG3].

After maternal discharge, parents confronted the logistical and emotional burden of travelling back and forth to the hospital to be with their infants, many for a five-month or longer NICU stay, and balancing time in the hospital with returning to work and other childcare responsibilities. As one Latina mother said,

“There wasn’t a night that I didn’t cry. I cried knowing that I couldn’t take her with me. As much as I wanted to pack up her stuff and take her home with me. I knew that she had to be there. It killed me inside.” [FG2]

**Satisfaction with quality of perinatal care**—The stressful and often traumatic experience of a neonatal complication was distinct from women’s perceptions of the quality of their perinatal care. Most women described prenatal and hospital care in positive terms, including “pleasant”, “informative”, “reassuring”, “transparent”, “personable”, “comfortable”, “genuine”, and “loving”. For example: “Basically the amazing experience we had with the nurses there was what saved me” [FG3] and “Even though I went through that traumatic experience, I did feel that I was in good hands, and I was treated very well” [FG1]. Women generally attributed negative experiences to the inevitable emotional distress accompanying a complicated birth and worry for infant wellbeing. They did not appear to place blame on clinicians, but rather on physiological processes beyond their control.

“...I wish mine [baby] stayed a little longer in [the womb]. So, it’s bittersweet, and I don’t think there’s anything that the doctors or the nurses could have done that they didn’t do.” [FG2]

### Relational processes influencing mothers’ experiences

**Communication from clinicians**—Mothers appreciated thorough communication of health information about perinatal risks and medical care for themselves and their infants to cope with the stress of the experience. Frequent descriptors of positive conversations with providers included “reassuring,” “thoughtful,” “comfortable,” and “informative.” Clinician communication helped prepare women with known high-risk pregnancies for potential complications in labor and delivery. As one woman noted, learning of her pregnancy risk was “terrifying” but receiving ample information to prepare was “quite amazing” [FG3]. Another described, “He [obstetric provider] had to set my expectations, make me listen and keep repeating things in a different way” [FG3]. The protective effect of such knowledge, however, was not universal. In some high-risk cases, women were caught off guard despite close monitoring and anticipation of delivering before full term: “I knew he was gonna come early, just not 27 weeks early” [FG2].

In the NICU, ample clinician-parent communication helped mothers to feel consulted and involved in care, which reduced anxiety when they were away from their infants. As one woman recounted,

“They always told me everything that was going on, whether it was a bath, whether it was a line change. They always gave me all the information I needed, I never felt worried when went home. I always felt like my baby’s safe, everything’s fine.” [FG2]

And another,

“The NICU team was amazing. They answered everything without me even having to ask. They sat down with me and spoke to me like a person. I wasn’t just another patient’s mom. They spoke to me like I was a part of their team.” [FG2]

A Latina mother suggested that increasing opportunities for the care team and family members to debrief at NICU admission would be useful in preventing communication gaps in infant care:

“I think it should be mandatory for you [the clinical team] to sit down with that family before you even meet their baby, just so that everyone has a general understanding. You don’t have to ask me the same questions that I told this person... a lot of things get lost in translation, and [sitting down together is helpful] just so that there’s no confusion.” [FG2]

**Personal attention from staff**—Mothers in each focus group described feeling a sincere warmth and attentiveness from physicians and nurses, both in the obstetric care provided to mothers and care for babies in the NICU. Women benefited from additional support to combat the uncertainty, fear, and stress associated with neonatal complications. Such support fostered confidence in clinical judgment and care. As one mother described her relationship with a NICU physician, “[she] and I had an amazing rapport. I had a lot of trust in every judgement call she made. I genuinely believe that a lot of her actions are really why we have the outcome that we have with our baby, a positive outcome” [FG1]. This trust was especially critical given the unique processes of motherhood in the NICU, where women had limited access to their children and had to relinquish much of their caretaking role to hospital staff.

One woman described the reassurance provided by meeting with NICU staff even before delivery, during a brief prenatal hospitalization at 26 weeks of gestation. She resisted speaking with NICU clinicians out of fear for her infant’s prognosis, but ultimately found that the information and attention she received rendered a critical shift in her mindset on the prospect of preterm delivery.

