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Lived experiences of stress of Black and Hispanic Mothers during hospitalization of preterm infants in Neonatal Intensive Care Units

Rachel E. Witt, MD¹, Bryanne N. Colvin, MD¹, Shannon N. Lenze, PhD², Emma Shaw Forbes, BA³, Margaret G.K. Parker, MD, MPH⁴, Sunah S. Hwang, MD, MPH, PhD⁵, Cynthia E. Rogers, MD^{1,2}, Eve R. Colson, MD, MHPE¹

¹Department of Pediatrics, Washington University School of Medicine, St. Louis, MO

²Department of Psychiatry, Washington University School of Medicine, St. Louis, MO

³Slone Epidemiology Center, Boston University School of Medicine, Boston, MA

⁴Department of Pediatrics, Boston Medical Center, Boston University School of Medicine, Boston, MA

⁵Department of Pediatrics, University of Colorado School of Medicine, Aurora, CO

Abstract

Objective: To characterize the lived experiences of stress associated with having a preterm infant hospitalized in the NICU among Black and Hispanic mothers.

Methods: We performed a qualitative content analysis of secondary data from two prior studies that included 39 in-depth interviews with Black and Hispanic mothers of preterm infants at 3 U.S. NICUs. We used a constant comparative method to select important concepts and to develop codes and subsequent themes.

Results: Black and Hispanic mothers described stressors in the following domains and categories: *Individual* (feeling overwhelmed, postpartum medical complications, previous stressful life events, competing priorities); *Hospital* (perceived poor quality of care, provider

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Corresponding Author: Rachel E. Witt, MD (witt_r@wustl.edu).

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Dr. Witt conceptualized and designed the study, coordinated and carried out analyses, drafted the initial manuscript, and reviewed and revised the manuscript.

Dr. Colson conceptualized and designed the study, designed the data collection instruments, collected data, carried out analyses, reviewed and revised the manuscript.

Drs. Colvin, Parker and Hwang and Ms. Forbes designed the data collection instruments, collected data, carried out analyses, and reviewed and revised the manuscript.

Dr. Lenze carried out analyses, reviewed and revised the manuscript.

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communication issues, logistical issues); *Community* (lack of social supports, lack of financial resources, work challenges).

Conclusions: The findings of this study suggest that stressors both inside and outside of the hospital affect the lived experiences of stress by Black and Hispanic mothers during NICU hospitalization.

Introduction

The preterm birth rate in the United States (U.S.) has continued to increase, most recently to 10% with nearly 380,000 infants born preterm in the U.S. in 2018. Both this rate of rise and the overall rate of preterm births has disproportionately affected Black and Hispanic families. The preterm birth rate for non-Hispanic white mothers was 9% in 2018, compared to 14% for non-Hispanic Black mothers and 10% for Hispanic mothers (1). Preterm birth and the subsequent neonatal intensive care unit (NICU) hospitalization of a preterm infant cause stress for parents (2–4), affecting 24–37% of mothers of preterm infants. This stress is associated with psychological sequelae including depression, anxiety, and posttraumatic stress symptomatology (5–9). Maternal stress is associated with adverse maternal and preterm infant health outcomes, including lower breastfeeding rates, negative and intrusive parenting behaviors, and long-term parent and child psychiatric illness (10–13). Thus, identification of maternal stress and development of interventions to reduce maternal stress associated with preterm birth and NICU hospitalization are important. However, the etiologies of this stress, particularly for Black and Hispanic mothers, are not well-understood.

A recent systematic review of qualitative studies explored parental experiences in the NICU and found that having an infant hospitalized in the NICU is a stressful experience for parents that can result in impaired parental psychological functioning (e.g., anxiety and depressive symptoms; sleep disturbance; feelings of grief and isolation, shame and helplessness) and/or an interrupted development of a healthy parent-infant relationship (14). Of the eight studies included in this systematic review, only two were conducted in the U.S., and neither reported racial/ethnic demographic characteristics. Another recent systematic review of qualitative studies explored coping strategies utilized by parents in response to stress in the NICU. Of the nine studies included in this systematic review, only four were conducted in the U.S., and only one included a sample that was representative of the U.S. population, with Black and Hispanic participants comprising slightly more than half of total participants (15). That study focused on stressors related to critical care in the NICU and whether parents believed that therapy was worthwhile, but did not investigate stressors not directly related to medical decision-making (16).

