

What Matters to Me: An Equity Lens on Patient Experience

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I recently received a diagnosis of acquired von Willebrand disease, a bleeding disorder so rare that my hematologist told me she has seen only 1 other patient in her career with this diagnosis. Or, as my doctor friends tell me, a disease they don't teach about in medical school but that shows up on the exam. My second recent diagnosis is multiple myeloma, or cancer of the plasma cells in the bone marrow.

I am also the director of the Disparities Solutions Center, director of equity in care implementation, and the administrative director of research for the Department of Medicine, all at Massachusetts General Hospital (MGH). I came to the United States as an undocumented immigrant when I was 13. English was not my first language. My mother was a single teen mother, and I've only seen my father twice in my lifetime. My childhood was filled with all the trauma that we hear about from many of our patients: domestic violence, drug addiction, mental health issues, foster care, and more. This is my North Star and what drives me, and I've spent the past 18 years at MGH working on racial and ethnic disparities and most of my life on social justice in one form or another.

My journey to these 2 diagnoses has been long and complicated. The unique intersection of the multiple hats I wear at work, while also a patient beyond basic primary care, challenged me to view the work I do from a different perspective. I share my observations in the hope that clinicians, researchers, hospital leadership, administrators, and staff understand why the work we do is important, but that achieving equity is a journey that will take time and resources.

The Impact of COVID-19 on Access and Capacity

We are all still reeling from the impact of the COVID-19 pandemic. Hospitals face the challenges of rising inflation costs, workforce burnout, staffing shortages, budget, and capacity issues. In this new environment, on average, it will take a new patient 6 to 9 months to get an appointment. When I called hematology in October 2022 to make an appointment for a different issue, the first opening they had was at the end of March 2023. It would have been June, except someone canceled. Once it became clear that I needed to see a hematologist sooner, it was only because the primary care nurse

TAKEAWAY POINTS

Sometimes being a patient in our health care system is a good reminder of what is important to a patient and an opportunity to assess the gaps in care from a patient experience perspective. This commentary includes strategies for the following recommendations:

- ▶ Considerations around barriers to access to specialty care
- ▶ Executing on diversity and inclusion training
- ▶ Addressing the barriers to recruiting more diverse patients into research

practitioner took the initiative to reach out to the hematologist and ask for an e-consult that things moved a little faster. My non-health care friends are still shocked that as a hospital employee I couldn't expedite getting seen by a hematologist. From my lens, I wonder how a Spanish-speaking patient from Chelsea, a town in Massachusetts with a majority Latino and 47% immigrant population, who works a low-wage hourly job would fare in getting an appointment.

Action point: *It's important for us to consider the barriers patients face when accessing health care, in particular those beyond primary care, and reexamine our systems' process map for how patients access specialty care.*

Race Still Matters, or How I Empowered Myself

Knowing all the data about health care disparities and unconscious bias is a double-edged sword. Once you see it, you can't unsee it. In my role, I see all the patient safety reports tagged with bias/discrimination for the entire hospital. Despite all the resources at our disposal, our system still faces the same challenges as many other institutions in dismantling structural and interpersonal racism. Being a patient at a large academic medical institution such as MGH can be overwhelming and intimidating, even for me. I level the playing field by wearing my MGH badge to all my appointments as a signal that I am part of the workforce, but also as a way to anchor myself in the face of the disparities that I know exist.

Action point: *We need to proactively identify strategies that will facilitate trust with communities of color and other marginalized communities.*

The Patient Portal Is My Lifeline

The pandemic highlighted the patient portal as a new central player in communication with our patients. We've worked hard to increase the number of languages in which our patient portal is available and to address the other challenges that arise when you solve the first one (eg, enrolling patients in the portal with the use of bilingual digital access coordinators, communication via the portal between patients and providers in other languages). The irony is not lost on me that, as a patient, I rely heavily on the patient portal to feel in control of my disease by seeing the test results as they come in and communicating with providers regarding laboratory results, test results, or appointments. However, we still have a long way to go to ensure that patients with limited English proficiency and low digital literacy can use this tool in the way that I have been able to use it.

Action point: Consider from the start what patients we may be leaving out when we build systems to engage patients in their health care rather than retroactively trying to fix the system once it's been built.

Diversity and Inclusion Training Is Much More Complicated Than We Make It Out to Be

As part of a systemwide United Against Racism campaign, the enterprise rolled out several mandatory health stream trainings on unconscious bias and racism. Changing systems takes time and effort. As I move through various clinical spaces as a patient, I realize that practices are so busy and short-staffed that there really is no capacity to think about operationalizing what we learn in the trainings. Dismantling racism and bias would take commitment, time, and effort from individual unit/floor/department leadership to have these difficult conversations about how to operationalize these tools. As a patient witnessing the busy practices, I was having a hard time visualizing how they would make space for this in the clinical day given the capacity issues.

Action point: Diversity and inclusion efforts should include both large-scale training and a commitment to resources and staff time at the unit/floor/division level to operationalize the training.

How We Recruit Patients of Color Into Research Is Still a Problem

One side effect of having a rare disease is that you attract researchers. I was reminded of Henrietta Lacks when I received an email from a researcher asking me very casually if I would agree to add my blood and bone marrow from my upcoming bone marrow biopsy to his

biobank for future research. His complete disregard or acknowledgement of how I might be feeling about my new diagnosis, as well as the upcoming painful bone marrow biopsy (which on the pain scale I would rate a 12), was a surprise. When my response included a mention of mistrust of research in communities of color, he saw it as an opportunity to press his case because I would add to the diversity of his biobank. Although the research community acknowledges that diversity in research is a challenge, we seem loathe to acknowledge the history of how this mistrust evolved in this country, as well as how we might personally contribute to it by not being more thoughtful in how we recruit patients.

Action point: Enrollment protocols for research should include addressing the fears and concerns of marginalized communities that have traditionally not been recruited successfully into clinical trials.

Language Barriers and Other Social Determinants Matter

Throughout my health care journey so far, it is painful for me to think how I would have fared if I were not employed at MGH, did not speak English, were undocumented or poor, had a substance use disorder, or had no stable housing. Our health care system is so complex and facing so many challenges that it has become a second job for me to manage the diagnoses and medical appointments. It is then no surprise that most of our diverse patients are seen in the emergency department, primary care, pediatrics, and obstetrics, but not in specialty care. I am hopeful that we can change this in the future by better understanding the barriers that patients face in accessing these services.

Action point: We need to move beyond collecting social determinants of health data to using the data to implement actionable strategies to ensure that these patients get the care they need and the outcomes that we are looking for. ■

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