“They brought somebody down [who] sat with me for an hour, while I was sweating and nauseous and miserable. She was so wonderful and reassuring and gave me tons of information and a lot of numbers. That changed my whole perspective –that was very important and a watershed thing for my experience.” [FG3]

**Differences among racial and ethnic groups**—Descriptions of explicit discrimination were rare. When asked directly about experiences of bias, nearly all mothers responded that they did not encounter inferior treatment based on their race or ethnicity. However, a few scenarios described by Black and Latina mothers indicated disrespectful care. In one example, a Black woman explained feeling dismissed and insulted when she wanted to participate in daily caretaking for her infant in the NICU:

“She [the nurse] was like, “Yes, I already started [the diaper change]. You know, I have a lot of things to do. I have a lot of babies.”...So, she can see my face that I’m really, really upset now. She’s like, “What’s wrong?” I said, “Nothing.” – my husband tells me, like in Creole, “I don’t know why you’re wasting your time, going back and forth with her.” So, she goes, “Oh, don’t speak your language here.” So, that was a whole ‘nother story. So, now I had to go and report her,

because you can't tell me, don't speak my language here. Meanwhile, you're speaking your language to another nurse there. So, I think there's a lot of like barriers to respect—They just think they can do whatever.” [FG1]

Both Black and Latina women described receiving or observing disparaging treatment from hospital staff for speaking a foreign language, while White and Asian women did not raise this issue. As a Latina mother observed: “Her and her husband speak another language and the nurse told them, we don't speak that language here, we only speak English here. That was a pretty sour day” [FG2].

Black women discussed shortcomings in clinical encounters when poor or ineffective communication from health care providers exacerbated the stress of pregnancy complications. Two Black mothers discussed the use of accusatory or overly alarming language. One explained, “She [the provider] was like, ‘Oh, are you sure you want to do this, because he can die.’ She made me feel like, if I had him, and something happened to him, it would be my fault” [FG1], while another mother said “it seemed like they were constantly preparing me for her [my baby] dying” [FG1].

Further, some Black mothers felt ignored or dismissed by providers, while this was not a theme of discussion in other groups. For example,

“She [a nurse] is like, ‘Well, you need to stop moving, because I can't get the heartbeat.’ And I'm [saying], ‘You have to relax. I'm having contractions.’ I kept telling her. And then, I just told her to call the doctor. The doctor came and she's like, ‘Okay, you're going into labor.’ That's what I been trying to tell her--it's hurting so bad and she's just being rude.” [FG1]

In one case, the mother explicitly attributed this treatment to race:

“...my fears and apprehensions were not acknowledged, and there wasn't any compassion there...I said, ‘I don't know if you would do this to me if I were a married, White lady’ ... even if you have those feelings, deep in your heart, you shouldn't be bringing it outside.” [FG1]

Conversely, White and Asian women did not report personal experiences of bias. Yet they described differences in the attention and respect clinicians provided to other women and felt that this treatment was based on sociodemographic characteristics:

“I feel like there is a big socioeconomic divide actually...Some people [clinicians] could be more dismissive with people [patients] who they might have perceived as a lower level of education...” [FG3]

“Well, you can see they [nurses] wouldn't spend as much time explaining, kinds of being a little impatient and not openly friendly...I think because of the [socioeconomic] background...the type of insurance of the parents of the baby in the NICU.” [FG3]

## Structural processes influencing the patient experience

**Number and mix of providers**—Perinatal care involved obstetricians, maternal fetal medicine physicians, advanced practitioners, labor and delivery nurses, neonatologists, neonatal nurses, and training residents and fellows. Mothers in each focus group addressed the importance of care coordination for maternal needs during prenatal and delivery care as well as over the course of the neonatal admission. In particular, the configuration of nursing care in the NICU, with constant shift changes and rotation of bedside assignments, sometimes caused inconsistencies in care or communication. Some mothers lauded the benefits of having a “primary nurse” to care exclusively for their infant and of opportunities for family meetings with the medical team. The primary nurse relationship particularly helped to alleviate concerns when women were away from the NICU: “I feel like they [NICU nurses] didn’t communicate well with me, but soon as I met his primary nurse, she would always call me and told me if things are wrong” [FG1]. Family meetings were preferred over participation in medical rounds as a more accessible mechanism of parental inclusion in treatment conversations. However, awareness of primary nurse services and family meetings was limited, and mothers in the White/Asian focus group in particular felt that there should have been more transparency in the process of primary nurse assignment.