Given these deficits in the literature, the goal of our study was to characterize the lived experiences of stress associated with having a preterm infant hospitalized in the NICU among Black and Hispanic mothers. Prior quantitative research has found that significant racial/ethnic disparities, independent of income status, exist in psychosocial measures during pregnancy. (17). Black mothers have been found to experience varying levels and types of stress in the NICU, as well as higher levels of distress associated with having an

infant in the NICU compared to white women (18, 19). Spanish-speaking mothers tend to have significantly lower levels of social support compared with English-speaking mothers, and immigrant families with preterm infants hospitalized in the Canadian NICUs are at increased risk of depressive symptoms compared to non-immigrant families (20, 21). Certain populations, including Black and Hispanic mothers, may be at high risk for mental stress and require greater or more targeted support in the NICU (22). Accounts of perinatal stress provided by Black and Hispanic mothers, in their own words, may inform development of more targeted measurements and interventions to address stress related to having a preterm infant in this at-risk group.

Methods

Design

We used the qualitative research method of content analysis in a secondary data analysis of in-depth interview transcripts aggregated from two prior studies (data set 1 (23) and data set 2 (24, 25)) that both included mothers of preterm infants. Content analysis is a widely used qualitative research technique used to interpret meaning from the content of text data (26). Specifically, we used the conventional approach in which coding categories are derived directly from the text data without using an *a priori* theory. This type of analysis is generally used with a study whose aim is to describe a phenomenon when existing theory or literature is limited and when a grounded theory approach is not possible, and is, therefore, a good fit for this study (27). Secondary data analysis of qualitative data involves investigation of previously collected data that is analyzed by the same or different researchers to explore new questions or use different analysis strategies than in the primary analysis (28, 29).

The prior study that produced data set 1 asked Black and Hispanic mothers about their perspectives on known barriers and facilitators of breastfeeding and skin-to-skin in the NICU setting. The prior study that produced data set 2 used the Theory of Planned Behavior to ask mothers about their infant care practices. While addressing maternal stress during NICU hospitalization was not the main focus of either prior study, mothers in both studies independently reported that stress impacted their behaviors. Since both prior studies used grounded theory methodology, stress emerged as a concept during the iterative process of reviewing transcripts and was noted to be more often discussed during interviews with Black and Hispanic mothers.

We therefore used these data sets to conduct our study where we focused on the following question: what are the sources of stress experienced by self-identified Black and Hispanic mothers of preterm infants during NICU hospitalization? In line with qualitative inquiry, we approached the data without preconceived theoretical ideas or hypotheses, instead allowing concepts and themes to emerge (30).

Settings and Sampling

These data were collected as part of two prior studies, which both examined the lived experiences of mothers of preterm infants during NICU hospitalization. Both prior studies conducted purposeful sampling for maximal diversity within their respective inclusion

criteria, in that they sought a racially and ethnically diverse group of mothers of VLBW and/or preterm infants who had been present and involved in their care during NICU hospitalization. The prior study that produced data set 1 included mothers who self-identified as Black and/or Hispanic, 18 years old at the time of delivery, spoke English or Spanish, initiated milk production to any extent, and gave birth to infants that were 1,750 g. The prior study that produced data set 2 included mothers who spoke Spanish or English, and had infants <37 weeks' gestation who were hospitalized in the NICU for at least 7 days. All 23 mothers in data set 1 and 16 of 23 mothers in data set 2 self-identified as Black or Hispanic, for a total of 39 Black and Hispanic mothers of preterm infants included in this secondary data analysis.

