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Parents Experiences of Racism in the Neonatal Intensive Care Unit

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Abstract

Few studies have investigated parent's experiences with racism in the neonatal intensive care unit (NICU). Our objective was to explore how parents perceive their interactions with NICU staff and if/how racism in the NICU was experienced. Parents of infants receiving care in an urban NICU completed fixed choice surveys regarding their experiences and demographics, with 6 open-ended questions to elaborate on their fixed-choice responses. Using a constant comparative method informed by Constructivist Grounded Theory, we identified 3 main themes from the comments provided by 97 respondents: Care and harm coexisting, racism often manifesting as neglectful care, and the power differential is most impactful during times of parent advocacy. Parents spoke positively regarding their experiences and also reported disparate treatment attributed to their racial/ethnic identity. Racism was experienced by inappropriate comments and apathy toward parent requests, occurring during intimate interactions between staff and parents. Descriptions of parental advocacy efforts highlighted the lack of power they held in relation to the NICU staff. We recommend strengthening the focus on equity and mitigating power imbalances in the NICU.

Keywords

clinician–patient relationship, survey data, relationships in healthcare, patient perspectives/narratives, culture, diversity, NICU, racism

Introduction

Black and Latinx infants experience worse outcomes and racially disparate care while in the Neonatal Intensive Care Units (NICUs) (1-7). Racism in the United States (US) is broadly defined as an anti-Black/pro-White power structure (8,9) that includes erasure of Indigenous populations (10). The Black/White binary is one aspect of racism in the US. Other ways in which racism manifests is in media narratives about Latinx people living in the US as "unassimilable," demanding their governance and management (11) or "Others" through language (12). Racism creates an inequitable environment in which Black, Indigenous and People of Color individuals are systematically denied access and opportunities in society leading to poorer quality of life across all dimensions, including health (9).

Racial and ethnic inequities are found in NICU standards of care and outcomes, including breastmilk provision, and administration of antenatal steroids and surfactant (3,7). A few qualitative studies provide insights into the experience and impacts of racial and ethnic inequities in NICU care delivery. Analysis of written comments from a national sample of NICU clinicians and family advocates found that disparities in care were observed for families with

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minoritized characteristics such as language, culture, and socioeconomic status and manifest as judgmental care, neglectful care, systemic barriers, and privileged care. White families were reported as the most common recipients of privileged care (4). Interview studies of parents of infants receiving care in NICUs across the US reveal that some parents felt judged and racialized by NICU staff (13), while others experienced overt racism in the NICU (14). Biased provider attitudes during pregnancy and childbirth compounded the challenges in navigating interactions with NICU healthcare providers (15).

In our quantitative analysis of surveys of parents and NICU providers about disparities in NICU care, we found parents reported experiencing racism and NICU providers reported witnessing racism. However, NICU providers reported witnessing and experiencing racism more often than parents (16). Given the limited research, we sought to examine the parental experience by analyzing the extensive parent responses to the survey open-ended questions. We aimed to characterize how parents perceived their interactions with NICU staff in everyday interactions to better understand if and how racism in the NICU was experienced by parents.

Methods

Design

This qualitative analysis was part of a larger study investigating structural racism in the NICU. The Racial and Ethnic Justice in Neonatal Intensive Care (16,17) study is a single-site study in an urban tertiary care academic medical center in the San Francisco Bay Area with a 58-bed level 4 NICU. The NICU serves Northern and Central California. The racial/ethnic and language demographics of the NICU patient population are similar to the San Francisco Bay Area with the exception of the Latinx population. The NICU Latinx population is approximately double that for San Francisco County (15.9%) and more similar to the overall California Latinx population proportion (40.3%) (18) because many infants are referred for care from the Central Valley of California. The mixed methods design included retrospective chart review to determine if differences existed in standards of care and patient health outcomes by race and ethnicity (17), surveys of NICU parents and providers to explore experiences of racism and discrimination (16), interviews with parents of NICU infants and providers, and the present analysis of open-ended survey responses to gain insights into the lived experience of parents in the NICU.