**Barriers to contact with infant**—Women confronted challenges in achieving closeness with their infants while still in the hospital during postnatal recovery and after maternal discharge. The hospital layout and facilities exacerbated the challenges of separation. Having the NICU and mother-baby units on different floors made going back and forth challenging for women with postnatal physical limitations. It was also distressing for women whose babies were in the NICU to share recovery rooms with other women whose infants were rooming-in. As noted by two women in the focus group with White or Asian mothers: “I was lucky my roommate was very respectful, but it was hard because her baby was not in the NICU... wouldn’t it be nice if you could be with someone who is also separated?” [FG3] and “I was stuck in this room with somebody I didn’t know whose baby was there, and my baby wasn’t there” [FG3]. Competing demands such as employment and other children at home often precluded women from spending as much time as they wanted at the infant bedside. Mothers stressed that opportunities for physical contact such as kangaroo care facilitated bonding and feeling useful in their infant’s progress.

**Differences among racial and ethnic groups**—Insurance coverage and provider selection varied markedly by race and ethnicity. Black and Latina mothers, mostly insured by Medicaid, typically chose a hospital as opposed to a specific obstetric provider and received prenatal care in the hospital clinic. All White and Asian mothers had commercial insurance, and tended to select a private obstetric practice first and deliver where the providers were affiliated. Consequently, White and Asian women typically had a stable group of providers that they met during prenatal visits while many more Black and Latina women encountered a rotation of residents with limited continuity across visits.

Despite these differences, Black and Latina women did not raise concerns with staffing or continuity of care more often than White and Asian women. Black mothers in fact conveyed the opposite sentiment, and were surprised at the level of communication among members of



the care team. One Black woman described prenatal care as a “group effort” where “they [the doctors] were on point with what was going on with you. It was like whatever they wrote in the notes was to the T for the next doctor to understand” [FG1]. Another echoed this opinion, “They knew everything. It’s like each one [doctor] I spoke to, they knew this was going on with me” [FG1]. A Latina mother noted that effective collaboration among clinicians continued from pregnancy through to delivery:

“Every time I came [to prenatal care] I saw someone different. They all worked together [and] when I actually went into surgery, I saw maybe about 3 different people that I have previously had care from, and I was happy with everyone that took care of me.” [FG1]

Conversely, two women in the discussion with White and Asian mothers perceived a lack of coherence in care when they received opposing medical advice across clinicians during prenatal care or in the hospital. One was overwhelmed by conflicting opinions across the specialists she encountered when she was hospitalized for six weeks prior to birth: “By the end, my care ended up being [with] so many different doctors, and they had conflicting opinions about some of my care, which was a little stressful” [FG3]. One Latina mother felt that clinical information sometimes was “lost in translation” among training residents and rotating staff, but this sentiment was not reinforced by other women in the group.

## DISCUSSION

The aims of this study were to describe the prenatal, delivery, and neonatal health care experiences of a racially diverse sample of women with a VPT or VLBW infant admitted to the NICU, in order to help identify potential levers for disparity reduction in perinatal health care quality. We employed two strategies to explore how experiences of care did or did not vary by race: (1) stratifying focus groups by race and ethnicity so that we could detect commonalities and differences across discussions, and (2) directly asking participants about experiences of felt or observed discrimination based on racial or ethnic background, language, nationality, or culture during clinical encounters.

We expected variation in how women of different racial and ethnic backgrounds assessed their care, with more negative feedback and experiences of bias and discrimination in patient encounters among Black and Latina women. What emerged from our findings, however, was a common experience among mothers, regardless of race/ethnicity, of the stress of neonatal complications and the struggles of parenting in the NICU. Despite these difficulties, women from all three groups had generally positive assessments of perinatal care quality. We identified several relational and structural processes of care that influenced the patient experience across the board. We also identified some deficiencies in clinical encounters, specifically in terms of respectful treatment and communication from clinicians, among Black and Latina as compared to White and Asian women.

