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The impact of being Black while living with a chronic condition: Inpatient perspectives

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INTRODUCTION

Understanding factors that weigh heavily on Black patients and families during hospitalization is key to minimizing the strain of admission and optimizing outcomes. Individuals with chronic conditions carry the cumulative emotional burdens associated with their illness into every hospitalization. Black patients carry the additional burden of the trauma of lived experiences of structural racism. As part of its strategic initiative on mental health, the American Board of Pediatrics launched the Roadmap Project with an aim to improve emotional health in children and youth with chronic conditions and in their families.[1,2] In a panel discussion about the experiences of Black patients in the hospital, three Black parents and one Black patient, members of the Roadmap Project Patient and Parent Advisory Group, shared their experiences of having chronic health conditions while inpatient. Their stories highlight how structural racism compounds the challenges of chronic illness and call attention to recognized areas of concern for Black patients and parents during hospitalization: (1) the impact of trauma associated with racially motivated current events on the hospital stay;[3,4] (2) the need for "code-switching" (adjusting one's style of speech, appearance, behavior, and expression to optimize the comfort of others) when interacting with hospital providers;[5] and (3) the concern of Black parents about the potential threat of Child Protective Services being called by hospital teams.[6,7]

The background trauma of lived experience

Tawanna Williams (mother of a 6-year-old daughter born with congenital heart disease who had five open heart surgeries before undergoing a transplant at 3 years of age)

> *For me, it has been difficult to respond in the hospital when someone asks, "how are you doing?" … I need to be in a safe space to feel secure enough to be vulnerable. It's the trauma of having a medically fragile child, it's the trauma of just being a Black individual in the world today. We carry around trauma. I don't think people are aware that past and current events play a part. It would be helpful if practitioners could pay attention to that. [For example,] I got pulled over by the police during the holidays in a suburban town. I changed the*

radio station from hip-hop and turned on the Christmas music right away. I've got my daughter's art stickers on the back of the car, and a car seat in the back. But none of that mattered-all I thought about was Sandra Bland and what happened during her traffic stop.

Christian Lawson (diagnosed with Crohn's disease at 8 years old)

It was a struggle to be young and Black and living with Crohn's disease. We traveled three hours to see the doctor. In the waiting room, we did not see anyone who looked like us. The doctor and nurses didn't look like us.

I ended up being hospitalized for a month. When you ask me "how I am doing," I often don't want to genuinely share the mental pain I am feeling because if I say that, then I think that you will look at me as weak when I am supposed to be strong. I know you are busy but taking time to acknowledge and validate the stress of living with a chronic condition, asking about my emotional health, and listening can make a difference.

Personal encounters with racism, as well as the trauma experienced by peers and communities, influence the daily lives of Black patients and parents. These lived experiences do not disappear upon entering a medical setting; instead, they form the lens through which patients and parents perceive hospital stays and the medical staff they encounter. Consequently, during a hospitalization, while busy clinicians focus on medical management, the combined stress of acute illness and chronic illness, set against the background of ongoing racism in the community, may be all-consuming for Black patients and families, yet easily overlooked by providers. Thus, even if well-meaning clinicians ask patients and their families "How are you doing?" for Black patients and parents, this question can be complex and nuanced.

Playing the Game by Code-Switching

Robyn Kinebrew (mother of young adult twin sons with sickle cell disease)

My husband and I were always cognizant of what we wore when going to the hospital. He would change out of a t-shirt and shorts into business causal so he wouldn't be thought of as "a thug." My husband noted that when he presented his insurance card with the name of his corporate employer, the perception of who we were changed. When I was there alone, there was often an assumption that I was a single mom with no insurance.

Every time a new nurse or doctor would come in, we tried to build rapport and let them know that we were concerned parents, we understand what's going on, we have questions, and to treat us the same as if we were White.

I had to make them accept us. I'm trying to talk a certain way, dress a certain way, be a certain way so that staff find us acceptable and feel comfortable talking with us. It is exhausting trying to deal with bias on top of worrying about your son's health and care. It was hard to let my guard down. I always knew that I had to be strong.

Surviving a hospitalization emotionally, especially a prolonged hospitalization, often requires Black parents to "code-switch" to garner the respect of medical teams and to be recognized as an advocate for their ill child. Code-switching entails carefully choosing words, gestures, and clothing to maintain an appearance that is considered acceptable. For Black families, code-switching occurs as part of an ongoing battle against pervasive racial stereotypes. Parents and patients worry that if they do not maintain an image acceptable to medical teams, their opinions and wishes may be disregarded.

The Child Protective Services Concern

LaToshia Rouse (mother of a 12-year-old son with autism and of 10-year-old triplets born at 26 weeks' gestation)

You learn that you have to be seen as non-threatening, well-educated, and strong in order for healthcare professionals to deem you acceptable.

