



Treating the Pain

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RACIAL DISPARITIES IN the criminal justice system are all over the media. Yesterday 5 Dallas police officers were killed and 7 injured in a mass shooting during what was supposed to be a peaceful protest against police shootings of black men. Just weeks earlier, 2 black men, Alton Sterling of Baton Rouge and Philando Castile of St Paul, were killed by police. In the context of current events, the prospect of today's discussion encompassing the topic of racial disparities in healthcare makes me a little uneasy. In addition to the usual prepresentation heart palpitations, I have a gnawing sense of uncertainty. I feel as if I am about to take a test.

One of the directors of SUNY Upstate Medical University's 4-week medical school summer immersion preparatory course¹ invited me to teach today's class. All accepted students are offered the opportunity to apply for this course, as extra preparation for fall classes. Today's topic is social issues related to sickle cell disease and the physician's role in patient advocacy. The director had pointed to my background in advocacy for underserved children as an endorsement of my expertise. Although the topic of sickle cell disease offers rich material to teach patient advocacy, my specialty is child abuse pediatrics, not hematology. Outside of my comfort zone, I knew I could not just recycle the PowerPoint presentation I had used for many previous advocacy lectures. Instead, I spent several hours researching sickle cell, developing sickle cell-specific discussion points, and creating new PowerPoint slides to highlight key points regarding patient advocacy.

This morning, I arrive early and many students are already seated. Backpacks are placed under table rows; some students open laptops and tap on their keyboards. Others are eyeing their phones. Crossing in front of the room, I duck behind the podium to slip my USB stick into the computer, then click on my slideshow. Twenty-two medical students, a small portion of the incoming first-year class, are participating in the course and are

here for today's session. Stepping forward to face the room, I push my glasses up and squint past the projector light. A few students look up. Before me, I see a variety of ages, genders, races, and ethnicities.

The students had a preclass assignment to watch a video about sickle cell disease. In the video, an emeritus pediatric hematology colleague, Dr Richard Sills, explains sickle cell disease: the genetics, hemoglobinopathies in general, treatments, and the signs and symptoms of crisis. He describes sickle cell disease as a "story of plugs in the vascular system." He also tells another story about the excruciating pain patients suffer while in crisis and the problem of undertreatment of pain due to provider biases. He looks squarely into the camera and informs future audiences that research in support of sickle cell disease is woefully underfunded.

As the clock hands shift to 9 o'clock and the latest arrivals slide into their seats, I straighten my shoulders, take a deep breath, and introduce myself. "Who has watched the video?" I ask. To my amazement, all hands go up. I flip to the first slide, then ask, "Why is cystic fibrosis, a disease that affects 1:3000 white children, funded at nearly 4 times the amount as sickle cell disease, a disease that affects 1:400 African Americans?"

After a brief pause, a student's voice calls out. "Maybe it has to do with the numbers—maybe the raw numbers of people are actually higher for those with cystic fibrosis."

"No. Good thought, but no," I state to the group, unsure of who spoke up. "The number of people in the United States with sickle cell disease is close to 90,000, and for cystic fibrosis, close to 30,000. In fact, research published in 2013 reveals an 11.4-fold higher rate of funding per affected individual with cystic fibrosis compared to sickle cell disease."

I could continue to recite more facts but think this approach to a discussion on racial disparities and advocacy for patients might be too abstract. I begin again. "So, why do you think that physicians sometimes undertreat the pain experienced by patients with sickle cell crisis? When people say they are in pain, shouldn't you believe and treat them?"

A student raises her hand, "What about overtreating for pain? Are you worried about contributing to the opioid

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epidemic?" I am distracted by my need to respond. I know I have no slides about opioids.

"Ah, yes, 4 in 5 new heroin users started out misusing prescription pain relievers," I answer with a memorized factoid. I pause. Opioid overuse was not the topic for this discussion, and I do not want us to get off track. I want the students to focus on why pain is undertreated, not over-treated. The words of a physician whom I had shadowed as a student come to mind. *Pain is subjective, and it is our responsibility to treat the pain.*

"Do you think providers are thinking about opioid overuse when they undertreat pain from sickle cell crisis?" I ask.

A student in the back raises her hand, holding a purple pen like a pointer. I strain to see her face behind the other students. I see just a young, brown hand and a pen.

"It seems providers might have a bias and think a black person is drug seeking, or does not feel pain in the same way, even if the person is in pain from sickle cell crisis," she offers.

"Do we treat patients with backgrounds similar to ourselves in the same way as patients with dissimilar backgrounds?" I take a deep breath and hold it.

I lift my right arm, gripping the projector remote tightly against my palm. I tap my thumb to scroll the slides, trying to find one that might assist in this part of the discussion. Out of the corner of my eye, I see my own hand—my white, wrinkled hand. In an instant, I realize I am plainly different from most of my students in terms of age, view of the world, experiences, and, for many, race. I wonder about my own words, "backgrounds similar to ourselves"—words that suggest the students and I share similar backgrounds.