Participants and Recruitment

Parents of infants receiving NICU care between April 2021 and October 2022 were invited to complete the anonymous online survey during their infant's hospitalization. Exclusion criteria were non-English or non-Spanish reading and speaking proficiency. Participants were recruited with flyers placed throughout the NICU and in-person outreach by a Latinx nurse researcher. Potential participants were contacted at their infant's bedside and invited to use the tablet provided to take the survey. At the end of the survey, participants indicated if they were willing to be contacted for interviews by providing an email address for further contact. Six months into recruitment, a Spanish biliterate and bilingual Latinx nonclinical research assistant joined the team and focused on recruitment of Spanish-speaking parents who had a stated preference for Spanish indicated in their infant's electronic medical record. Participants were offered the option to complete the survey by telephone interview in Spanish and if interested, provided contact information for that purpose. All participants provided written informed consent and received a $5 gift card upon survey completion. The study was approved by the site's Institutional Review Board.

Instruments

The survey consisted of 12 fixed choice items, including the 7-item Discrimination in Medical Settings Scale (19) and 6 general demographic questions. Six open-ended questions invited parents to share more about their experiences in the NICU overall and elaborate on their numeric ratings of questions in the survey regarding respectful or disrespectful treatment, information giving, shared decision-making, and disparities in treatment of themselves or their infants (Table 1).

Data Analysis

Surveys completed in Spanish were translated to English by a professional translation service. The bilingual research assistant checked the translation prior to the analysis. All responses were deidentified, open coded across all questions and organized into main themes and subthemes using constant comparative method informed by Constructivist

Table 1. Open-Ended Survey Questions.

1. Please describe your overall care experience in the Intensive Care Nursery (Neonatal Intensive Care Unit)?
2. Please describe a time when the doctors or nurses made you feel like your opinion did/didn't matter.
3. Please provide an example of when you have felt respected/disrespected by a member of your health care team.
4. In what ways did you feel adequately/inadequately updated on your child's medical condition and future interventions or plans?
5. Please provide an example of when your thoughts or wishes were/were not incorporated into your child's care.
6. Can you describe a situation where you felt you were treated differently because of your race or ethnicity by your health care team?

Grounded Theory (20). One author read all comments and created first-level open coding, defining, and assigning labels to the text. A second author reviewed and commented on the coding and the 2 discussed and agreed the list of overarching categories and final codebook. The categories were organized into higher-order themes and subthemes with illustrative quotes from the dataset. These were discussed and preliminarily agreed with the full research team. A member-checking group session was conducted to review the emerging themes and assess the degree to which the findings reflected the views of participants. Among those participants who provided contact details for further contact by the study team, 4 responded to the invitation to participate in the member-checking session. The 4 member-checking session participants self-identified as Black, White, Latinx, and Indigenous. Feedback from these participants affirmed and refined the themes and subthemes.

Results

A total of 113 parents completed the survey, with 97 (86%) providing comments. Of those, the largest racial/ethnic self-identified groups were Hispanic/Latino (hereafter, Latinx; 37.1%), followed by 28.9% White. Most (84.5%) completed the survey in English. Additional participant characteristics are shown in Table 2.

Overall, parents described 3 main types of interactions: how the infant was treated, how the parent was treated, and staff reactions to parental advocacy on behalf of their infant. Across the 3 types of interactions, we identified 3 common themes, as shown in Figure 1: (1) care and harm coexisting; (2) racism often manifesting as neglectful care; and (3) the power differential is most impactful during times of parent advocacy. Themes and subthemes are described in greater detail below with illustrative quotes followed by participant number and demographic characteristics in parentheses.

