

Rethinking Race in Parent Experience of Hypoxic Ischemic Encephalopathy Survey

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Introduction and Aims

In a prior study, parents of children with Hypoxic Ischemic Encephalopathy (HIE) were surveyed regarding experiences of communication and parental involvement in the Neonatal Intensive Care Unit (NICU)¹. While self-identified race data was collected as part of the survey, this variable was not considered in prior analyses. This re-analysis aims to correct this oversight.

The primary goal was to amplify the voices and experiences of non-white parents to direct further inquiry into possible manifestations of inequity and discrimination in the NICU. The secondary goal was to join an ongoing discussion about the meaningful and thoughtful use of a race variable in studies of patient experience the ultimate goal of which is to shift the empirical focus from race to racism as a fundamental social determinant of health disparities^{2,3}.

Prior studies have demonstrated the presence of racial health disparities in the NICU but the many have centered on systemic factors such as geography and health care access⁴. Direct interpersonal factors impacting the experiences of non-white parents in the NICU are less well characterized in part because they are harder to observe at scale and are less amenable to direct measurement⁴. In revisiting this data, we aimed to gain insight into any interpersonal factors that might contribute to these disparities.

Methods

This is a re-analysis of data from a 29-question anonymous survey posted on a parent support website available for a two-week period in September 2020 (<https://www.hopeforhie.org>) and sent to members via e-mail. Responses from open-ended questions were re-coded by two investigators (Z P-J and ES) who were not part of the original study team. Investigators were blinded to self-identified race during initial coding. Qualitative data was assessed using thematic content analysis followed by a cross-sectional analysis of themes to examine similarities and differences in NICU experiences among non-white and white respondents; conclusions were drawn based on consensus between both independent investigators. Findings were reported both by theme frequency as a percent³, and by a count of respondents who elicited a given theme in each group to maximize transparency given disparate sample sizes. Quantitative survey items asked participants to rate their satisfaction with communication and involvement on a 5-point Likert scale (1=Very Dissatisfied to 5=Greatly Satisfied). Satisfaction scores between white and non-white respondents were compared via Brown-Forsythe, though analysis was limited by the relatively small sample size of the non-white group and the presence of outliers.



Results

Of the 164 individuals who completed the survey including self-identified race(s), 85% (140) identified as white and 15% (24) self-identified as holding a racial identity other than white. The vast majority of respondents in both groups identified as mothers (96%). The majority of white and non-white respondents were age 24-44 at the time of birth (>70%) and had children born in 2016 or later (>65%). Clinical outcomes were similar for both white and non-white respondents with approximately half of infants being moderately to severely impacted by HIE. Across both groups the vast majority of infants received an MRI (>90%) and a majority of infants were treated with therapeutic hypothermia (>50%).

Responses to Likert scale items demonstrated that overall both groups reported feeling satisfied with the degree of parental involvement with over 75% of respondents in each group reporting being satisfied or greatly satisfied (Figure 1). Parents were less satisfied with communication in the NICU with just under half of respondents being dissatisfied or neutral about communication (Figure 2). Feelings of parental involvement and satisfaction with communication did not significantly differ between groups (p-values were ≥ 0.447).

Figure 1. Parental Involvement in the NICU: Satisfaction Score Distribution by Race Category

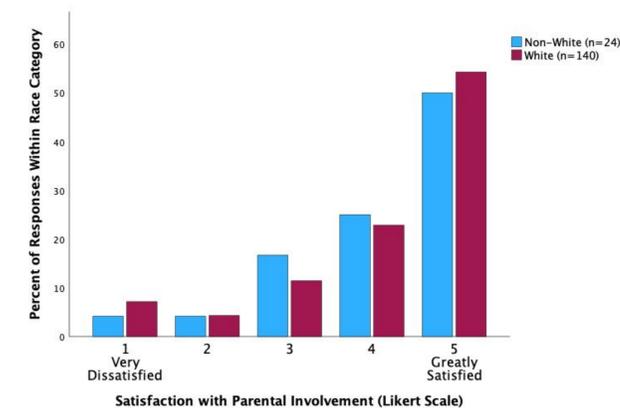
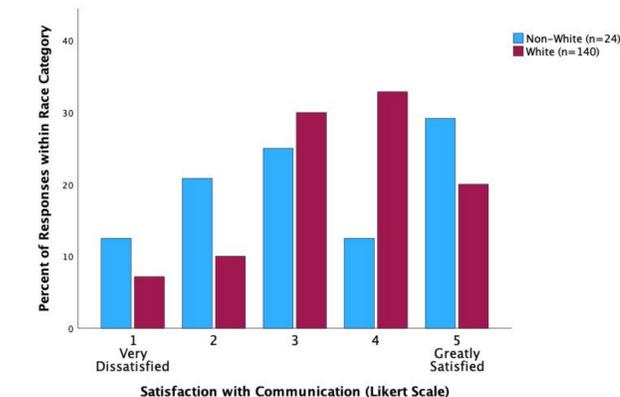


