

Perspectives on Race and Medicine in the NICU

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Current data regarding racial and ethnic disparities in health outcomes of newborns requiring care in an NICU reveal significant differences in quality and access to care that disproportionately affects infants of color, particularly African American infants. These inequalities result in an increased infant mortality rate for Black children and higher preterm birth rates, as well as an increase in deaths due to low birth weight and decreased gestational age. Concurrently, there is emerging research exploring the role of diversity and adequate representation among medical providers in patient outcomes in Black communities. In this editorial, we present commentaries from a medical student, a neonatologist, and a parent of former NICU patients to further explore race in the NICU from different perspectives and understand what can be learned from their experiences about these systemic issues and why representation is a critical component of successful change.

According to data from the Centers for Disease Control and Prevention, in 2018, the infant mortality rate for Black children was 10.8 per 1000 live births compared with a rate of 4.6 for non-Hispanic white children.¹ Similarly, there is a nearly 50% higher preterm birth rate for Black children, as well as a fourfold increase in deaths due to low birth weight and decreased gestational age.²

Unfortunately, race-based inequality in medicine is all too familiar to clinicians today. Over time, the field of pediatrics has taken strides toward addressing these inequities. However, it is the systemic nature of racism within health care that is the primary barrier to change.³ Therefore, when facing an issue of this magnitude, namely, the disparity in outcomes for Black infants in America, it is important to analyze it from different perspectives to allow for the identification of areas of improvement that are both tangible and feasible to address.

New research indicates that representation, here defined as congruency between the racial diversity of providers and their patients, may be one of these areas of focus. In a recent study looking at data on hospital births in Florida from 1992 to 2015, researchers found that the mortality penalty suffered by Black newborns cared for by Black physicians was reduced by a factor of 2 when compared with those cared for by white physicians. These findings were consistent when controlling for training, meaning that a similar reduction was found along racial lines among both general pediatricians and neonatologists.⁴ Similarly, using data collected from a randomized control trial conducted with an adult population, researchers found that Black men assigned to a racially concordant doctor sought more preventive care, resulting in a projected 19% reduction in the Black-white male gap in cardiovascular mortality.⁵

abstract

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Ms Adams helped to conceptualize and develop this project and was responsible for communicating and coordinating with coauthors as well as drafting, reviewing, and revising the manuscript; Ms Davis helped to draft, review, and revise her individual comments; Dr Lechner conceptualized this project and helped to draft, review, and revise the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: <https://doi.org/10.1542/peds.2020-029025>

Accepted for publication Dec 2, 2020

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Adams SY, Davis TW, Lechner BE. Perspectives on Race and Medicine in the NICU. *Pediatrics*. 2021;147(3):e2020029025

We contend that emerging data make the strong case that representation among medical providers matters when assessing patient outcomes. Therefore, in this submission, we present comments from a medical student, a neonatologist, and a parent of former patients in the NICU to further explore race and the importance of adequate representation in the NICU from different perspectives.

SHANNON ADAMS: MEDICAL STUDENT

As a student-doctor buried within the hierarchy of medicine, one can often feel small, with everything you do filtered through the countless levels above you so that your role is not always clear or meaningful. I experienced this many times in my 4 years; however, as a Black woman, there are some interactions in which I saw genuine value in my presence. The first was in the PICU with an 8-year-old girl recovering from a severe asthma exacerbation. On my final trip to her room, her grandmother looked down and nudged her. “Tell her,” she said, “Don’t be shy.” The girl giggled and ducked behind her grandmother’s shoulder shaking her head. “What?” I asked, “You can tell me.” She peeked between her braids to look at me. “When I grow up, I want to be a doctor like you.” I laughed and bent down on one knee. “Girls like you and me can grow up to be whatever we want to be.”

Another moment came in the emergency department. I stood behind the attending and resident as they told the family what to expect. When they were through, we turned to file out of the room, but as I reached to close the curtain, the patient’s wife spoke. “Tell me something. How are these doctors over here? Are they any good? Do you trust them?” I looked up at the ring of brown faces standing proudly around the hospital bed, like soldiers sworn to defend and protect. “They’re the

best,” I said. “I’d trust these doctors with my family too.” She nodded and rubbed her husband’s shoulder. As I stepped back again, the brother spoke. “Keep representin’, doc. Make us proud.”

