

NARRATIVE MATTERS



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Confronting Racism In Pediatric Care

A primary care pediatrician calls on his profession to address racism in pediatric care.

BY BENJAMIN DANIELSON

Some years ago one of my young patients, a medically complex nine-year-old who was chronically ill with a lung disease, had been hospitalized for about a week. The head nurse caring for him, a long-time colleague and friend, reached out to me as a courtesy.

“Ben, I’m calling about one of your patients,” the nurse began. “Actually, it’s about the mother.”

I had cared for this child and his siblings for at least a dozen years as a primary care physician. I knew the mother

well, and I knew how loving, supportive, and capable she was of caring for her son.

“The hospital team is becoming increasingly concerned,” the nurse continued. “They’re saying she doesn’t seem to be emotionally impacted by the state of her son’s condition. She’s not showing up to the hospital until the evening, and she’s missing meetings with the care team. They’re questioning if she understands how serious his condition is.” She paused, “They want to know if there is something about the mother’s intellectual development or mental health

needs that we should know about.”

The way she was describing this woman was a complete disconnect for me; it was a person I didn’t recognize. During my years spent caring for this family, we joked together and shared recipes. The mother talked emotionally about her sick son and with great passion about the love she had for her family. She knew her son’s health care needs better than me. She could easily tell the nuances of a bad or good day for her child well before they showed up clinically for us on the care team.

“I just want to let you know that they’re holding a social care conference tomorrow to discuss it.” The nurse trailed off.

We both knew what that meant. A machine had been activated, one with deep-rooted, racist structures, and there was very little either of us could do about it at this point. A call to Child Protective Services would likely follow, and because this was a Black family who was also living below the poverty line, there was an alarmingly high risk that the child would be taken away from the mother—that the system had no choice but to “save” him. In health care and other settings, poverty is racialized, biases are deeply embedded in policies and practices, and child protective systems are put in place that can trigger serious negative consequences when racism affects evaluations and decision making. For example, a 2002 study on racial differences in the evaluation of pediatric fractures for abuse by Wendy Lane and colleagues showed that there is a higher likelihood of Child Protective Services being called if you are a Black family than if you are a White family, even after controlling for the likelihood of abuse.

The Social Care Conference

I attended the social care conference for my patient, uninvited and maybe not particularly wanted. I listened as a room full of health care professionals described the mother—nearly medically assessing her—without actually knowing her, without her being in the room

to speak on her own behalf. Their words were soft and caring in delivery, but the judgment was clearly there: This mother was not meeting the expectations of how they wanted a mother in this situation to show up and behave.

It was quickly decided that a referral to Child Protective Services would be made. The insinuation was that the mother wasn't capable of caring for a medically complex person—that, for instance, the medication schedule (six to seven medications, two to three times a day) was too complicated for her. They cautiously hinted that this was perhaps the reason for the current hospitalization (which, in my medical opinion, was not the case).

The implications of this referral, and the domino effect it could have on the family, were tremendous. I was not invited to speak at the meeting, but afterward I urged the social worker to give it more time. She was firm on the decision, but she would give me time to speak to the mother that night.

Medical Trauma Across Generations

I met with the mother when she came to see her son that evening. We both lit up when we saw one another, and we had a long talk. She was exhausted. She told me that she was on the verge of being fired from her job because of missing shifts while staying with her child in the hospital. Now she could only come at night, after work, after going home to feed and care for her other children, and then taking the hour-long bus ride to the hospital.

She shared her concerns about her other children. This hospitalization had been hard on all of them, and they had always been fiercely protective of their brother, who had been sick since birth. Now she worried about her other children's behavioral health needs.

"But Dr. Ben, there's something else," she started. "People here look at me weird. And they speak to me strangely—so slowly, like I don't understand English. They keep questioning the medication routine with me, but I know it by heart. I even had to correct the nurse about the medication routine when we first got here. I know how to take care of my son—the schedule, the potential side



effects, and things to look out for. But they're acting like I don't know what I'm doing. It's been really stressful."

She sighed before sharing with me details of her past that I didn't know.

"When I was a kid, my sister was really sick, too. When she was hospitalized, my mother was so scared and worried, and she let it be known to the care team. They decided she was acting too emotional—unstable maybe. This led to the hospital watching her closely when she visited, even having security guards sit outside of the room. They started to consider her aggressive for getting upset and frustrated. In the end they banned her from visiting and called Child Protective Services. We were all put into foster care. It was horrible." She paused. "I'm trying to be as tough and unemotional as possible when I come here. I'm so scared of history repeating itself. I don't want them to get any wrong ideas about me or my children. I never want them to go through what I went through."

This kind of generational trauma repeated under the judgment of hospitals is sadly all too common. Other parents have shared stories like this. Other community-based primary care colleagues, especially those who look like the families of color they serve, have related to me that they've heard of similar multi-generational experiences. Whether it's expressing too much emotion or too little, many families of color find themselves highly scrutinized and punished.