Women’s recollections of pregnancy and neonatal complications were distinct from their perceptions of health care quality. With respect to their experience of complications, participants described challenges across a range of prenatal and birth experiences, including the distress of early delivery, concern for infant prognosis, the sudden interruption of

maternal-newborn bonding, and the demands of a prolonged NICU stay. Narratives exposed common themes of powerlessness and lack of autonomy as high-risk patients and mothers in the NICU that have been identified in earlier research (17, 19). A loss of control and the alteration of parenting roles were the most prevalent themes in a systematic review of qualitative studies of parental NICU experiences (19). Fenwick et al. (2008) similarly found that navigating restrictions on mothering tasks and feeling like “visitors” with limited access to their infants caused significant distress for NICU mothers in Australia (11).

With respect to quality, however, women in these focus groups described the quality of perinatal health care in largely favorable terms. They talked about how transparent and attentive care provided reassurance during otherwise stressful pre- and postnatal experiences. Women often have an idealized vision of how pregnancy, delivery, and initial motherhood will unfold. Respectful and informative communication prepared these women’s expectations throughout obstetric and neonatal care, fostered trust in clinician skill and judgment, and helped to mitigate feelings of disappointment, worry, and blame (26). Fenwick et al. reported that maintaining provider communication of medical information, achieving physical closeness, and participating in infant care were strategies for NICU mothers to demonstrate authority and ownership (11). Our findings corroborate the benefit of such opportunities in affirming maternal identity and building postnatal connection and confidence.

While instances of overt or intentional discrimination were rare, communication deficiencies were one way in which the influence of racial/ethnic background or nationality manifested in the care experience. Black women reported clinicians speaking to them in a dismissive or accusatory manner. A growing body of evidence suggests that women of color experience power imbalances in health care encounters that result in withheld information, disrespectful treatment, and stressful clinical interactions (21, 22). The most explicit examples of verbal discrimination were reports of clinical staff discouraging patients’ use of a language other than English in the hospital. Language barriers have been associated with perceived discrimination in patient-provider interactions in maternity care (27), disparities in labor pain management (28), and increased frequency of medical errors (29, 30). Hospitals are federally mandated to provide language services to patients with limited English proficiency, including free interpreters and accurate translations of print materials in languages common among the patient population (9). The hospital in this study offered 24/7 language services for patients, which suggests that ensuring respectful care goes beyond the availability of translation services. Our results highlight the importance that hospital personnel are educated on patients’ rights and provision of culturally appropriate care, and are skilled in linking women and their partners or families to services to help navigate health information and clinical encounters (31).

Further, subtle differences in provider communication among racial and ethnic groups may reflect cases of implicit bias. Implicit bias occurs when an individual’s beliefs and stereotypes unconsciously influence behavior towards others because of characteristics such as race, ethnicity, age, gender, etc. (32). In medical care, implicit biases may cause providers to attend to patient symptoms and concerns or provide treatment differentially based on race/ethnicity. The potential impact of such biases is particularly salient in cases of high-risk

pregnancy and emergent delivery care, where providers draw heavily on automatic, conditioned behavior and unconscious beliefs (9, 33). The prevalence of implicit bias in health care and its associations with patient-provider interactions and treatment decisions are well-documented (34). Specifically, higher levels of racial stereotyping have been associated with a lower likelihood of patient involvement in clinical decision-making, less patient-centered dialogue, and greater clinician verbal dominance in encounters with Black patients (35). In a survey of health professionals' observations of disparities in NICU care, one-quarter of neonatal clinicians and family advocates identified instances of judgmental staff attitudes or differential resource allocation by race, culture or ethnicity, language, or social class (23). In our study, a few Black mothers described feeling ignored or dismissed by providers, unlike women in other groups, and White and Asian women reported on observed examples of a "socioeconomic divide" in health care delivery. These findings underscore the importance of training providers to recognize and remediate unconscious biases in themselves and others, as well as instituting robust reporting systems that provide recourse without fear of retaliation for employees, patients, and visitors who experience or witness instances of discrimination and disrespectful care (9).