Panicked thoughts rush through my mind. What do I really know about advocacy in the context of racial disparities in health care? What if a hidden bias, unbeknownst to myself, manifests, right here? What if I inadvertently use a trigger or push-button word? Everyone has biases; I too must have some. Although hematology is not my area of expertise, I long to stand safely behind the podium and to confine my remarks to a lecture about the science of sickle cell disease.

My hand is still suspended in the air and the students are watching. They are pin-drop quiet. My question, intended as a way to direct the students to a discussion about using empathy to support advocacy for patients, was also dangling in the moment. Without personal experiences related to a disease or pain, doctors might not truly empathize with someone else's pain. A doctor whose background differs from a patient might have to work harder to bridge the distance and partner with a patient. This is the conversation I anticipated. In the stillness, I wonder if I had instead touched a nerve.

One young man, wearing a faded gray T-shirt and sitting in the front row, breaks the silence. He introduces himself as Jeremy and asks if he can speak freely.

"Of course," I say, hoping that I do not sound too obviously relieved to be handing over being the center of attention.

"If I say anything to offend anyone," he begins, "I just want to say right now that I am sorry and to please come talk to me afterward." The students lean toward him and I wish, at that moment, that I had thought to use such a disclaimer. Later, I would realize that Jeremy, with these words, had changed the conversation in a way that would create a safe space for discussion.

"I am an African American and have been studying and reading about health care disparities for a long time." Jeremy turns and faces his classmates. "It would help if more people of color were in positions where we could advocate for the needs of black patients and for the needed research for diseases that might be more common in African Americans—diseases like sickle cell disease. Why aren't there more black doctors, particularly black male doctors?"

Many students nod their heads in silent agreement, realizing before I do that this was a rhetorical question. Another young man, white with reddish hair and a short beard, pulls out his phone and searches Google. He references a recent report by the American Association of Medical Colleges and the disappointing numbers showing stagnation and a reduction in the numbers over the past 35 years in black male applicants and matriculants to medical schools.²

Looking around the room and noticing a number of black men, I inadvertently interrupt the student. "I thought that the numbers of black male medical students were on the rise," I blurt out. My face flushes. It feels as if the students are all staring at me in disbelief—staring at the white woman pediatrician who is supposed to be teaching them. Then I see small smiles on the faces of the students in the front row. They watch me and wait, just as a gentle teacher might do, as I slowly recover from my confusion. I know I am wrong. At least half of the students in the room appear to be of color. I made an assumption based on the presence of the black men in this classroom, clearly not representative of medical school classrooms everywhere.

Like patients with sickle cell disease, there are students, of all races, ethnicities, and genders, who face biases on a regular basis. My thoughts circle back to yesterday's mass shooting and the prejudice against black men in the criminal justice system. I do not want to believe that we, as health professionals and educators, treat people differently. But the facts of the story of sickle cell disease and of the shootings of black men say otherwise. My assumption about the student numbers reveals my own bias—an inaccurate belief that we are making great headway on goals for inclusion and diversity among medical students.

My heart is pounding again, like it had been when I entered the room. If this were an actual test, I think I might be performing poorly.

"It's a pipeline problem," an older black student, quietly states, expressing the concept as if there were a glitch in the plumbing. The simplicity of the word belies the many complicated factors that create or block the route to the field of medicine. Introducing himself as Anton, he explains that he is a nontraditional student. That is, he

followed a longer, more indirect and challenging path, facing many obstacles along his journey to medical school. I pull a chair from the side of the room and sit down facing the students.

The students offer suggestions for ways doctors could better connect to their patients, especially patients from different backgrounds. We talk about gender-specific biases facing women as well as the dilemma of patients who request to see doctors of a specific race, religion, or gender. They share their own stories of inspiring role models as well as disappointments and barriers to their successes. They recognize the need to sometimes challenge the culture of health care through advocacy for their patients, for research of underfunded conditions like sickle cell disease, and for reducing the differences in opportunities facing children as future health professionals.

As the hour comes to a close, I notice that I hardly used any of my slides. Slides would have organized but also limited the discussion about advocating for treatment of pain in children with sickle cell crisis. Instead, the students' conversation enabled a deeper understanding, addressing undertreated pain by exploring how this problem is a piece of the larger societal structure of racial disparities. My presentation would have left out the students' stories and experiences, sources of their own pain. A slideshow would have kept me behind the podium and

prevented me from taking on the challenge that I feared: the test of allowing myself to be vulnerable.

As I log out of the computer, the course director pops her head into the room and greets me. "How'd it go?" she asks. "Good," I say. "We all learned to treat the pain."

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