Care and Harm Coexisting

Parents reporting positive experiences, including subthemes of humanity, and kindness and attentiveness also described experiences of harm, including subthemes of feeling disrespected and treated dismissively or racialized by the NICU staff. Thus, experiences of they and their infants being cared for as well as harmed, coexisted for NICU parents. Most parents used qualifiers such as "good" to describe their and their infant's NICU care. Many described feeling validated, included, and treated with respect. The subtheme of *humanity* was derived from a parent's comment that simply stated, "they make you feel human." (#30, Latinx female, 45 years or older). Other parents echoed the sentiment reporting, "the doctor relating to us as a fellow parent and giving advice on taking care of ourselves to make sure we get a good night's sleep and not feel guilty for going home at night." (#62, White male, 25-34 years old), and "the staff has always respected us and introduced themselves and wanted to know our names." (#56, White male, 25-34 years old). Similarly, "[When staff say], 'Go ahead, go home. Go rest, we got you.' It makes you feel like, Okay, I'm a person, I also have feelings. I also need to take care of myself." (#37, Latinx female, 25-34 years old).

Many parents asserted that their infant was treated with kindness and attentiveness. One parent said the staff, "Treat him as if they were their child." (#18, White/Latinx female, 24 years or younger). Humanity was illustrated in this comment: "…When my son was passing away, I remember going into the room with the doctors and the nurses and they were crying and that's something that you don't really see…And that to me made me feel like, okay, like they cared." They cared enough to a point where they also felt our heartbreak. So, it made us feel like, "Okay, this was a good place." (#37, Latinx female, 25-34 years old).

Positive experiences were not uniform throughout parents' experiences. Several parents described feeling dismissed, disrespected, and confronted with aggression from staff. Two different parents described incidents where staff "pushed" (#22, Latinx female, 24 years or younger) or "threw" (#33, white female, 25-34 years old) objects into

Table 2. Demographics of Survey Participants who Provided Comments.

Demographics	N (%)
Race	
Hispanic/Latinx	36 (37.1)
White	28 (28.9)
Asian or Asian American	14 (14.4)
Black or African American	6 (6.2)
American Indian/Alaska Native	2 (2.1)
Native Hawaiian /other Pacific Islander	2 (2.1)
multiple answer	8 (8.2)
No answer	1 (1)
Gender	
Female	73 (75.3)
Male	24 (24.7)
Age	
45 years or older	3 (3.1)
35-44 years old	44 (45.4)
25-34 years old	36 (37.1)
24 years or younger	14 (14.4)
Survey Language	
English	82 (84.5)
Spanish	15 (15.5)
Speak a language other than English at home	
Yes	51 (52.3)
What other language spoken at home (free text)	
Spanish	36 (70)
English	5 (9.8)
Chinese	2 (3.9)
Punjabi	2 (3.9)
Hmong	1 (1.9)
Mam	1 (1.9)
Tagalog	1 (1.9)
Vietnamese	1 (1.9)
No answer	2 (3.9)