Figure 2. Communication in the NICU: Satisfaction Score Distribution by Race Category



Theme	Non-White (n=24)		White (n=140)	
	Count	%	Count	%
Doctors	4	16.7%	67	47.9%
Nurses	11	45.8%	52	37.1%
Mentions Doctors Positively	0	0.0%	10	7.1%
Mentions Nurses Positively	4	16.7%	33	23.6%
Rounds	1	4.2%	29	20.7%
Encouraged to Participate	2	8.3%	36	25.7%
Transitions of Care	1	4.2%	30	21.4%
Desire Clearer Diagnosis	9	37.5%	37	26.4%
Desire Clearer Prognosis	9	37.5%	37	26.4%
Desire Clearer Explanations	8	33.3%	34	24.3%
Desire More Updates	6	25.0%	31	22.1%
Desire Peer Support	8	33.3%	28	20.0%

There was considerable overlap in themes between groups. Some themes which were similarly present in both groups were: 1) the desire for more clear communication of the diagnosis including use of the name "HIE", 2) more discussion of possible outcomes, 3) the desire for more frequent updates and better explanations, 4) generally positive comments about interactions with nurses but not doctors and 5) the desire for early connection to a peer support network (Table 1; Table 2; Table 3).

However, noteworthy differences in subjective experiences of the two groups emerged; 1) non-white respondents mentioned physicians and doctors far less frequently than white respondents, 2) a smaller proportion of non-white respondents reported being actively encouraged to participate in cares, 3) white respondents discussed dilemmas in care coordination and transitions of care far more extensively than non-white respondents and 4) white respondents mentioned physician rounds more often (Table 1; Table 2; Table 3).

Themes	Quotes
Nurses	"The nurses were very clear"; the best tool for involvement was "teaching care as the nurses cared for him"
Diagnosis and Prognosis	"HIE was not communicated till after we discharged from the NICU." Wanted "a conversation about [prognosis]. Future outcomes."
Peer Network	Wanted "information on support network or groups available so not so alone."
Better Explanations	Wanted "more information, better explanation"; "in depth communication of what was happening"

Themes	Quotes
Nurses	The best tool for involvement was "nurses involving us, nurses support"
Diagnosis and Prognosis	Wanted "a better understanding of HIE not just the possibly grim future"; to know the "range of outcomes"
Peer Network	"It would be extremely helpful to provide peer support."
Doctors and Rounds	Preferred communication was "straight from the doctors during rounds"; would like "doctors having better bedside manners"
Encouraged to Participate	Appreciated "encouragement from NICU staff to get involved despite my nervousness"; "I was encouraged to do all routine care"
Transitions of Care	"Juggling appointments through insurance" was difficult; "There should be highly trained case managers that help more with the transition to home."

Discussion

Given the lack of robust sociodemographic data in the current study and the limited non-white sample size few conclusions can be drawn, but these findings suggest several areas for deeper inquiry.

While our quantitative assessment suggested that white and non-white parents' satisfaction with communication and involvement in the NICU did not significantly differ, thematic analysis of open-ended questions yielded a more nuanced understanding of parental experiences. Results suggest that non-white parents may have fewer quality encounters with physicians including involvement in rounds. Whether this reflects a disparity in time spent with a physician, a qualitative difference in exchanges, degree of interpersonal connection to physician, or another as-yet unidentified variable is not clear from this data but warrants further study. The prominence of dissatisfaction with transitions of care among white respondents suggests that either white parents were receiving less of care coordination, that the non-white group did not expect the same degree of support or it may reflect more referrals for follow-up (and therefore greater demand on families in adhering to treatment) among white infants as seen previously⁴. Finally, that white parents were more likely to describe being actively encouraged by nurses to participate in cares raises whether nursing communication or its reception are impacted by biases; dissatisfaction with nursing support among Black mothers has previously been observed⁴. However, sentiments about nurses were positive overall. This is another area for further study. Overall these results suggest differences in interpersonal experiences between white and non-white parents in the NICU which may reflect biases within healthcare teams and/or systems of care delivery.

Conclusion

In this re-analysis we consider race as a social construct which has historically been used inappropriately as an explanatory variable in biological phenomena. In light of this paradigm shift, researchers must be thoughtful and intentional in the collection and use of race and ethnicity data. The most appropriate use of a race variable is as a proxy for racism and this is how it has been operationalized here.

The original survey was not designed to delineate the specific sociodemographic and interpersonal variables contributing to disparities among parental experiences in the NICU, but as this analysis demonstrates, perhaps it should have been.

These results suggest that further inquiry into parental experiences of HIE in the NICU with respect to parental sociodemographic variables is warranted. Further studies should include more robust sociodemographic data including geographic location, language preference, socioeconomic status, NICU setting, nursing ratio, and hospital resources. It should also include detailed questions regarding interpersonal interactions with care team members.

Sources

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