We sought to represent a broad range of perspectives in this secondary data analysis, so we included Black and Hispanic participants recruited from five hospitals with level 3 and 4 NICUs in three U.S. states from 2016 to 2019. All are part of larger health systems and were teaching hospitals with trainees. The study that produced data set 1 recruited participants from two hospitals: Boston Medical Center (BMC) in Boston, Massachusetts where ~50% of patients identify as non-Hispanic Black and 25% identify as Hispanic; Beth Israel Deaconess Medical Center (BIDMC) where ~14% of patients identify as non-Hispanic Black and 13% identify as Hispanic. The study that produced data set 2 recruited participants from four hospitals: BMC again; Saint Louis Children's Hospital in St. Louis, Missouri, where ~30% identify as non-Hispanic Black and 3% as Hispanic; Children's Hospital Colorado in Denver, Colorado where ~5-10% of patients identify as non-Hispanic Black and 30% identify as Hispanic; University of Colorado Hospital in Denver, Colorado, where less than 5% identify as non-Hispanic Black and ~40% identify as Hispanic.

This study was reviewed and approved by the Institutional Review Board at Washington University School of Medicine. Informed consent was obtained from all participants.

Data Collection

In both prior studies, a single research associate conducted each in-depth interview in person, by phone or by teleconferencing platform 2-18 months following discharge from the hospital. These research associates had backgrounds in qualitative research, as well as training and experience in conducting in-depth interviews. These research associates were also specifically not health professionals and did not provide care to the mothers or their infants, allowing for interviewer and interviewee to have honest conversations. The in-depth interview guides for both studies were created in an iterative fashion, with changes made to questions based on what was learned through review of the previous transcript.

In the prior study that produced data set 1, mothers were informed that interviewers wanted to hear their perspectives about being a Black and/or Hispanic mother providing human milk for and participating in skin-to-skin care with their very low birth weight (VLBW) infant during NICU hospitalization. In the prior study that produced data set 2, mothers were informed that interviewers wanted to hear their perspectives about their own preterm infant care practices, specifically in the areas of sleep, feeding, smoking and immunizations. In both prior studies, Spanish-speaking mothers were interviewed by a bilingual English- and Spanish-speaking Hispanic research associate. The interviewers asked open-ended questions

to probe about facilitators and barriers to implementation of any practice change. The interviews were audio recorded and transcribed by a Health Insurance Portability and Accountability Act (i.e., HIPAA)-certified, independent transcription service. The interviews that were conducted in Spanish were translated by a professional service. In areas where there was confusion, Spanish-speaking research team members reviewed the transcripts.

Data Analysis

For this study, content analysis was conducted which included a line by line review by at least two researchers: a physician (R.E.W.) and at least one and up to three other members of the research team, comprised of physicians with subspecialties in neonatology, pediatric hospitalist medicine, and psychiatry and a research associate with a background in qualitative research. A senior physician-scientist with expertise in qualitative research (E.R.C.) also provided oversight and critical review of the process. Some of the same researchers from both parent studies were included to ensure integrity of data analysis with regards to original data collection. Different researchers without prior involvement in the parent studies were also included to provide novel perspectives.

We performed initial open coding with each transcript to identify concepts, with a lens specifically on maternal stress. Using the constant comparative method of analysis (31), we then reviewed all transcripts with the set of codes that had been developed by grouping the codes into themes. This method of analysis systematically compares concepts within each interview, between interviews and between groups of interviews (data set 1 vs. 2), so we were able to categorize, code, delineate categories and connect them inductively. This process increases internal and external validity of the data. When applicable, disagreements regarding coding and theme development were discussed until consensus was reached. NVivo software was used for organization of the data.

Results

This study included a total of 39 Black and Hispanic mothers of preterm infants: 19 (49%) non-Hispanic Black; 16 (41%) Hispanic (any race), Spanish-speaking; 4 (10%) Hispanic (any race), English-speaking. Participant demographics are found in Table 1. Themes that emerged from the mothers' lived experiences of stress were in the domains of 1) the *Individual* mother 2) the *Hospital* experience and 3) the local *Community* and encompassing society.

Individual

For stress related to the *Individual*, mothers described personal stresses that included feeling overwhelmed and powerless when their infant was hospitalized, medical complications related to their own postpartum recovery, the impact of previous stressful life events on their experience of the current life event (birth and illness of infant) and competing priorities.