At some point, a nurse happened in on our talk. She was surprised by the warmth and animation in our conversation and later asked me what had changed with this woman, who was now

so expressive, so clearly worried about and involved in the well-being of her son.

How could I express that nothing had changed? That she had always been this way, but she was trying to play a safe role to protect her children and herself from the racist system that no one else around her seemed to see, even though they were very much a part of it?

The next day the referral to Child Protective Services went through. The mother was interviewed and had to attend many meetings. She knew that, just like at her job, she was again under a microscope and that missing any meeting would count against her. This meant more time missed at work, and she was fired. This was a family with very little resources; that job was precious. Meanwhile, Child Protective Services put a hold on her son, which meant that, pending further investigation—including numerous home visits, caseworker meetings, a scrutiny of her extended family, and parenting assessments—the child could not be released from the hospital.

There were potential harmful health outcomes that could result from this delay and from keeping the mother away. When a patient is chronically ill, there is a sweet spot for the duration of a hospital stay. If a patient stays past that point, there is a greater chance of other complications arising. This is a subtle concept, but one that can have great implications for many families caring for children with complex medical needs. Everyone claimed to be doing this process for the welfare of the child without seeming to realize that they were potentially putting his health in more danger, not seeing that he had a loving mother and siblings waiting for him at home who had done an outstanding job caring for him all his young life.

On release from the hospital, the child was put into the medical foster care system, which enables children with complex health care needs to continue to receive needed health care and supervision in a foster care setting outside of the hospital when parents are not deemed able to take care of them. During the following weeks, the mother was put on a strict routine. She had to find a new job, attend a slew of Child Protective Services-related appointments, and es-

Policy Checklist

The issue: Families of color face both structural and interpersonal racism in health care and in other systems that drive racial and ethnic disparities in health and well-being. Implicit and explicit racial biases compounded by a lack of trust and dignity, as well as punitive policies and systems, including in child welfare involvement, often lead to worse health outcomes for Black pediatric patients and other patients and families of color. Pediatricians have a role to play in calling out racism in health care systems.

Related reading:

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tients and other patients of color and their families.

When Health Care Harms

In the US, racism affects every aspect of people's lives, including personal health and the health care system. Research shows that families of color face both structural and interpersonal racism in health care and in other systems that drive racial and ethnic disparities in health and well-being. This is as true in pediatric care as in health care for adults. According to a 2015 study by Monika Goyal and colleagues, a Black child in pain who is brought into the emergency department is 80 percent less likely to get adequate pain treatment for the same cause of pain than a White child. Black children are also less likely to receive the imaging tests that would help make an accurate diagnosis, according to a recent study by Jennifer Marin and colleagues. In addition, if a hospitalized Black child needs an operation, their chance of dying in the month after surgery is more than three times higher than that of a White child, according to 2020 work by Olubukola Nafiu and colleagues.

But structural racism doesn't just affect the medical care that pediatric patients receive. Studies such as those by Yannis Valtis and others show that there is a higher likelihood of having hospital security called on Black patients and Black hospital visitors compared with their White counterparts. A recent study published in *Health Affairs* found that Black patients are almost three times more likely to have negative, biased, and stigmatizing descriptors such as "aggressive" and "noncompliant" included in their electronic health records than White patients. Mandated reporting policies for child abuse and neglect are meant to protect children but can cause harm when there is bias involved. These racist inequities cause untold emotional distress and trauma for patients and their families and can have lifelong repercussions, including fear and mistrust of the medical system, that can lead to delays in seeking needed care.

My patient's mother didn't need data to tell her all of that; she lived it every day.

In my work I saw a stark difference in

essentially "be on her best behavior." She was no longer allowed to make decisions about her son's care, his well-being, or even where he called home. She had to make sure to express herself in a way that the powers that be deemed acceptable and appropriate for a mother in her position, and with just the right smile or the right concern on her brow. Meanwhile, the child seemed to take longer to recover compared with previous hospitalizations.

Eventually the family was reunited, but they should never have had to go through the trauma and scrutiny that comes from the embedded racism that

is fraught in the medical system.

This was a few years ago. The siblings are now grown. I ran into one of them recently, a young woman entering college. We reflected on the past a bit, and then she told me that she was studying to become a doctor. I was touched to hear her say it was partly because of her family's experiences at the primary clinic. But—and this was painful to hear—it was mostly because she wanted to ensure that no other parent had to go through what their mother, and their grandmother, had been through. The choice to become a doctor was a defensive decision made to protect Black pa-

how my patients were treated in our primary care clinic compared with in the hospital. For nearly two decades I had the great privilege of serving as the medical director at Odessa Brown Children's Clinic, the primary care clinic in Seattle, Washington, where this family sought care. The clinic was in a historically Black community and served mostly families with low incomes. Nearly 80 percent of our patients used Medicaid. The clinic was designed to be a medical home, with dental, medical, and behavioral health care provided all in one place. The clinic waiting area felt like a mini-United Nations. Its tagline was "quality care with dignity," and we truly aimed to place dignity in an inextricable bond with the best technical care.

