Why Are Health Disparities Everyone's Problem?

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CHAPTER 1

The Personhood of Patients

LEARNING BY EXAMPLE

MY FATHER WAS MY FIRST ROLE MODEL for how a patient should be treated. Many of my friends and their parents told me how much they admired him and how he had provided just the right medication, performed a life-saving surgical procedure on them, or simply listened to them and comforted them during a difficult time. He took the time to know their families and hear their stories. While in this era of ever-more patients, ever-shorter office visits, and ever-greater documentation demands on health care workers it’s harder to reach that level of knowledge, he lived the words of Sir William Osler (the famous clinician and diagnostician—and the first physician-in-chief of the Johns Hopkins Hospital): “It is much more important to know what sort of patient has a disease than what sort of disease a patient has.”

Other than my father, perhaps the person who taught me the most about patient-physician relationships was Elijah Saunders, whom I met when I was a medical resident at the University of Maryland Hospital. Dr. Saunders was extraordinarily learned and
had a wealth of clinical experience, yet he was always humble and respectful in his interactions with patients and colleagues alike. He spent many hours late into the evenings and on weekends pursuing the appropriate tests and consultations from specialists to ensure that his patients were getting the best clinical management. He had a life-long commitment to learning, often citing the most recent journal articles on topics relevant to a patient’s care and encouraging his residents to seek the most current evidence to guide decisions.

Over the time that we worked together, I saw Dr. Saunders use many relationship-building approaches. He listened to patients and their family members with respect, solicited their concerns and opinions about diagnoses and treatments, answered their questions, empathized with them, and demonstrated his commitment to them and their well-being. Dr. Saunders taught me the importance of putting the patient first. And because he knew so much about his patients, their family members, and the communities in which they lived, he also taught me the importance of understanding patients’ unique needs and circumstances.

UNDERSTANDING WHAT PEOPLE NEED

A few months after I completed my fellowship training and joined the faculty at Johns Hopkins on the clinical investigator track, I was excited to see that the health care field was
beginning to place a new focus on addressing patients’ needs and concerns through a movement toward “patient-centered care.” The phrase had been introduced by psychoanalyst Michael Balint in 1964 to express the belief that each patient “has to be understood as a unique human-being.” Over time, it had evolved from a guide for individual clinicians interacting with individual patients to a comprehensive way of delivering health services for any organization; it encompassed domains such as understanding the whole person from biopsychosocial perspectives, seeking common ground or sharing power and responsibility, and the patient-doctor relationship (a therapeutic alliance with agreement on goals of treatment and tasks and a personal bond based on reciprocal positive regard). I received my first grant from the Picker-Commonwealth Scholars Program, developed to contribute new talent in research on patient-centered care, which launched my research career. I would still see patients and teach medical and public health students, but now it was clear that most of my time would be spent doing clinical research.

To help the socially disadvantaged groups surrounding me, I needed to learn more about what they wanted, needed, and received. How do attitudes and beliefs affect relationships, the quality of care, and health outcomes? I needed to examine the ways in which patients from African-American and other vulnerable communities viewed health and used the health care system.
To look at these questions, I began to study patients’ attitudes and preferences regarding mental health. I focused on mental health because I noticed that it was one of those areas in which African American patients and their doctors seemed to have challenges getting on the same page. Patients would complain about physical symptoms such as fatigue, headaches, or pain, and doctors would end up ordering a lot of tests before realizing that the patient might have depression or anxiety. In fact, when asked directly about depression or anxiety, a lot of my African American patients would tell me, “I’m too blessed to be stressed.”