With regard to feeling overwhelmed and powerless in the NICU, several mothers described not knowing how to help their infants. In explaining this experience, these mothers described seeing their infants acutely ill:

“I mean you see the little baby struggling for breath, you know sometimes you know she goes – sometimes she looks like her skin will go pale. You know just like a second or two. I mean I don’t even want to remember those things. It was pretty scary. You know I’ve seen, I remember the first time I saw it at NICU I practically – I mean I was just crying like a baby. Like what is this? My baby is struggling to breathe, my baby is losing her breath. I was just screaming” [Interviewee 1].

“The problem with him was his breathing... when they give you all that information, you think, and stress starts because you think about it- will everything turn out okay or will something bad happen?” [Interviewee 2].

“They told us she was doing poorly, that’s when I got very stressed out, since she was born prematurely you worry about her” [Interviewee 3].

“That was hard... depressing, sad... baby was so small, I was scared.” [Interviewee 4].

“He had a hole in his heart. When I heard about that, I was like, ‘Am I going to lose [him]?’ I think I had a lot of stress at this time [Interviewee 5].

“It was a bit nerve-wracking not knowing exactly what was going to happen or try to prepare yourself for when that time came” [Interviewee 6].

This mother described how stressful it was to watch her infant undergo painful procedures: *“I... be in there on the inside screaming ‘Get off my baby!’ because they are pricking him, and they are giving him all these medicines and all these fluids... that can overwhelm a parent” [Interviewee 7].* Similarly, another mother described how scared she felt by caring for her acutely ill infant in the NICU, saying: *“I used to just look and was like, ‘Oh my God, like I got a baby this small.’ I was scared to hold him. I was scared to help change him. They always, you know, ‘You want to help?’ I was scared, like, I didn’t want to – to hurt him... I know a lot of times I be like, ‘Well, I want to touch my baby,’ but I was – I was scared because I didn’t want to harm my baby, so I let him grow” [Interviewee 8].* This mother described not feeling like a mother to her preterm infant in the NICU: *“When you have regular birth and have kids on time, they’re in the room with you... and you can hold them and kiss them... with [my preterm infants], I didn’t feel that for a while, until maybe a month, maybe two months into the NICU... that I actually felt like, ‘Wow, these are my kids.’” [Interviewee 9].* Another mother shared how frustrating it was to be unable to provide breastmilk for her daughter and how scared she was to eventually initiate breastfeeding with her preterm infant: *“I felt helpless that I couldn’t feed my daughter as I wanted to... It was frustrating for me to pump out milk because I didn’t see the quantity I wanted, or that they expected me to take to the hospital. So I was sad to get to NICU and take out the containers because it was very little milk...” and “I thought my daughter was so fragile, so small, so innocent, so I was a bit scared that they would put her on my breast” [Interviewee 10].*

Additionally, some mothers described the stress they felt related to their own postpartum recovery. As an example, one mother said: *“Well, you know, usually when a mother had a baby, they need to stay at home and take care of themselves. But [for] me after my surgery, I just came to the NICU to see my kids. And it was a lot of stress, I think” [Interviewee 5].* Another mother shared similar sentiments: *“That was very, very hard because I had just*

given birth, and I really didn't get a chance to rest" [Interviewee 11]. The severity of the mother's illness during the perinatal course added an additional layer of complexity to the stress of the NICU experience. For example, one mother stated: *"It was stressing, it was traumatic, honestly. So many painkillers, antibiotics, because after the two surgeries my wound got infected in the hospital. So, all that depressed me, stressed me out, and I think it affected me"* [Interviewee 10]. Another mother said: *"Usually when a mother had a baby, they need to stay at home and take care of themselves. But me after my surgery, I just came to the NICU to see my kid. And it was a lot of stress, I think"* [Interviewee 5]. This mother described temporarily losing her vision in the perinatal period: *"I was blind for three days... that was a very difficult thing... I was scared, and I thought that I wasn't going to see again"* [Interviewee 12].

