



Racial Disparities in the Neonatal Intensive Care Unit (NICU)

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Background and Aim

A qualitative survey spearheaded by Ashley Randolph (founder of *The Alliance for Black NICU Families* and *GLO Preemies*) explored the experiences of 55 African-American families whose infants received care in NICUs across the United States. These first-hand accounts reveal persistent disparities in communication, emotional support, cultural sensitivity and representation within NICU settings. The study sought to understand how structural and interpersonal biases shape family experiences and to highlight actionable improvements.

Methods

- **Recruitment:** Participants were recruited through community networks, advocacy organizations and social-media outreach. All respondents identified as Black/African American.
- **Survey design:** A combination of open-ended and binary questions (with open follow-ups) captured nuanced experiences. Researchers conducted thematic analysis to identify barriers to culturally sensitive, equitable care.

Key Findings

Communication gaps

- **Insufficient information:** Many families reported that NICU staff provided minimal or unclear updates on infants' conditions. Medical terminology was often used without explanation, leaving parents feeling confused and fearful.
- **Feeling unheard:** A majority of respondents answered "*somewhat*," "*to some extent*" or "*no*" when asked if they felt listened to. Communication issues were particularly pronounced in Southern states such as Texas, Oklahoma, Georgia, Alaska and Kentucky.

"The doctor wasn't speaking in terms that I can relate to." – **Mother of a preterm infant**

"They [the staff] were speaking in code to us – we didn't understand." – **Mother of a preterm infant**

Racism and microaggressions

- **Perceived bias:** Nearly all participants felt that structural or interpersonal racism affected the quality of care. Examples included being judged, spoken to condescendingly, or stereotyped about socioeconomic status.
- **Prevalence:** 81.8 % of respondents confirmed facing race-related challenges or barriers and believed racism impacted their NICU care.

“They always looked at us different because we were an interracial couple.” – **Mother of a preterm infant**

“The doctor always talked to me differently.” – **Father of a preterm infant**

Lack of emotional and cultural support

- **Mental-health resources:** Many parents received no emotional or mental-health support during or after their NICU stay. Access to chaplains, peer groups or culturally competent staff was rare despite the trauma of preterm birth.
- **Representation matters:** About 85 % of respondents believed that having more Black professionals (doctors, nurses or support staff) would have improved their experience, though many emphasized that respect and effective communication are essential regardless of race.

“I had some [emotional support] but I could have used more.” – **Amelia**

“I received help from the chaplain and ministry.” – **Maryland**

“Black mom support group could have helped a lot.” – **Anonymous**

Barriers to resources

Families often struggled with insurance, financial stability, transportation and childcare, forcing them to juggle work and NICU visits. These systemic disparities compounded stress and negatively affected their NICU experience.

“I had friends who helped and loaned me money.” – **Amelia**

“Transportation issues sometimes; mental health support [was lacking].” – **James**

“Too many patients and not enough doctors.” – **Multiple respondents**

Participant Voices

The qualitative survey captured poignant comments that illustrate the lived realities behind these statistics. Selected quotes, grouped by theme, are presented below.

Theme	Representative quotes
Disconnection and isolation	“It felt like they just took our baby and we had no say.” – K.P.
“There is a disconnect between the parent and child and I need that as a mother and I can’t always be there.” – Amelia	
Communication and information	“I wish they would have communicated with me more.” – Anonymous
“The doctors gave me guidelines/communication that was very difficult.” – Adelita	
“I wanted answers to why she (the baby) came early... years later I found out my doctor thought I had an infection but I never did.” – Jashaya	
Support and care	“I would rather talk to the doctor – but it depends if they are listening; if not, the social worker.” – Anonymous
“I wish I was supported by the doctor and given counselling.” – Adrian	
“Having a private room was most helpful.” – Anonymous	
Cultural sensitivity and representation	“There was a lot of insensitivity for Black mothers... it makes you have to advocate by yourself.” – Maryland
“Black mom support group could have helped a lot even for 10 minutes per week over coffee.” – Anonymous	
“More English-speaking staff would have helped—it was a mainly Spanish hospital.” – Anonymous	
Education and knowledge	“I wish I was educated on temperature regulation.” – Angela
“I only just got educational support.” – Adelita	

Advocacy and empowerment	“Too many patients and not enough doctors; peer mentors [would help].” – Anonymous
“I was scared but supported by staff when I first got to the NICU.” – Tekila	

Visualizing the Survey Results

The survey captured quantitative measures of respondents’ perceptions. The following bar chart summarizes the proportion of families who endorsed key interventions to improve NICU care:

Figure 1. Percentages of respondents reporting racism impacted care, preferring more Black representation, supporting mandatory sta training and seeking peer support.

Recommendations for Improving NICU Care

1. **Implement comprehensive cultural-competency training** for all NICU personnel. Training should address implicit bias, trauma-informed care and specific challenges faced by Black and other marginalized families. Respondents overwhelmingly (≈93 %) agreed that mandatory staff education would improve care quality.
2. **Establish robust communication protocols** by assigning each family a dedicated point-of-contact (e.g., case manager or nurse). Provide multilingual resources—including translated guides, visual aids and professional interpreters—to ensure families understand medical information.
3. **Develop family-centered mental-health and emotional-support programs.** Hospitals should offer peer-support networks, chaplaincy, mental-health professionals and online support groups.

Approximately 89 % of respondents said that access to peer support would have improve their care.

Additional support in areas such as financial assistance, food, transportation, preeclampsia education and counselling would further promote equitable, compassionate care. The Alliance for Black NICU Families remains committed to raising awareness and advocating for policies that ensure every family receives respectful, culturally competent NICU care.