In a cross-sectional analysis of data from two randomized trials of patient-provider communication interventions, Cooper et al. demonstrated that differences in service delivery from provider biases were associated with poorer visit quality ratings, particularly from Black patients (35). Surprisingly, the examples of sociodemographic imbalances described in our study were rare and did not translate to serious critiques of perinatal health care. On the contrary, feedback was generally positive in all focus groups. Women did not identify major deficiencies in medical treatment or attribute blame for neonatal complications to the clinical care they received. Barriers to physical presence in the NICU, such as transport difficulties and conflicting work or other familial responsibilities, may be more prevalent and intensify stress among lower SES women but we did not identify such differences by race/ethnicity.

Racial and ethnicity are often highly correlated with socioeconomic characteristics that affect quality of care. We observed patterns in payer and source of care by race/ethnicity, with half of Black and all Latina women publicly insured by Medicaid. These women typically received care from rotating residents in a hospital-based prenatal clinic. Quality deficiencies related to provider skill level or continuity of care may be more prevalent in outpatient resident clinics than in private practice (36). However, differences in insurance coverage and source of care did not translate to systematic differences in satisfaction with NICU care by race or ethnicity. In this circumstance, though, processes in the NICU including physician, nurse, and bed assignment were not dependent on insurance type, which might explain why we found limited variation in patient experiences in the NICU setting. Further, our study design would fail to capture indicators of quality not perceived by mothers, and results may omit important unobserved technical or structural disparities in medical care.

Limitations of our study include recruitment from the patient population of a single urban hospital. Our analyses represent a convenience sample of patients whose babies experienced adverse neonatal outcomes and are not intended to be generalizable. In interpreting our

findings, it is important to note that while mothers in our focus groups endured traumatic childbirth experiences and their babies had extended NICU stays, we only included mothers of living infants and most were discharged or soon to be discharged successfully by the time of our study. It is possible that women recalled positive aspects of their care because they emerged from this experience with the desired result, a baby they could take home. However, the qualitative design elicited detailed narratives of clinical interactions and mothering in the NICU, providing insights into under-researched elements of perinatal health care in mothers' own words. We divided focus groups by categories of race/ethnicity in line with major U.S. perinatal disparities. Further research on this topic would benefit from finer stratification of participants from a wide range of racial and ethnic backgrounds, including non-English speakers, and direct observation of clinical interactions during obstetric care and in the NICU.

## CONCLUSIONS

Women described a considerable emotional burden accompanying adverse perinatal outcomes but spoke positively about the quality of obstetric and neonatal care and credited providers with the survival and health of their infants. We identified differential provider communication and responsiveness by patient race and ethnicity; further investigation of the scope and consequences of these inconsistencies is a research priority. Health service interventions should emphasize educating all staff on the prevalence and underlying causes of racial and ethnic health disparities, training supervisors to identify and intervene in cases of discriminatory treatment, and creating effective reporting and response channels to hold stakeholders at all levels of the health system accountable for equity in perinatal care.

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**Table 1.**

Characteristics of the Study Population (n=20)

Variable	N (%)
<b>Race/ethnicity</b>	
White or Asian	8 (40) <sup>a</sup>
Black	8 (40)
Latina	4 (20)
<b>Age (years)</b>	
<20	0 (0)
20–29	3 (15)
30–34	7 (35)
35–39	5 (25)
40–44	3 (12)
No response	2 (10)
<b>Education level</b>	
Less than high school	2 (10)
High school graduate or GED	2 (10)
Some college or 2-year degree	5 (25)
4-year college graduate or higher	9 (45)
No response	2 (10)
<b>Parity</b>	
One	9 (45)
Two	4 (20)
Three or more	5 (25)
No response	2 (10)
<b>Insurance Type</b>	
Medicaid	8 (40)
Private/Commercial Insurance	10 (50)
No response	2 (10)
<b>Marital Status</b>	
Married/Living with a partner	8 (40)
Divorced/Separated	1 (5)
Never married	9 (45)
No response	2 (10)
<b>Employment Status</b>	
Employed	8 (40)
<b>Nativity (US-Born)</b>	
US-Born	16 (80)
<b>Primary Language</b>	

Variable	N (%)
English	17 (85)
<b>Annual Income</b>	
Less than 15,000	4 (20)
15,001–30,000	4 (20)
30,000–45,000	1 (5)
More than 45,000	9 (45)
Don't know/no response	2 (10)

<sup>a</sup>Two participants in the White/Asian group did not return questionnaires and were missing all demographic characteristics.

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