Some mothers described experiencing heightened stress from their NICU experience due to previous stressful life events. One woman, for example, described a previous infant loss and the impact it had on her experience in the NICU: *"I had a baby that at 25 days he passed away..... with my baby premature and I had to take him to the NICU and he was in the NICU that was like [my] baby passed away all over again..."* [Interviewee 13]. This mother described previously being in a victim of domestic violence: *"The biological father is not involved... me and him broke up, like the minute I found out I was pregnant, he was abusive"* [Interviewee 14]. Another mother described a previous personal traumatic experience she had using public transportation, which limited her ability to visit her infant. She said: *"I used to feel bad because I didn't have a way to get up here all the time. I would take the bus. I know a lot of people would say "Take the bus," but before I got pregnant, I went through an incident where my cousin was paralyzed and I was stabbed, so I'm really paranoid when it comes to public transportation. I always feel better when I'm in a cab or in a car"* [Interviewee 15].

It was not unusual for mothers to also describe the stress they felt from competing priorities in their lives while having an infant in the NICU. For example, mothers with other children described the need to be with their sick infant while tending to older children at home. One mother expressed this issue by saying: *"But when I left [the NICU] it was hard, because I didn't want to leave, but I also have another child who I couldn't leave alone, or I couldn't neglect"* [Interviewee 10]. Another mother commented on the difficulty of having her twins discharged from the NICU at different times, with one still hospitalized, and being geographically separated from her oldest child: *"It's so hard. It still is, because now I have Twin A is home and then my little Twin B is still up there, so I feel like I have to be here and I have to be there too. I felt really bad, and I couldn't bring him to go see them because, you know, no kids on the NICU, so it was kind of hard to explain to him, "Now I was pregnant, but now I'm not pregnant anymore. I'm coming home, but I have to go stay with the babies, but where's the babies?" and "I think it was because of some stress because it was quite a complicated experience for me, too. I had just arrived here. I left my daughter, she got sick. So, it was quite difficult, I had him in the hospital, my daughter was sick in Guatemala, no money to take her to the doctor. It was quite hard. So I think I run out of milk because of the stress"* [Interviewee 15]. This mother described her caretaking responsibilities for an older family member: *"My schedule became kind of hectic at the time. My mom was in the*

hospital, she had just had open heart surgery, so I did a lot of running back and forth trying to help her and stuff” [Interviewee 16].

Hospital

Factors at the hospital and NICU-levels that contributed to mothers’ experience of stress included perceived poor quality of care, provider communication issues, and logistical issues that made visiting difficult.

Some mothers expressed their concern regarding their perceived poor quality of care received by their infants. For instance, one mother said: *“The fact that they [the nurses] weren’t taking good care of him. Imagine that, I have never found a nurse there with him, looking after him. Every time I came, he was always alone. Always” [Interviewee 17].* Another mother shared, *“... I feel like in the NICU you don’t see the doctors a lot unfortunately. I didn’t really get in touch with the doctors until the end. You only see the nurses... I’m so aggravated with the nurses sometimes... I actually met up with a group of parents... and everyone was feeling the same way, and then like, ‘They [the nurses] leave my baby alone. I feel like every time I walk in and she’s alone.’ And I’m like, ‘Yeah, I feel the same way’... just the simple fact that the baby in the baby room all by herself, not feeling any body heat, not hearing any voices like they would if they were in the belly.” [Interviewee 14].* This mother recounted a negative experience from Labor and Delivery that made her wary to leave her infant in the NICU: *“I had already had a bad experience in the other area, so I wanted to be near my daughter, because I thought, if they treat me like this, then they will treat my daughter the same way in the other area” [Interviewee 10].* Another mother detailed her mistrust of a social worker: *“It was the social worker I didn’t like... she’s rude... she’ll give me attitude... I wrote a request that I didn’t want her to take care of my daughter.”* When asked how this experience added to her stress while her infant was in the NICU, the same mother said: *“Because I would see her. When I would go up there, I would see her near my daughter... I’ll make another request like I’d say that I didn’t want her around my child... and they was like ‘... We put that in the computer... she should have never be in there...’ I didn’t want her around there and she would just be always, you know?” [Interviewee 18].*