In the NICU, one of my patients was the child of a young Black mother, with a history of psychiatric diagnoses and a medical file that labeled her as “argumentative.” While her son was feeding and growing, she stayed by his side diligently, always thankful and never questioned the team. On one of my night call shifts, I saw the light on in his room and came to sit with them while she fed him. “How are you doing, Mom?” I asked her. She held him closer. “As long as he’s good, I’m good. Are you studying to be one of those doctors?” I nodded. “Hopefully one day.” She pulled down her mask to look at me, fully. “Good for you, girl. Good for you. There needs to be more of Us in here anyway.”

As a medical student, I have seen that the connection between doctors and some of their patients is warped; irrevocably fractured by the actions of a broken system that has operated as both a stopgap between life and death and a facilitator of morbidity and trauma. Black Americans have not forgotten the atrocities committed against those who came before them: the untreated victims of Tuskegee, the generations lost to forced sterilization and eugenics, the family of Henrietta Lacks, and the experimental subjects of Dr James Marion Sims.⁶ Their suffering reverberates through the hearts and minds of an entire racial identity, a group of people who have been given many reasons to doubt our oath to do them no harm. But when I knelt beside that girl, spoke to that family, and sat across from that mother in the NICU, I could feel the gap closing between us and them.

For me, “representation” means a cohort of physicians who mirror the communities they serve, so that in

them, their patients can see their neighbors, their families, and themselves. By creating a system that encourages diversity at the highest level, with physicians, allied health professionals, and administrators from every walk of life, we can move toward promoting equitable care for all patients, increasing patient satisfaction, and improving health care outcomes for those who need it most.⁷

BEATRICE LECHNER, MD: NEONATOLOGIST

Many years ago, I cared for an infant in the NICU whose mother I immediately bonded with. We shared key life experiences, both juggling the roles of wife, mother, and professional at the beginning of our respective careers. I saw myself in the way she approached having a sick infant in the NICU by being at the bedside around the clock, asking detailed questions about the science behind our treatment plan, gathering her extended family around her for support, and remaining optimistic. Thus, I experienced our relationship as a collaborative, trusting physician-parent partnership: that is, until the day her infant unexpectedly became gravely ill. Overnight our dynamic changed. There was less warmth in the room and more questions that felt like questioning. Suddenly, I was struggling not only with my attempts to save the infant’s life but also with an unexpected and confusing fracture in our relationship.

At the time, I attributed this shift to the family’s stress of having a very sick infant. Although I will never know what this particular family was thinking or feeling, looking back, I can say this: something had broken their trust in us. In hindsight, after many years of reading and learning, I have tried to place their experience within the broader social context. They were an African American family, I was a white neonatologist; in fact, no one on the care team was Black. As I

would later appreciate, our relationship as doctor and patient came to be as a part of a long, sordid history between African Americans and medicine. Within the power structure that exists between providers and patients, as well as the record of wrongdoings perpetrated by others in white coats, our relationship was understandably complex before I had even entered the room. And when their infant suffered a complication, with no one else around who looked like them, they were given yet another reason to second-guess the system.

There is substantial research exploring medical mistrust in minority communities and the impact it has on usage of health care resources, adherence to treatment regimens and screening protocols, belief in expert recommendations, provider interactions, and ultimately patient outcomes.⁸⁻¹² These data reveal that the historical treatment of Black Americans by our civic systems has had a lasting effect on the relationship between some members of these groups and their sources of medical care and wellness. This is an alarming reality we must confront as providers. As the daughter of immigrants, I have always drawn on my experiences growing up in multiple cultures around the world and prided myself on my ability to slip into various parental perspectives in an effort to achieve therapeutic human connections. Although I was humble enough to realize that my technique had significant limits, I was nonetheless proud of my perceived wide horizon. And yet in this case, I didn't think about the parts of this family's personal narrative and identity that may have played a role in how they experienced the NICU. I didn't think about how their trust in me, despite all of my hard work, long hours, attention to detail, and dedication to the practice of evidenced-based medicine, was not guaranteed.