One triplet had several medications, a G-tube, oxygen, and a heart monitor. I wanted to be sure that the hospital team knew I could handle taking him home. I made sure that I always presented myself with the attitude "I have this" because some fear was always in the back of my mind about Child Protective Services.

As a Family Advisor in the NICU, I would coach Black families about talking with the care team. Black men tend to talk with their hands. I explained to them that that is seen as a threat. Say everything you need to say but sit down while you do it and keep your hands quiet. And with Black moms, sometimes I'd spend an hour talking to them so that they could get some of their emotions out so that by the time they talked to the doctors, they would not be seen as emotional and angry.[8] *I would tell Black parents, "I want you to be able to come see your kid. You don't want them to say you can't come back up here. Your baby needs you."*

While navigating the complex culture of health care systems, Black parents worry about the potential consequences of emotional responses

that occur during stressful hospital stays. Demonstrating anger, frustration, or even small emotional fluctuations that may be expected under the stress of an admission may lead to labeling as a "difficult" family, belief that a parent is unable to handle their child's care, or worse, involvement of Child Protective Services. These fears are amplified for Black families in the inpatient setting. Many parents also fear that hospital staff may propagate negative information about parents to other medical providers, a fear supported by the literature.[9,10]

Moving forward

Awareness of the perspectives of Black patients and parents who have the dual lived experiences of chronic illness and racism is an important first step in addressing bias and inequities. However, many hospitalizations are brief, and interactions may be rushed due to heavy patient loads and increasing acuity. Though it may be difficult to establish trusted relationships with patients and families in the inpatient setting, demonstrating sensitivity to concerns of Black patients and families and taking action are necessary to mitigate poor outcomes. The lived experiences shared by the Roadmap Project members created a unique opportunity to address these issues and compose the following recommendations. Use of these strategies can promote understanding and drive personal, practice, and system change to remove barriers to equitable and respectful care delivery.

1. **Incorporate educational opportunities to raise awareness and deepen understanding of the lived experience of Black families**.

- Implement implicit bias training as an initial step to promote self-reflection and discussion.
- Follow implicit bias training with anti-racism training.[11,12] This training identifies the need to address the role of systemic racism in creating inequities and incorporates historical context on the lasting effects of systemic racism on care delivery. Learners are encouraged to actively engage in challenging racist policies and systems. Additionally, upstander training is often included in anti-racism programs and provides learners with tools and skills to actively call out racism.
- Learn how past trauma from racism and discrimination can impact emotional well-being and become familiar with trauma-informed care practices: safety, choice, collaboration, trustworthiness, and empowerment.[13]
- Dedicate regular time at division meetings and Grand Rounds to share patient and community stories and/or data that highlight challenges, disparities, and bias.
- Determine if your institution uses race-blind guidelines for social work or CPS referrals[6,14]; if not, advocate for that change.

2. **Make deliberate efforts to establish trust**

- *Take time* to listen empathetically to concerns and be aware that assumptions may stand in the way of excellent care delivery.
- Recognize current events that represent racial attacks and how these may affect the emotional state of the patient and family, for example, the murder of George Floyd, and church shootings in Charleston.

3. **Promote interdisciplinary and cross-divisional collaborations to address bias and inequities**.

- Partner with nursing colleagues to develop shared approaches.
- Consider cross-divisional collaborations with colleagues who share similar challenges with time-limited patient encounters, e.g., emergency medicine.

4. **Address system issues**.

- Encourage your health system to highlight data, stories, and strategies pertaining to racial equity.
- Ensure the collection of accurate health data that include self-identified race and ethnicity. Explain to patients and families the importance of gathering accurate data and why you are asking.
- Regularly review and analyze internal data on patient and family feedback, clinical practices, processes, and outcomes by race and ethnicity to identify disparities in your setting. Promote a feedback system for patients to report experiences of discrimination that they face with a plan to follow up on the events.
- Create an inclusive clinical environment that reflects diversity in posters, brochures, magazines, coloring books, toys, and dolls in playrooms so that individuals see themselves represented.

Advocate for increased diversity in the workforce and create a position for a diversity, equity, and inclusion officer if this position does not exist.

CONCLUSION

Black individuals with lived experience of chronic conditions and racism have highlighted key concerns related to inpatient stays. Intentional and focused strategies are needed to address systemic racism and ensure equitable care and support for Black families during hospitalization.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

ETHICS STATEMENT

The Roadmap Project Learning Collaborative, which included the panel discussion that forms the basis for this article, was deemed non-human subjects research by the Cincinnati Children's Hospital Medical Center IRB.

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