Regarding communication with providers, several mothers who spoke Spanish expressed concerns about language barriers. One mother said: *“So there were many times that I wanted to discuss things with them and they didn’t understand me. That’s when I used the interpreter, at first; then I learned to communicate better with them. I used the translator on the phone and so did they, so with time we started to get used to it. But yeah, it’s quite difficult and complex. When you don’t know English it’s quite hard” [Interviewee 19].* Similarly, this woman shared: *“Nobody ever talked to me in Spanish here. Only that lady who was very nice. She did speak Spanish but not a lot, just a little. But she did understand some parts of what I said; and mostly his dad spoke. He doesn’t speak perfect English, but he can talk and he understands a little. More than I do. He would ask how the baby was, and I stood like this, what did she say? Oh, she said he is fine. But I never heard them say in my language, oh your son has eaten, your son is fine. Never.” [Interviewee 17].*

Logistical issues such as transportation and parking provided by the hospital created cost and convenience barriers for several mothers. One mother said: *“When you did say if there was anything that I wished that I could tell another mom or that if there was anything I think the NICU would be able to work on, it’s transportation, because people don’t expect to be in the NICU, you know? It’s something that just happens, and sometimes it happens when the mom’s not even prepared for the babies, let alone prepared to be running back and forth to the hospital. I think that would be the only thing that—they gave me clothes. They helped me with diapers, a bed. They helped me with a lot of things, but the only thing that they couldn’t help me with was transportation”* [Interviewee 15]. Specifically related to parking, one mother said: *“I would park in the garage, which was expensive. I feel like they should have a better parking system for that, especially if my child is here and I have no option. I feel like that is something that they should work on, because it’s like... just adding more stress, especially with me”* [Interviewee 20]. This woman was not made aware of discounted parking services for families in the NICU: *“I was paying a lot [for parking], because I didn’t know in the garage... you could leave your car there and present a bracelet or a letter they give you at the parking office so that you only pay 7 dollars, regardless of how much time you spend here. I used to pay 30, 31 dollars. It was hell, because I spent a lot more money. And it was a bit difficult”* [Interviewee 21].

Restrictive hospital visitor policies with regards to other children compounded these issues, as one mother described: *“I mean I think it would be probably different if it was the only child where you can just go up there; but having other kids, where at the hospital, they couldn’t come up there. So that was the most difficult part, and especially we were having snowstorms and they got parking bans, and you can’t make it up there because it’s like a snow emergency and you’ve got your baby in the hospital. That was stressful, too”* [Interviewee 22]. Similarly, another said: *“It’s just that I couldn’t bring [my other daughter] into the NICU. They told me, and I always had her with me, so it was hard for me to keep going back and forth upstairs, but I couldn’t bring her”* [Interviewee 18].

Community

Regarding community, mothers experienced stress related to lack of social supports, lack of financial resources, and work challenges that they faced.

A number of mothers described challenges related to social supports from friends and family. One mother, an immigrant to the U.S., described stressors related to the geographic distance from their more extended social supports. She said: *“Well, I don’t [have] any relatives, right? They are all back in my country, and so are my husband’s. So, it’s just him and me and my children to support each other”* [Interviewee 23]. Similarly, this woman shared: *“...Every time I would get in some kind of bad mood about my son, it was kind of stressful... ’cause I keep thinking I need [family and friends] to come out to the hospital... something else is wrong... so that was stressful... I wasn’t around my family and my friends who are back home [in Antigua], you know? Sometimes, I wish all of them can come up here, but they can’t”* [Interviewee 24].

Some mothers referred to financial challenges that they faced. One mother who was experiencing homelessness worried about where she would take her child upon discharge.

She said: *“Well, it was very hard, very hard; I didn’t know what to do because my mind was on my child, but at the same time, I didn’t know where I was going when she was discharged” [Interviewee 25].* Other mothers with described financial hardship they experienced. One mother said: *“It was very stressful because I always worked and my husband works and I had to stop working and you know that when you have less money at home a lot of things happen... So that was one of the things that also stressed me out... we were short of cash” [Interviewee 11]* Similarly, another mother said, *“Coming from a family where there’s only one working parent, when you have to cut your hours from being on bed rest, staying time in the NICU, your paychecks are cut shorter” [Interviewee 20].* This mother spoke of the unexpected costs related to having an infant born preterm and hospitalized in the NICU: *“It was something we didn’t expect. You have control over how things will go, but actually in the end, things happened differently, so this caused some imbalance in many things. We cut down on many things because it was necessary to look after the girl. I could not skip seeing her one day, so that caused a lot of stress. Not only financially, but also physically, in my health... it wasn’t easy” [Interviewee 10].*

