Diversity, Equity, Inclusion, and Justice

When We Fail

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We each have a patient's story that burns a hole into our memories and compels us to revisit the story again and again. For me that story is about Sean, a 38-year-old former Division I college football player who I met while he was lying in bed, dying of heart failure.

As the rheumatology fellow on call, I was asked to see Sean to evaluate for an underlying autoimmune disease that could be linked to his cardiomyopathy. Five years earlier, when he noted unusual salt-and-pepper type changes of the skin on his chest, back, and forehead, he was told this was vitiligo. That presumed diagnosis entered into his medical record and, ever since then, was passed on as established fact. What it really had become was chart lore—a misinterpretation of reality that, through the copy-forward function of the electronic medical record, had been solidified into "the truth." This explains why, when admitted earlier in the year with severe shortness of breath, the echocardiogram showing an ejection fraction of 10% was not evaluated in the context of his unusual skin changes.

A massive workup ensued, but when nothing obvious turned up, it was assumed this was a viral cardiomyopathy with no treatment available to improve his situation. In the ensuing months, Sean repeatedly found himself in the hospital with progressive worsening of his condition and no new answers. That is until one resident, who had recently completed his rheumatology rotation, looked at Sean's skin and wondered about the possibility of poikiloderma, something he had seen in patients with scleroderma.

This was the point at which my attending and I were called to weigh in. I knocked on the door of Sean's hospital room and heard the words "come in" reverberate in a deep baritone. Sean was a tall, muscular man, with the cut-from-marble physique of a former elite athlete. Yet where previously only rope-like veins would have been found on his arms, he now was ensconced in a tangle of lines and wires. I asked if I may take a look at the skin of his back, where rows of long dreadlocks cascaded over his broad shoulders like a waterfall. He consented and, indeed, his skin changes on the torso and extremities were those of classic scleroderma.

As I spoke with Sean and listened to his story, the pieces of his medical puzzle fell into place with the heartbreaking clarity that only hindsight can provide. The appearance of his skin changes, the onset of new Raynaud phenomenon, the development of heartburn that had not been there before—each part of his narrative ticked another box for the rheumatologic disease that we feared.

Only one thought flashed through my mind when leaving Sean's room: we, as a medical community, had failed him. Patients like Sean rely on us to think broadly, to continually ask *why*, to challenge our assumptions, and to revisit their stories many times over, most of all when they are declining. We had, to date, not seen the forest for the trees, and Sean had suffered the consequences. Perhaps, I hoped, the astute resident's novel observation had not come too late to make a difference.

A series of tests confirmed that scleroderma was most likely to blame for Sean's heart failure, and we quickly initiated pulse dose steroids and immunosuppressive therapy, but each subsequent day revealed that we were not making any progress—the genie was out of the bottle. Try as we may, there was no undoing the damage that had already occurred, and discussions soon turned to consideration for a heart transplant. Although finding a suitable organ donor is challenging in any situation, we shared with Sean several reasons for guarded optimism given that he was young, previously healthy, and that his disease was affecting only one organ.

As we got deeper into discussions with the transplant evaluation board, however, our hope began to diminish. There seemed to be reservations about transplanting an organ into a patient with scleroderma. I conceptually understood the hesitation, centered around the fear that the transplanted heart would fall victim to the same inflammation and fibrosis as its predecessor. There was thus a pervasive gestalt about the low likelihood of transplant success for Sean as compared to another patient not afflicted with his rare disease. In addition, the fact that Sean was Black statistically meant that his chance of transplant was lower; even though more

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minority patients are listed for cardiac transplantation than in years past, racial disparities persist.

While we as a group of physicians had failed Sean in the first place regarding his missed diagnosis, it now seemed like we as a society were failing him on a much larger scale. I had the strange feeling that the implications of Sean's skin alone—its sclerodermatous texture and its black color—had put him at a significant disadvantage with respect to a potentially life-saving procedure. Systemic issues that seemed far out of our reach to correct, at least in time to make a difference for Sean, were now the difference between life and death.

As I returned to his room day after day to lead bedside rounds with our consult team, Sean sunk into a deeper and deeper depression. Our march of white coats into his darkened room, in which he kept the shades drawn, felt like a funeral procession. Our large team, huddled around his hospital bed, seemed to further intensify the atmosphere of dread and foreboding that he surely felt. I found that I could not escape delivering each day's update in a monotone drawl that mirrored Sean's affect and only seemed to add to his sense of despair.

One day our team's new attending—a loquacious and somewhat quirky clinician—listened patiently to my drab report and then turned to Sean and said one word: "pretzels." Sean, for the first time since I had met him, curled his lips into a bemused smirk and asked, "What?" Our attending, noting that Sean's alma mater was in Philadelphia, proceeded to discuss with him at length the ways in which the Philadelphia soft pretzel is superior to all others around the country. It was a pleasantly unusual conversation, and honestly it seemed to hit Sean just right in that moment as he could finally think about something other than his medical ordeal.

I realized then how I myself had failed Sean. I had failed him through my inability to helpfully engage with him and support him in his time of need. I had been busy musing about the ways in which the medical community and society at large had let him down, but right in front of me was the opportunity to provide Sean with an outlet to express himself, to connect with him and to provide him with some semblance of comfort. While I could not change the medical facts of his situation, I could talk with him about the things that still gave his life meaning or just made him laugh or smile. I could have made him feel more human.

Soon, a new fellow took my place, and it was not until several months later that I heard from a colleague that Sean had been admitted to another hospital and died while still waiting for a heart transplant. I had failed—we had failed—and there was no getting around this fact.

I am haunted by Sean's story, and I think of him often. Why do we, as doctors, revisit these stories in our minds, seek to share them with colleagues and trainees, and write about them for our peers? Perhaps it is to remind us of the humanity of the patients whom we have cared for, the real-life individuals who have suffered such seemingly surreal tragedies. Perhaps it is so that the students and residents who we teach will learn from our mistakes and use these lessons to help their own patients. And perhaps, for ourselves, it is so that we can try to make sense of it all, to ask what we could have and should have done differently, and to feel that our patients have not died in vain. When we fail, reflection does not change the outcome, but maybe, little by little, a modicum of introspection moves us toward being the doctors that our patients deserve and that we aspire to be.

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