My first study involved three focus group discussions related to patient experiences and concerns regarding treatment for depression. The first focus group comprised seven health professionals—four physicians and three social workers—involved in the care of patients with depression; the second comprised eight White patients with a recent episode of depression; and the third comprised eight Black patients with a recent episode of depression. The study divided Black and White patients into groups to better understand how patient attitudes, preferences, and help-seeking behaviors might vary across racial groups. Questions asked during these focus groups addressed experience with depression, seeking help from health professionals or others for one’s problems, treatment preferences, and perceived barriers to mental health care. Discussions were audiotaped, transcribed, reviewed, and then grouped into categories with specific themes.
Black patients cited spirituality as a way of coping with their depression more often than White patients. Black patients also discussed using their church and church members for support more frequently than White patients. In addition, the Black participants perceived stigma as a particularly important barrier to getting treatment. Many of them felt that the idea of seeking professional help for mental health problems was not culturally acceptable to them or to their family members or peers. Admitting to mental health struggles, they felt, signaled a weakness of character or inability to cope with problems that were just a part of living as a Black person in America. In the Black patient focus group, participants also raised issues of cultural mistrust and concerns about being used as guinea pigs for medical experimentation. Furthermore, Black patients cited the dearth of mental health professionals from their own gender, race, and religious background as concerns. Patients of both races saw health professionals’ technical skills and interpersonal skills as important in their decisions of whether to disclose their innermost feelings and to accept any recommended treatments.

I then did studies with larger numbers of patients from different parts of the country. I found that, compared with Whites, African Americans, Asians/Pacific Islanders, and Latinos were more likely to prefer counseling to medications, less likely to believe that medications were effective and that depression was biologically based, and more likely to believe that antidepressants were addictive and that counseling and prayer were effective in
treating depression. One of the most intriguing findings was that patients, regardless of race or ethnicity, told us that their relationships with doctors and other health professionals were the most important reasons they ended up accepting treatments and adhering to recommended tests and medications. Along with the specific attributes of medications and counseling, the most important aspects of care were being able to trust the health professional to act in one’s best interests, having information and knowing what to expect from treatment, and health professionals’ interpersonal skills (knows their patients, listens, understands patients’ problems, approaches patients as individuals, makes patients feel comfortable, supports and encourages patients), and physicians’ recognition and validation of patients’ depression (recognizes depression, believes patients’ symptoms are real). Slightly lower on the list of concerns were the affordability of mental health treatment and having health insurance to cover it. These early studies gave me a better understanding of how cultural and social factors might influence willingness to both seek and use health care and other health behaviors of patients from communities of color. They also piqued my interest in better understanding how patient-physician communication and other aspects of the patient-physician relationship, such as trust, might impact health outcomes, and whether any differences in these relationships could explain the racial and ethnic disparities in health care that were starting to be revealed through the research.
THE PATH FROM MISTRUST TO TRUST

Good relationships are essential to building trust, and trust is vital to successful health outcomes. Scholars define trustworthiness as the ability to be relied upon by others based on benevolence, integrity, or the competence of persons and institutions. Patients need to trust their physicians enough to share their personal histories and to follow their treatment plans. Physicians need to trust their patients enough to believe what they say and arrive at the proper diagnosis and path for recovery without making hasty or moral judgments—without blaming the patient before they fully uncover the causes of their issues, or making erroneous assumptions. Unfortunately, many members of disadvantaged groups distrust the health care system, driven by historical oppression, structural racism, disparities in care, and personal experiences of discrimination.

Trust is based on shared understanding. Disadvantaged communities witness and experience the far-reaching and devastating effects of disproportionately poor health outcomes while struggling to understand how to use the health care system to their maximum advantage. On the other hand, physicians diagnose and treat these poor health outcomes but don’t necessarily understand how to tailor their treatments to reflect the underlying drivers of health disparities. As tax-paying, contributing members of society, many disadvantaged individuals believe that the health care system should address the many causes of
their poor health outcomes. In contrast, though many health system leaders recognize the complex causes of health disparities, they view their role in eliminating these disparities as confined to the equal—but not necessarily equitable—provision of health care across populations they serve.