A number of mothers spoke of work-related challenges such as inadequate maternity leave, unsupportive breastfeeding/pumping policies, and/or immigration issues. One mother shared the difficulties keeping her job with the complicated pregnancy that had persisted during her infant’s hospitalization in the NICU. She said: *“Because I had a lot of issue with my pregnancy, I stopped working... Now I’m on unemployment benefits, because they couldn’t give me the possibility to leave on maternity leave, so I had to quit. So now I’m on unemployment benefits”* and replied affirmatively when directly asked by the interviewer in follow up whether this situation was stressful [Interviewee 5]. Another mother who immigrated said, *“Even when I was pregnant I had to go to Immigration and Customs Enforcement (ICE) office to report myself. And then when I had her, after about three months after she was born, I also had to go there ICE office. So, I was tormented because my child was born here; as the situation is right now, I don’t even know...there was a moment when they told me ‘you can’t stay here, you have to leave’, so what’s going to happen to my baby? That was my torment... As I haven’t been able to work because I don’t have a permit... in my case, I had a bit of depression. I had my baby, I had no place to stay, my [legal] status isn’t clear.” [Interviewee 25].* Another mother noted that her immigration status limited her employment options: *“I haven’t been able to work because, honestly... you know we are immigrants here, and if I have to go to work, I have to look after [my infant], because... in order to put him under someone’s care, they have to be highly specialized... I couldn’t do it, because if they look after him, then I would make money only to pay for his care. Because as you know, without a work permit here in the US... and as I can’t speak English, the pay is very little. So, if I go to work and put him in daycare... I would be working to get money only to pay for his daycare. So, for the time being, even though it’s hard, because my husband is the only one who is working, and it’s quite difficult to pay for rent and so many other expenses” [Interviewee 19].*

Discussion

We conducted this qualitative study to characterize the lived experiences of stress associated with having a preterm infant hospitalized in the NICU among Black and Hispanic mothers.

Black and Hispanic mothers in the U.S. have been underrepresented in previous studies in this area, both quantitative and qualitative. We included in this secondary data analysis only Black and Hispanic mothers who participated in the prior studies. We identified stressors in the domains of: *Individual*, *Hospital*, and *Community*.

While prior qualitative studies of mothers of preterm infants hospitalized in the NICU similarly found stressors in the domains of *Individual* and *Hospital*, the domain of *Community* had not previously emerged (14, 15). Additionally, while a scoping review of existing quantitative studies suggested that common socioeconomic factors and public policy may place parents at a greater risk for developing distress, it was limited to a brief discussion of the recommendation for screening for socioeconomic risk factors while in the NICU and was not based directly on parents' perspectives (32). These previous studies included no or few Black and Hispanic participants. Our examination of the perspectives of Black and Hispanic mothers regarding their stress associated with preterm infant hospitalization in the NICU is novel, as the perspectives of these groups had not yet been explored. Participants in our study described both inter-personal with members of their families and community, as well as and larger structural factors as stressors in the Community domain. As Black and Hispanic mothers may face stressors that differ from white mothers and therefore require different strategies to address such stressors, it is crucial to fully investigate this population.

The findings from our study are consistent with the socio-ecological model (SEM), which is an existing and widely-used theoretical framework that focuses on multiple domains as targets for health promotion interventions (33, 34). Use of this model also takes into account stressors from a wide variety of domains that may impact Black and Hispanic mothers. Given our findings, the SEM could be applied as a theoretical framework for future research in this area and for the development of screening, prevention and treatment. Current screening tools for stress in the NICU have not considered the sources of stress seen in our findings and as delineated in the SEM. For instance the, Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU), which remains the most widely used assessment tool in research on parental stress related to the NICU, only measures the effects of the experiences and surroundings physically present in the NICU (35). Measurement that considers stressors in all three domains, *Individual*, *Hospital* and *Community*, are important in order to best measure and address sources of stress for Black and Hispanic mothers.