Within our clinic we sought to create an environment in which our patients were valued, believed, and able to show up as themselves. We also aimed for our clinical staff to reflect the populations served, in terms of race, ethnicity, and lived experiences. But I always worried when sending them to the hospital the clinic was associated with, where, similar to so many other hospitals across the US, most of the staff didn't reflect the populations being served. I worried because I felt that the treatment they received would be different in the hospital than in our clinic and that my patients and their families could face adversarial and racist structures (and hospital staff who knowingly or unknowingly upheld these racist structures).

Deciding To Quit

My patient's story is painful, but it's not unique. It's just one example among countless others. Colleagues continue to share similar stories with me. Things aren't getting better. This is why, in late 2020, I made the heartbreaking decision to leave my job at the clinic.

The decision to resign from the best job I ever had was a long time coming. Over the years Black parents of children with sickle cell disease shared tragic experiences of their children's symptoms being minimized in the hospital. Other Black parents shared stories of hospital security being called on them or, as in the story shared above, of the hospital calling Child Protective Services because a job prevented the parents from visiting

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their child as often as they wanted to or because they did not act in a way the hospital deemed acceptable.

As primary care providers for these families, I and other clinic providers felt that one of our most important roles was to protect Black families from racism in the hospital's practices, so I made sure that I was a regular presence on the hospital wards. Despite this, hospital practices continued to harm Black families. I resigned in protest of the racism that seemed to poison the hospital that oversees the clinic. Racism that it, like so many other hospitals, was too blatantly practicing and too insincerely addressing. I hoped to better support my Black community and compel greater change at the hospital from outside its walls.

Racism affects every aspect of the health care system, in policies and daily practices, and it harms people. Racism harms pregnancy outcomes for mothers and newborns, increasing mortality for both, increasing neonatal complications, and reducing dignity. Racism harms the care that children of all ages receive, decreasing the quality of care. Racism harms the workforce as well. The burnout among health care professionals has been growing, but the issues are compounded for providers of color, who are struggling to recapture their own power and their drive to be of service to their fellow human beings.

Of course, the harm of racism reaches beyond the health care system, curtailing children's lifelong development and dreams. Racism scars disciplinary practices in education, beginning in the earliest years. Generations of racism have trapped families in poverty. Racism infects the environments in which young people grow up, limiting access to nutritious food and safe places to play and learn. Racism harms young people involved in systems such as foster care

and juvenile detention. Racism harms unhoused youth. Racism layers trauma upon trauma.

A Critical Role For Pediatricians

Across the US, racism has formally been named a public health crisis. An intensifying call has been made, from all corners of US society, to take meaningful action to address it. Now is the time for pediatricians to collectively compel the nation's health care system to make antiracism as integral to health care success as addressing asthma.

This is highly personal for me. Like so many of my colleagues, I dedicated my career to the field. Primary care pediatricians hold precious space in health care—we're the first health care touchpoint for most people, and the bridge to lifelong health. In our offices, children are celebrated, healthy development is encouraged, the earliest concerns about health problems surface, and lifelong seeds for health and well-being are cultivated. Pediatrics is the heart and head for children's health: warm and welcoming, seeing strengths and possibility, and applying the best talents and tools. It is innovative, compassionate, and thoughtful. And this is why primary care pediatrics, especially, must play a leadership role in addressing the societal scourge of racism.

The potential amplifier effect is real. Pediatric primary care can drive health care funders to invest in undoing racism. There is a strong business case for doing so—from avoiding costly disparate outcomes to enhancing care efficiency, preventing staff turnover, and in the current environment, ensuring that children in every community get much-needed COVID-19 and other vaccines.

Transforming child health care needs to go beyond medical care and focus on advancing the long-term individual and societal benefits of improved health and well-being. Primary care pediatricians can do more to push health care systems to adopt antiracist practices and policies that are based on dignity and that advance health equity; to create and foster equitable partnerships among patients, families, and providers that build trust and incorporate patient and family perspectives into day-to-day decision mak-

ing; and to focus on identifying family strengths and community solutions that can help children and their families thrive.

For example, policy and practice transformation solutions include providing cultural humility, implicit bias, and race equity training to health care providers to reduce unnecessary child welfare involvement and other harmful outcomes; developing staff recruiting, hiring, and retention strategies to better reflect patient populations served at all levels of health institutions; examining hospital security policies and proce-

dures with an antiracist lens; and conducting strengths-based training on the usage of patient screenings for health-related social needs, which are not risk-free for families of color.

Pediatrics is at the ethical heart of health care. Amazing staff in clinics across the nation make meaningful differences in the lives of children. We are truly the ones we've been waiting for to show up for the kids and families we serve. When families are at their most vulnerable points, it is time to build on their strengths, identify their needs, and support them in every way we can.

Now it is time for us to lead the hard and worthy work of addressing the disease of racism. ■

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