Trust in the health care system is also low among minority groups because historically underserved populations continue to have limited access to primary care. Instead, they often have to rely on more expensive and fragmented health care services, such as emergency departments. In one of the early studies my colleagues and I undertook to examine this issue, we administered a telephone survey to 118 adults in Maryland and asked respondents to rate their level of trust in physicians, health insurance plans, and hospitals. We found that Blacks were 37 percent less likely than Whites to trust their physicians. Although the racial difference in trust of hospitals was not statistically significant, Blacks were more likely than Whites to be concerned about personal privacy and the potential for harmful experimentation in hospitals. We concluded that these differences in trust might reflect divergent life experiences of Blacks and Whites in American society, and we called for improved understanding of these factors in efforts to enhance access to care and quality of care among African Americans.

Mistrust of the medical system has many sources. The Tuskegee study of untreated syphilis is infamous; during this study, the US Public Health Service withheld treatment from 600
Black sharecroppers and their families in Alabama for nearly three decades after penicillin became the accepted treatment for syphilis. In Baltimore, many cite the experience of Henrietta Lacks, the African American woman who was the unwitting source of the HeLa cancer cell line—a defined population of cells that can be maintained in culture for an extended period for research purposes. In 1951, Lacks had a tumor biopsied during treatment for cervical cancer at Johns Hopkins Hospital. As was standard practice at the time, her physicians didn’t seek her consent before using her tissue for research. Extracted cells from her tissue were cultured to create the HeLa cell line—the first “immortalized” human cell line and one of the most important in medical research; it’s still in use today. At the time, there were no federal regulations or restrictions on the use of patients’ cells in research; however, the cells have been used in developing the polio vaccine, gene mapping, in vitro fertilization, cancer therapies, HIV research, and more, by scientists all over the world. Mrs. Lacks’s story has been known in the research community for a long time, but it became more widely known after the publication of a best-selling book titled *The Immortal Life of Henrietta Lacks* in 2010. Despite the many research breakthroughs that Mrs. Lacks unknowingly enabled, it wasn’t until many years after her death that her family learned about her contributions to medical progress. In 2013, the National Institutes of Health announced that it had reached an understanding with the family of the late Henrietta Lacks to allow biomedical
researchers controlled access to the whole genome data of cells derived from her tumor. The policy gives the Lacks family the ability to have a role in work being done with the HeLa genome sequences and track any resulting discoveries. All researchers who use or generate full genomic data from HeLa cells are now asked to include in their publications an acknowledgement and expression of gratitude to the Lacks family for her contributions.

Within underserved communities, a lack of transparency around addressing the root causes of health disparities within the American health care system raises questions about the extent to which the system is truly committed to advancing the health of these populations. The resulting tension intensifies the historical lack of trust between health systems and underserved communities. People from at-risk groups and historically disadvantaged communities can feel that they’re not being respected and are being stereotyped by clinicians and researchers, or worse, taken advantage of. Building and sustaining trust between patients and their doctors, and health care systems and their communities, will be essential to improve the health of disadvantaged groups and to eliminate health disparities.

**DELVING BELOW THE SURFACE**

The studies that I undertook in the first decade of my career pointed to the importance of the patient-physician relationship in health disparities. Much was already known about the
importance of these relationships in producing better patient outcomes, including more engagement in care, improved self-rated health, and greater adherence to treatment. But much less was known about relationships across social differences such as race, ethnicity, language, and culture.

Researchers who study the impact of culture on health often use the metaphor of an iceberg. The point they make is that the portion of a person, an organization, or a group that is visible above water is, in reality, only a small piece of a much larger whole—the tip of the iceberg. Many other facets of that person, organization, or group, while less visible, are just as essential to our understanding of how they think and behave. Visible characteristics include age, gender, social class, ethnicity, race, language, and physical fitness, among others. Invisible characteristics include beliefs, behaviors, attitudes, values, preferences, and role orientations that influence relationships. The iceberg also symbolizes risk. Improving relationships, especially across cultural and social differences, is a risky business. Issues are deep, complex, longstanding, and emotionally charged.

At this stage in my career, I knew that if I wanted to truly understand how relationships might be contributing to health disparities, I needed to delve below the surface.13 I needed to better understand the various dimensions of the patient-physician relationship and the potential impact of several characteristics of each participant—visible and invisible—on the relationship and its outcomes.