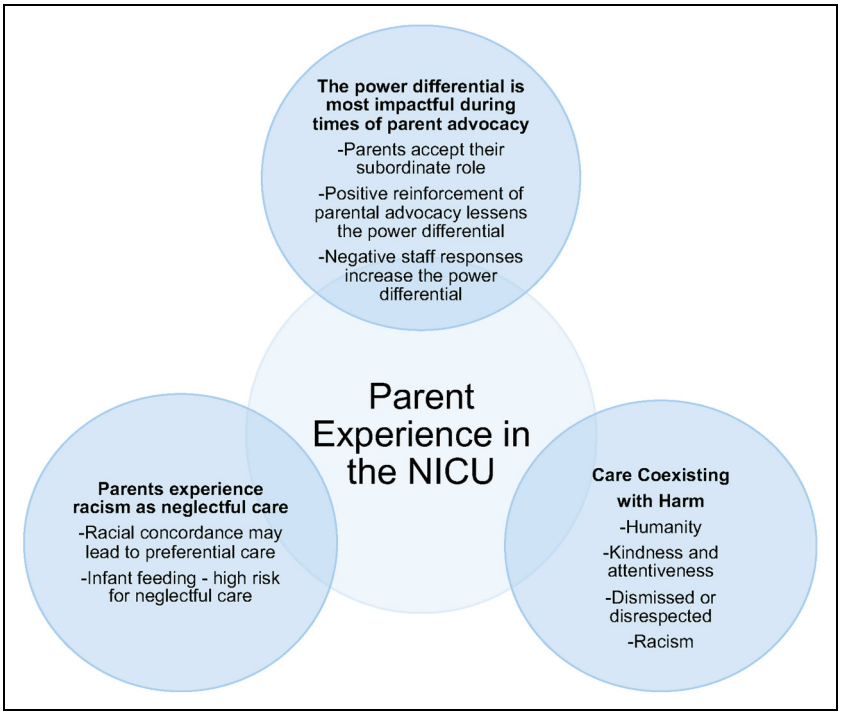

Figure 1. Themes and subthemes describing the parent experience in the NICU. NICU, neonatal intensive care unit.

or out of parents' personal space. A Latinx parent wrote, "When I tried to say something that I didn't like and they don't care what I said." (#19, Latinx female, 25-34 years old). A Black parent shared, "[I felt] disrespected when occasionally [his] care seems an afterthought—his bed is wet, his hair/face are slightly unwashed." (#55, Black female, 35-44 years old).

A Latinx, Spanish-speaking parent shared, "When I asked that the surgery my child needed be done by an experienced person, a nurse who heard me laughed, and [I] felt that it was a lack of respect on the part of the nurse." (#100, Latinx female, 35-44 years old, interpreter). An Asian parent described an interaction that made them feel disrespected and racialized, "A nurse came into our shared room while we had prayers on a very low volume on the tablet. She asked jokingly what the chanting was. Then physically moved our belongings without our permission while we were out of the room into a private room so the other baby wouldn't be 'bothered,' and we could enjoy our prayers. She was laughing when she said this." (#32, Asian female, 35-44 years old).

A Latinx, Spanish-speaking parent described an experience with racism as, "… when a social worker told me that I had the right to stay at night and, like, the nurses, like, didn't want me to…I felt a little bit out of place." (#107, Latinx female, 35-44 years old, interpreter). A Black parent wrote, "a provider made me cry with their uncaring bedside manner, explained things to me as if I were stupid, and kept looking at their watch." (#107, Latinx female, 35-44 years old, interpreter). Another Black parent shared her experience, saying, "it was the way they communicated with me. It was like I was 'slow' basically…" (#8, Black female, 25-34 years old). Prior to this comment, the parent had maintained that all her interactions with the NICU staff were positive.

Racism Often Manifesting as Neglectful Care

Parents described instances of neglectful care as ways in which bias and racism were manifest in the intimate spaces of the NICU. When it occurred, neglectful care appeared obvious to parents because they could easily see how other infants or parents were treated. They often attributed instances of neglect in treatment to being rooted in racial bias or racism. Subthemes included racial concordance leads to preferential treatment and infant feeding as a being particularly at risk for neglectful care. Parents indicated sensitivity to the apparent racial and ethnic identities of the NICU staff and how that might affect the care of their infant or parent–staff interactions. For example, "I feel sometimes it can be my baby's care times but the nurse will not come because she is with her other patient whose family is the same race as them." (#22, Latinx female, 24 years or younger). Another parent was concerned about their lack of racial or ethnic concordance in the comment, "I do not know if my race or ethnicity has anything to do with the way we have been treated but it could be possible. We are a minority. My only concern is my baby what if an emergency comes up, would they still deny him surgical care, or specific imaging? He was scheduled brain MRI, which

they canceled because of the COVID-19 isolation. I saw it on MyChart that it was scheduled so I called and asked the nurses and the nurses told us it was canceled." (#75, Asian, female, 35-44 years of age).

Infant feeding was a time when disparities in care were often noted because of parents' heightened awareness of the importance of feeding and how "every bit of oral intake is important for us to meet discharge goals." (#33, White female, 25-34 years old). One parent described, "When they don't try to feed baby with bottle, and they just do the [feeding] tube." (#19, Latinx female, 25-34 years old). Another parent elaborated on what it felt like to experience neglectful care of their infant, "it is frustrating…when you see your baby in a condition like that it feels like they don't care when they should be in a position to care." (#37, Latinx female 25-34 years old). A parent who did not initially identify their race wrote the following example of when they were treated differently because of their race or ethnicity, "A lactation consultant asked me if I would be afraid if my mother-in-law would give my son refried beans after I told her that she was coming from Mexico." This parent later participated in the member-checking session and shared, "I think that people experience—the racism that's experienced in the NICU is just a reflection of what we're experiencing in our communities." During the session, this parent informed the group she identifies as "Indigenous." (#87, Indigenous female, 35-44 years old).