Over the course of the ensuing years, caring for and learning from families of marginalized communities, I began to more deeply understand the need for culturally sensitive care from all providers. But I also realized that although the ability to be sympathetic as a physician is critical, the ability to be empathetic is priceless. In the America of today, one of the pillars of good medicine has become the development of a health care workforce that reflects the community it serves. Our attending physicians, interns, residents, medical students, nurses, department chairs, and all of the people in between need to be as diverse as the landscape of our nation. To best treat our patients, we need to build teams of people who have walked in a family's shoes, grown up in their neighborhoods, and shared in their challenges. Increasing the diversity of the medical field will not only help to decrease the African American neonatal mortality rate but will also facilitate the development of a workforce that can provide exceptional care to all vulnerable populations.

TANIKA DAVIS: NICU PARENT

The infants were born too small. Their tininess birthed a kind of love and fierce protectiveness I never knew existed. It also frightened me to my core.

How then can I express my profound gratitude for the NICU staff who warmly and assuredly cared for my boys? I cannot say enough good things, except that I could not have survived without those angels in colorful scrubs. I think of them so fondly that I sometimes forget how much internal stress I was under. I so desperately wanted my infants to be safe and healthy that I trusted nearly anyone who said they knew best how to guarantee such an outcome.

But I knew that it is human nature to help people who you like, so every day I entered the ward, I did my best

to be likable. I needed the nearly all-white staff to know I was smart and friendly and gracious and involved. I needed them to know I was educated. I was employed. I was married. So badly did I crave their help, I consciously played the role of "respectable Black woman." And I played to win. I remember feeling that I had to be strong, so that they would know I was capable, but not so strong as to come off as angry. I didn't want to seem overly emotional, for fear that that kind of expression would loom too large and overshadow, in their eyes, my intelligence and capability of processing information about my children's health and well-being. So, I saved my tears for my husband at home and sobbed in the car in the hospital parking lot.

I later learned that I was not alone in my worries. My aunt shared with me that when her son was born with a genetic disorder, a NICU nurse who was a woman of color pulled her aside and gave her two pieces of advice. The first bit was crucial: "Your baby will need all your strength," she told her. "Whatever you have in you, you bring it!" The second bit of advice, however, was this: "Don't let them see you cry. You can cry with me, but don't let them see you cry." The "them" in that sentence was clear to my aunt and to me when she recounted the story: the white doctors and nurses.

Anthropological analysis reveals that the importance of projecting an image of strength is deeply engrained in the Black female psyche.¹³ Like my aunt, many of us are taught from a young age to appear resilient and self-sufficient, often to the detriment of our own needs and psychological well-being. As psychologist Regina Romero wrote in the book *Psychotherapy with African American women: Innovations in Psychodynamic Perspective and Practice*, "'Strong Black Woman'...is a mantra for so

much a part of US culture that it is seldom realized how great a toll it has taken on the emotional well-being of the African American woman.¹⁴ And yet, at the same time, we are faced with stereotypes that depict us as “too strong.” We are “angry,” “domineering,” “loud,” “disagreeable,” or overly assertive in situations in which it is deemed unwarranted.^{15,16} So, although to some the fear of being judged as a parent in the NICU may seem like a universal experience (and in many ways they would be right), as a Black parent and specifically a Black mother, I am keenly aware that there are stereotypes unique to my identity that hold historically negative connotations and have a well-documented impact on our medical care.¹⁷ Research reveals that my background and upward socioeconomic mobility alone are not enough to protect me or my children from the adverse birth outcomes experienced by Black women for generations.¹⁸ So although no one explicitly advised me to repress my natural emotions, somehow it felt that the doctors and nurses would be incapable of handling my tears, incapable of seeing me, a Black woman, fully. And if they could not see me fully, then they would not see my infants fully, which was an outcome I could not allow. So, I made sure to form my Rs clearly at the end of words. I smiled when I was exhausted. I was the “right” kind of Black NICU mother, and my boys came home with me safe and sound.

