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“I See What You Do”: A patient’s view of equity

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Abstract

As a Black woman and a patient, the author describes what it is like navigating healthcare as a person of color in the U.S. Fully aware of the disparities that exist in healthcare, she shares her personal roadmap for assessing equity as a patient searching for a new provider. In the absence of standardized ways to assess equitable outcomes, she has created her own metrics and uses them to draw her own conclusions. From her experience as a Patient and Family Advisor, the author provides clues for assessing diversity within healthcare organizations. Imagining a new existence in healthcare, the author calls for organizations to look inside at their practices and policies to do this new thing called equity. A transformed healthcare system can become a reality but only in those organizations where “what you do” matches “what you say.”

Keywords

Disparities, diversity, equity, implicit bias, equitable care, cultural competence, harm, safety

One is in the impossible position of being unable to believe a word one’s countrymen say. “I can’t believe what you say,” the song goes, “because I see what you do”—and one is also under the necessity of escaping the jungle of one’s situation into any other jungle whatever.¹
~James Baldwin

This quote from writer, James Baldwin, summarizes much of my personal experience in healthcare. The mission statements and equity statements on organizational websites are “what you say,” while the data on health disparities is “what you do.” The jungle of navigating healthcare as a person of color in the US is one I cannot escape.

As a patient and a Black woman, I am more than aware of the disparities that exist in healthcare²; my safety and care depend on finding the right providers and organizations to care for me in a way that protects me from these disparities. Many studies have shown that a majority of Americans have a negative bias against Black Americans, even in the healthcare professions.^{3,4} Implicit bias can have a direct effect on patient safety, outcomes and engagement,⁵ which requires that I remain on the lookout for signs that I might not receive equitable care. A receptionist who is dismissive or unfriendly can lead me to believe that people who look like me might not receive good care at that location. A provider who is judgmental or terse might do the same. Black patients might even avoid the healthcare setting entirely, with the very rational fear that they won’t receive good care.

Assessing equity as a patient

When I am searching for a new healthcare provider, I have to navigate the equity jungle by considering several factors to help me determine whether I can feel safe in my care.

What is the provider’s experience with diverse patients?

I look at the provider’s online bio to find out where they went to school, where they completed their residency, and where they have worked. I lean toward providers who have diverse identities themselves, or those who completed their education in places that were likely to have diverse populations, with an intent to avoid interaction with providers who might have not developed cultural competency through their work experience. This self-developed metric is certainly not foolproof. I might be incorrect in my assumption that a provider has experience with diversity based on where they were educated, and I might also pass over providers who are culturally competent in ways that don’t show up in their work history.

Where is the provider located?

The neighborhoods in which a provider is located offer me a clue about whom they intend to attract as patients. A provider who seems to work only in distant, homogenous suburbs might not have frequent experience with people of color, making it more likely for me to have a negative experience colored by racism. Being accessible to diverse populations makes it more likely that a provider has experiences that expand cultural competence, thereby reducing my likelihood of a negative experience. This metric also has flaws, since many providers don’t decide

independently on the location of their practices, and there is no guarantee that a provider who practices in a diverse community is more culturally competent.

How does the provider interact with me?

In my interactions with healthcare providers, I am constantly evaluating social signals. Does the provider look at me? Does the provider ask probing questions or do they seem to make assumptions about me? Does the provider talk in a condescending or directive way rather than in a collaborative way? Does the provider demonstrate a lack of cultural competence when it comes to my culture? Even in the vulnerable space of receiving care, naked under a paper gown, my safety depends on assessing and analyzing the provider and our interaction. This process is exhausting, and it happens with every single healthcare encounter. Every single one. Most disappointing is when I have developed trust with a provider and the provider makes a major blunder in cultural competency. I might have no way of reporting this encounter in a way that feels safe. As a patient, I then have two choices: I can continue to work with a provider I don’t really trust anymore, or I can start the process again with a new provider and hope for a better result.⁵

All of these actions and processes give me a sense that I am self-advocating to avoid medical harm, but these individualized, piecemeal approaches to safety are neither sufficient nor reliable. It feels like tiptoeing through a minefield. Despite my efforts, I always sense my vulnerability to harm in the healthcare setting, and with good reason. The data on disparities, combined with historical and ongoing harm to my cultural community, along with my personal experiences of bias and harm, point to the necessity of standardized ways to assess equitable outcomes.