Using the SEM to conceptualize the stress associated with having a preterm infant hospitalized in the NICU could prove to be foundational to providing equitable care in the NICU. The lived experiences of stress of Black and Hispanic mothers examined in this study highlighted the confluence of *Individual*, *Hospital*, and *Community* factors. Increased understanding of the different ways in which Black and Hispanic families experience this stress may elucidate the mechanisms by which socially racialized factors at the *Individual*, *Hospital*, and *Community* levels contribute to racial and ethnic disparities that exist in maternal and preterm infant health. Since racism drives health disparities across the life course, including for newborn infants and their families, it will be critical to examine its impact on the lived experiences of stress for Black and Hispanic families to inform clinical, research and quality improvement initiatives to mitigate racial disparities in maternal and preterm infant health (36–38).

The American Academy of Pediatrics published a policy statement in 2019 entitled “The Impact of Racism on Child and Adolescent Health” in which they cited burgeoning literature in maternal and child health linking the impact of racism and birth disparities, with maternal stress as a critical mediator (39–42). While we did not specifically examine racism as a contributor to stress, future research could build upon our findings by following a similar framework to examine how systemic racism and implicit bias could impact stress associated with having a preterm infant hospitalized in the NICU in the domains of *Individual*, *Hospital* and *Community*. In addition, the results of this study can be used to develop an improved stressor scale for use with NICU mothers that includes questions regarding specific stressors described by these mothers. This could provide a more complete and inclusive quantitative measure of stressors across these domains. Additionally, future studies should include fathers and other non-birth parents, again with a focus on Black and Hispanic parents.

This study was limited by its reliance on previously obtained data sets. This precluded a traditional iterative process of collecting and analyzing data, as in grounded theory methodology. However, since stress emerged from participants as a concept in both of the prior studies, it was explicitly explored in the in-depth interviews. This study is also limited by the lack of racial/ethnic concordance between interviewers and interviewees for the Black and English-speaking Hispanic participants. We believe that a strength of this study is that it aggregated data collected across a wide geographic distribution, thus representing a broad array of perspectives of Black and Hispanic mothers. However, we recognize that results may have differed if mothers from other parts of the U.S. and all levels of NICUs were included. These data sets also did not include fathers and other non-birth parents amongst the participants. Since our goal was to understand the perspectives of Black and Hispanic mothers, we did not compare stressors described by participants in this study with those of white mothers. Thus, we are unable to draw any conclusions regarding differences between stressors experienced by these groups. Additionally, despite attempts in the prior studies to recruit Black Hispanic participants, they did not include this racial/ethnic subgroup. While this is likely because there are relatively few members of this subgroup in the U.S., the lack of data on this subgroup is a limitation. There were roughly 2.4 million Black Hispanic people in the U.S. in 2019, which was 5% of the total Black population that year, but this subgroup is growing rapidly making it an important subgroup to include in future studies (43). Despite these limitations, this study is useful because it provided access to the perspectives of Black and Hispanic mothers of infants hospitalized at level 3 and 4 NICUs. These findings should be used to develop further qualitative studies examining the unique experiences of Black Hispanic mothers and quantitative studies to assess prevalence in a national way, including at hospitals with different patient demographics.

Conclusion:

The findings of this study suggest that stressors both inside and outside of the hospital affect the lived experiences of stress by mothers during NICU hospitalization of preterm infants, consistent with the SEM. Measurement that considers *Individual*, *Hospital* and *Community* factors are important in order to best quantify and address sources of stress for Black and Hispanic mothers.

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Table 1.

Participant characteristics

Characteristics	Data Set 1	Data Set 2
Number of interviews	23	16
	<i>Median (Range)</i>	
Maternal age (years)	28 (21-40)	34 (21-38)
Infant gestational age (weeks)	30 (24-36)	34 (29-36)
Infant birth weight (grams)	1,015 (620-1,760)	1,835 (790-2,980)
	<i>N (%)</i>	
Multiples	2 (9%)	1 (6%)
NHB, English speaking	11 (48%)	8 (50%)
Hispanic (any race), Spanish speaking	9 (39%)	7 (44%)
Hispanic (any race), English speaking	3 (13%)	1 (6%)