Today, 10 years later, my feeders and growers are long-limbed and ravenous. They make me laugh until my sides hurt. I remain immensely grateful for their care team’s expertise and the combination of professionalism and ministry that made them so good at tending to the tiniest and neediest of humans. But if my daughter, born 2 years after the twins, ever has an infant who needs

time in the NICU, I will pray that she is part of a health care system with an arc that is bent toward equality. I will tell her, “Your baby will need all your strength. Whatever you have in you, you bring it!” And I will also tell her this: “Cry. Cry all you want, whenever you want. Let them see your fierceness, baby girl. Let them see your tears.”

DISCUSSION

Year after year, hundreds of thousands of Americans continue to show the world that they want Black lives to matter, and with each iteration of the movement, our nation feels the discomfort that comes with monumental but necessary change. Discussions about race and racism are made difficult by the enormity of it, coupled with its immateriality and the subtle complexities of human interaction. However, as these essays reveal, the road to progress is lined by a diversity of thought, experience, and identity among those in power. In short, increasing the presence of traditionally underrepresented minority groups in the physician workforce can help to address the issues of structural racism in medicine and, maybe, help to decrease Black newborn mortality as well.

Currently, Black or African American people make up 13.4% of the US population.¹⁹ According to data from the US Census Bureau, the size of racial minority groups is only increasing. Between 2010 and 2019, racial and ethnic minorities accounted for all of the nation’s population growth, with an 8.5% increase in the Black community alone.²⁰ However, according to the Association of American Medical Colleges, among active physicians, only 5% identify as African American, with <3% identifying as Black men.^{21,22} This is problematic. Nevertheless, it allows us to isolate an area of critical need.

Given the data presented here, we contend that the medical field must work toward achieving a minimum Black physician workforce of 10% within the next 5 to 7 years. There are 3 identifiable points along the education time line at which we can begin to tackle this issue.

The first is in early education, specifically the elementary, middle, and high school levels. This is the time when a career in medicine initially becomes a viable possibility for children. Medical schools and hospitals, particularly those in areas that serve a large minority community, must either put forth initiatives that directly engage young people of color or partner with local organizations that are working in this space. Some examples include STEMcx (Science, Technology, Engineering and Mathematics Conference and Expo), an organization based in Baltimore “committed to putting non-traditional students into the STEM jobs of the future through exposure, mentoring and giving these students a chance to see someone who looks like them achieving.”²³ Similarly, Black Men in White Coats brings students together for youth summit events hosted at medical centers around the country. As one parent said when interviewed at their 2019 event, “I think it’s good to see the representation, to see someone that looks like them who has gone through the career pathway, so that way, they know that it’s very feasible. That it’s very possible for them.”²⁴

The second point is at the medical school admissions level. In the 2020–2021 academic year, 7.5% of the total US medical school enrollment was Black or African American, compared with 7.2%, 7.0%, and 6.8% in the preceding academic years.²⁵ This must continue to trend in a positive direction. Residency admissions data should also mirror this trajectory, indicating that Black medical students are supported

enough to ensure retention and completion of their medical school education, and that residencies are prioritizing minority recruitment and adequate representation among trainees.

The third and final point is at the attending physician level. In 2019, of the 154 department chairs in pediatrics surveyed by the Association of American Medical Colleges, only 7 were Black or African American.²⁶ That is <5%. Clear career development pathways must be established for junior faculty members from underrepresented groups to facilitate the advancement of these persons to positions of power, with the impetus that increased diversity among pediatric leaders will help to improve the culture of equity and inclusion from the top down.

CONCLUSIONS

There are many ways to approach the larger issues put forth in these narratives, namely, the promotion of trusting, therapeutic provider-patient relationships and the improvement of patient outcomes. Cultural sensitivity, structural competency, patience, and understanding by all medical providers are necessary components of progress. We have, however, chosen to focus on representation in this article because it is both significant and feasible to address in a stepwise, targeted fashion. As medicine continues to grow and evolve in exciting and positive ways, it is our responsibility as medical professionals to push for the change that our patients deserve. Infant mortality and neonatal-perinatal outcomes should have nothing to do with race. As providers and participants in our health care system, it is on us to shift the narrative so that every child has the same opportunities, and increased diversity is an integral part of that journey.

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Pediatrics originally published online February 16, 2021;

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Pediatrics originally published online February 16, 2021;

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