In the absence of standard measures that could help me better understand a provider’s or organization’s success with equitable care and outcomes, I have had to create my own metrics and use them to draw my own conclusions. Not having a standardized way to measure and understand equity creates additional workload and stress for patients from marginalized communities. It also disrupts the continuity of care each time a patient has to change providers or organizations due to a negative experience, which can have its own health implications.

Assessing equity as a Patient Family Advisor (PFA)

My self-developed system for assessing equity extends beyond my experience as a patient. As a patient and family advisor (PFA) I look for signs of equity, or its absence, in the organizations I work with. I notice the visible diversity of the staff in an organization. When staff diversity only seems apparent among housekeeping and service staff, it

signals to me that the internal processes of the organization might not be equitable.

When I share my patient story with a hospital’s management team, I notice the lack of visible diversity in the room. It’s an indicator, to me, of a history of hiring practices that did not prioritize diversity and equity. When I speak to a new nurse orientation group, I see the absence of visible diversity there, too, shining a light on how that history of inequitable hiring might be continuing into the present day. When I am invited to participate on committees and initiatives, I evaluate whether I truly have a voice, or whether my presence is simply a way for the organization to check the diversity box.

After George Floyd’s death in May 2020, as the social climate in the US shifted and COVID health inequities came to light,⁶ I noticed an increase in requests from organizations that were newly focused on equity. Equity and diversity committees seemed to pop up everywhere. Some organizations looking to increase diversity on their boards and advisory councils had seemingly never seen their lack of diversity as a problem before. At first, I was conflicted about getting involved with such organizations. Obviously diverse voices are needed, especially in these spaces; however, being invited to sit at tables where I might not have been welcomed before prompted my scrutiny as well.

When I engage with an organization as a PFA, I try to determine whether black, indigenous, and other people of color (BIPOC) were previously unwelcome and what structures might have kept, or driven, them away. I consider whether an organization is really safe space to use my voice, or whether I am being tokenized so the organization can add my identity to an annual report summary of their increased diversity. Is their effort toward equity just a trend, or has it become part of the structure of the organization? Is the organization satisfied with simply reducing disparities, or is there a real commitment to eliminating them? When I feel uncertain about the answers to these questions, I often decline to participate with the organization. I do this to avoid exploitation and protect my efforts as a PFA, and not carry the equity water for organizations that are only committed on a cosmetic level.

It’s easy for an organization to assume the care they are providing is equitable in the absence of measurement, but this assumption defies what we all know about disparities: they are pervasive, persistent and consistent. While healthcare organizations are working on improving cultural competence and equitable care, patients and PFAs like me are still navigating providers and systems, wherever they are in the process. This means while professionals are developing their skills and organizations are developing their practices and policies, we as patients are still left to

work around their deficits. This workload in itself is inequitable and will undoubtedly continue to produce inequitable results well into the future, until a true commitment toward equity comes to fruition.

Imagining a New Existence

Never before have equitable health outcomes for Black Americans been achieved. In order to transform healthcare and gain the trust of marginalized groups, healthcare as a whole has to do something that has never been done before. This requires a realistic look at where we are now, followed by intentional action. Until “what you do” matches “what you say”, the healthcare system can expect the skepticism of patients who have no reasonable expectation of equitable outcomes. Healthcare organizations have to be willing to look inside at their practices and policies, and look externally at the larger systems, to do this new thing called equity. Equity cannot be a trend; patients’ lives depend on actualizing health equity for the first time in our history.

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