The Power Differential Is Most Impactful During Times of Parent Advocacy

The third common theme emerging from the analysis of parents' comments highlighted the power differential between the NICU staff and parents, which became problematic for some during times when they were advocating on behalf of their infant for themselves. Parent advocacy is defined as a parent speaking up on behalf of their child and engaging with the healthcare team to direct or redirect care (21). Subthemes included parent acceptance of their subordinate position in the NICU, positive reinforcement of parental advocacy efforts that lessens the power differential and negative overt or covert responses to parental advocacy efforts that maintained or increased the power differential. Parents indicated their tacit or implied acceptance of their subordinate position in the NICU through their use of language such as "they let us," "allowed us," with one parent acknowledging, "We let them handle the child's care just because they are trained for this and being a first-time parent is challenging for us to put any input," (#38, Latinx male, 24 years or younger). This framing signifies the subordinate position parents maintain when juxtaposed with the physician and other healthcare team members in the hospital setting.

Parents provided examples where the NICU staff provided positive reinforcement of their advocacy efforts, which reduced the NICU staff–parent power differential and promoted relational autonomy for parents. One parent described how their advocacy was met with concern and action on behalf of the healthcare team, "My little [baby's name] was having a hard time keeping her heart rate up and oxygen saturation high because she got morphine due to a procedure. Because [baby's name] was having a hard [time], I thought she might need some stimulation, so I suggested that we give her caffeine. The idea was well received and eventually implemented. The nurses made me feel as if I had a good suggest[ion] … Later that night when I went home, I was told that they gave her a little caffeine. This made me feel good because as a mother, I want to be able to provide care for my daughter. I felt that I was heard and respected." (#87, Indigenous female, 35-44 years old).

In contrast, another parent's advocacy was met with a negative response of apathy and inaction, reinforcing the power differential between NICU staff and parents, "There was a time when I expressed to a nurse that my baby had a very stressful day. He had blood work done, new…line inserted and was intubated at the time. I asked if we could hold his bath until the next day. The nurse was very rude and condescending. [They] said 'babies like mine who have [surgical condition] are never happy and cry all the time and he needed a bath.' The following day my son had a fever for hours. I asked the nurse if labs could be ordered, and he kept brushing me off and said it wasn't necessary. He said 'babies like mine are always hot.' I again told him his fever had went on for hours and I wanted labs to be done. He told me the baby would have to wait then he would call the doctor. Finally, he seemed annoyed by me being persistent. Labs were done and my son did have an infection." (#4, Latinx female, 25-34 years old).

Discussion

This analysis of free-text comments on a survey exploring perceptions of racism of racially diverse NICU parents revealed both overt and subtle ways in which parents experienced or witnessed disparate care attributable to racial/ethnic bias and racism. These experiences sometimes co-occurred with treatment of the infant and parent that was caring and compassionate. Thus, overall comments were generally positive, harmful experiences and interactions were revealed through parents' free-text comments across the open-ended question prompts. Neonatal intensive care units asking only about general parent experiences may miss learning about bias and racism that are present and cause harm. Lack of care and concern were typical ways that parents experienced racism in the NICU. Acknowledging that instances of racist treatment were rare does not minimize the importance of addressing racism.

Given the ordinariness of racism in US society, it is unsurprising that racism would be found in the most intimate spaces where neonates receive lifesaving care. When Black parents experience racism, they continue to be classically racialized as uneducated and treated with contempt

(4,14,15,22,23). Acknowledging that all racism is rooted in antiblackness (8), our findings expand the current literature to recognize other assemblages of racism beyond phenotype (10). For instance, the Asian parent who felt racialized when a staff member referred to their "prayers" as "chanting" and laughed, or the parent who had a staff member ask her if she was worried that her mother-in-law would feed her infant refried beans when she arrived from Mexico. The social dominance exerted by the lactation consultant's seemingly innocuous question to the parent while assisting her with breast feeding, characterizes the parent's Latinx mother-in-law as the "abject Other" population in need of careful management (11,12).

