Racially/Ethnically Diverse Parents Experience the NICU Differently. How Can We Offer Better Support?

Health Equity

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The demography of the U.S. is rapidly evolving. For the first time, racially/ethnically diverse children under the age of 15 are now in the majority. These demographic changes demand an increased understanding that diverse people respond to challenges differently, which becomes particularly relevant when thinking about our most vulnerable pediatric populations.

The Stressors Associated with NICU Care

In pediatrics, our sickest patients are often found in intensive care units, with almost 500,000 preterm infants delivered yearly in our country utilizing these facilities. Of those half a million babies, we know that an increasing portion of them are diverse children, particularly African American and Asian-American/Pacific Islander.

While having a child in the hospital is an extremely difficult experience for any parent, having a child in the neonatal intensive care unit (NICU) is uniquely stressful. Parents of preterm infants are concerned about their baby's ability to survive, thrive and "graduate" from the NICU, while simultaneously being unable to perform everyday tasks of new parents such as feeding and comforting their babies.

On top of these stressors, parents may have other worries including financial concerns, health care coverage and the impact of the NICU hospitalization on the family as a whole. All of these stressors have been shown to profoundly affect not only parental health and well-being, but also infant neurodevelopment. We now know that

mothers with children in the NICU have higher rates of mental health disorders. We also know that all facets of early child development and parenting are impacted if distressed mothers aren't appropriately identified and don't receive adequate services and support. This could lead to altered parenting styles, such as stopping breastfeeding early or the inability to read their baby's cues, leading babies to respond in ways that may not contribute to their optimal development. Therefore, untreated maternal psychosocial distress during this critical period can have a long-lasting impact on parenting and healthy infant development.

As an infant psychiatrist and researcher, my concern is that ethnically and racially diverse families and their infants are even more vulnerable to these stressors due to a history of significant disparities in care.

How Disparities in NICU Care Impact Baby Development

Understanding families' experiences in the NICU is particularly important because of growing evidence showing the impact of an infant's early environments (including parenting) on their developing neural pathways.

Research reflecting disparate and inequitable care for racially/ethnically diverse populations is, therefore, extremely troubling. Studies have highlighted disparities in delivery rates of preterm babies and in diagnosis, access to care and treatment of perinatal mental health issues among ethnically/racially diverse mothers compared to non-Latinx white peers. The fact that African American women have high rates of perinatal complications and higher rates of morbidity and mortality than their non-Latinx white peers is cause for national concern. The unconscious bias that could be influencing the differential treatment of women of color and women from underserved backgrounds should be a clarion call for all health care practioners to use a more nuanced perspective in how they interact with and care for diverse families.

We are beginning to understand the catastrophic impact that differential care from practioners has on patient's health, particularly women's health. However, little is known about *how* cultural differences impact mothers' experiences of preterm birth and NICU care and what types of interventions might be most impactful. Very few studies investigating the relationship between maternal mental health and infant outcomes have specifically looked at the impact of race, ethnicity and culture on this vulnerable population. We need studies that focus not just on the stress of having an infant in the NICU, but also on the unique stressors that are *specific* to particular communities, like perceived discrimination, lack of culturally-informed screeners and lack of materials available in multiple languages.

Learning From Our Families

The research is clear: NICU hospitalizations confer greater long-term risk for future mental and/or behavioral disorders for both parents and infants regardless of background. However, as we serve increasingly diverse families in the NICU, we need to better understand how ethnic and cultural variations affect how parents express and respond to distress. It is only by working closely with families and communities that we can know *how* to be of service, *when* to intervene and *which* interventions are likely to be most effective.

We must also remember that families have wellsprings of strength and resilience. If there is enough meaningful support to the family and infant through partners, extended family and friends, and their community, this support can help to mitigate some of their stressors. These kinds of psychosocial supports can be protective for both physical and mental health conditions and are associated with improved outcomes in both adults and developing children.

In times when families are in crisis as their children are hospitalized, it is incumbent upon providers to learn how to best serve the family in front of us. We can accomplish this through inclusive research that adds to our knowledge base about ethnically/racially diverse communities. By better understanding how to support diverse families, we can ensure that *all* children, including the most vulnerable infants, have appropriate interventions and supports ensuring that they thrive.

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