Consistent with previous literature, we identified a power differential directly imbedded in parent and healthcare provider interactions influencing how infants receive care (13,14,21,24,25). Neglectful care that Latinx parents experienced as racialized was found in other qualitative studies regarding racism in the NICU (4,13,14). The degree of racialization of parents and infants in the NICU leads to a range of responses by the healthcare team to parent advocacy, from partnered engagement to apathy. The power dynamics of the NICU, with the physician at the top of the hierarchy, and the hospital setting, a predominantly White institution, contributed to a climate where structural biases, discrimination and racism manifest, negatively impacting parental autonomy and decision-making (26). Parents' relational autonomy within the social hierarchy of the NICU, racial and otherwise, is revealed in how the staff react to them can inform the parent's perception of self and their autonomous decision-making, or lack thereof (21). Furthermore, this power differential belies parent autonomy, making the autonomy parents experience relational to their interactions with staff (24).

Strengths and Limitations

Asking parents directly about experiences of bias and discrimination in the NICU setting is a new area of research and methods to respectfully explore the topic are evolving. The study included multiple methods to offer different opportunities for participants to share their experiences and views. Nonetheless, participants may have felt vulnerable, unsafe, or shame among other emotions and been reluctant to disclose experiencing racism and discrimination (27). The comments likely also reflect disparate treatment related to other biases or structural discrimination (28). Further research is needed to determine the prevalence and manifestations of racism in NICUs, as well as the contextual factors that promote or inhibit bias, racism and discrimination. Our study was a humble inquiry, not designed to find statistical significance, nor to cast blame, but rather to critically examine how providers and hospital systems may perpetuate interpersonal and structural racism and contribute to racial disparities. The study prompted deep internal reflection in our center at all levels. We found that taking part promoted introspection about health equity among individuals and the institution as a whole. Our methods can be used by other centers seeking to promote antiracism and racial equity.

We recommend further explorations to identify other assemblages of racism in patient care. We also stress the importance of identifying strategies to minimizing the power differential (22) and ensuring that interactions with staff promote parental advocacy and partnership. Specific actions healthcare systems can take include quality improvement projects that address disparate outcomes by race, regular survey of parents' care experiences, including direct inquiry about racism and discrimination. Finally, community advisory committees can contribute to practices, policies, monitoring, and identify areas to improve parent and staff relations (29-31).

Conclusions

In summary, we found that care and harm (racism) often coexist in the NICU. Parents experience racism through neglectful care in intimate circumstances. The power differential that exists between staff and parents can negatively impact parent advocacy and decision-making. Further research may enlighten mechanisms by which racism operates in healthcare spaces, how to measure it, and interventions to combat harm to patients and families. Concurrently, healthcare systems can act to implement community-based recommendations to address racism in the healthcare setting.

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Authors' Note

Data Access Statement: Research data supporting this publication are available from the lead author at Olga Smith: olgasmith05@gmail.com. *Ethical Compliance:* All procedures performed in studies involving human participants were in accordance with the ethical standards and approved by the Institutional Review Board of University of California San Francisco.

Author Contributions

Maria D. Gonzales-Hinojosa, BS, Sarah Lewis-Zhao, PharmD, and Taylor Washington, BS, contributed to the data collection and writing of the manuscript. Kayla L. Karvonen, MD, MAS and Elizabeth E. Rogers, MD contributed to the design and implementation of the research, data analysis, and writing of the manuscript. Olga Smith, MS, RN conceived the study. Monica R. McLemore, PhD, MPH, RN supervised the project and contributed to writing of the manuscript. Linda S. Franck, PhD, RN contributed to data analysis and writing of the manuscript.

Declaration of Conflicting Interests

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