Chapter 3: A Root Cause Analysis: Why Do Racial and Ethnic Disparities in Care Exist?

> ***"For hospital executives that don't think they have a problem with disparities, if you haven't looked at your data then you don't have any basis for saying that, unless you're in some kind of nirvana."***
> – William Fulkerson, MD, Chief Executive Office, Duke University Hospital.

The existence of racial and ethnic disparities in health care does not imply that a hospital or its providers are intentionally discriminating against certain groups of patients. Disparities are ubiquitous and multifactorial. Just as hospitals now work towards quality improvement and patient safety by emphasizing a culture of systems improvement rather than blaming individuals, we must begin to create the same environment for the issue of disparities. With this in mind, the following section describes what is known about the underlying causes of racial/ethnic disparities and builds a solid foundation for action.

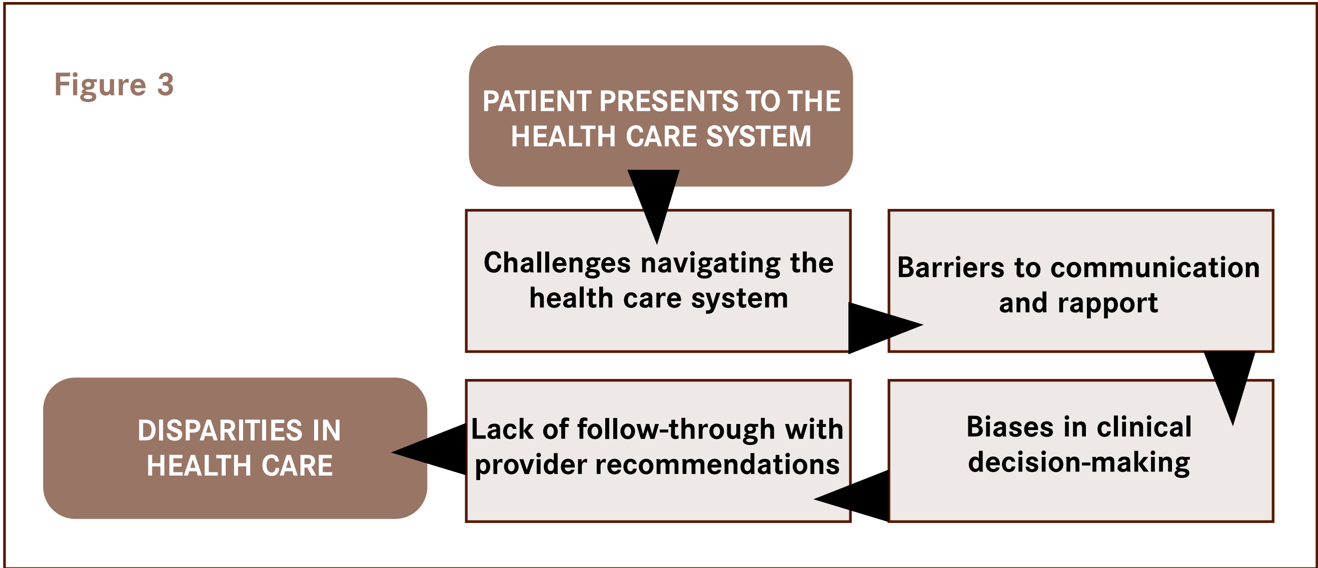
The IOM's *Unequal Treatment* report provides an exhaustive overview of hundreds of studies documenting racial/ethnic disparities in health care across a wide range of services and disciplines, and health care organizations. Most of these studies focused on disparities between black/African-American and/or Hispanic/Latino patients compared to white patients, but new findings continue to emerge revealing disparities in different racial/ethnic populations, patients with limited-English proficiency and other vulnerable groups. Racial/ethnic disparities are due not only to differences in care provided within hospitals, but also as a result of where and from whom minorities receive their care (i.e. specific providers, geographic regions, or hospitals that are lower-performing on certain aspects of quality).[14, 100-102] That being said, it is incumbent on all hospitals to monitor quality by race/ethnicity, and address disparities and equity issues following the recommendations of both *Crossing the Quality Chasm* and *Unequal Treatment.*

The root causes of disparities in care are complex and multifactorial. *Unequal Treatment* groups them into three basic areas (see figure 2):

Figure 2. IOM Unequal Treatment Classification of Root Causes of Racial/Ethnic Disparities

Health System-Level Factors	Care-Process Variables	Patient-Level Variables
These include issues related to the complexity of the health care system and how it may be poorly adapted to and disproportionately difficult to navigate for minority patients or those with limited-English proficiency.	These include issues related to health care providers, including stereotyping, the impact of race/ethnicity on clinical decision-making, and clinical uncertainty due to poor communication.	These include patient's mistrust, poor adherence to treatment, and delays in seeking care.

In order to illustrate the many factors that can contribute to racial and ethnic disparities in health care, we have developed a flow diagram (see figure 3) that follows a patient's experience with the health care system. This model is modified from work by Einbinder and Schulman on cardiac care, and cross-links with the three major areas highlighted above in *Unequal Treatment.*[103] Detailed evidence supports how each step of the model can lead to disparities in care. We have adapted and broadened this model to apply to disparities in all types of care, and to emphasize the role that health care leaders can play in eliminating disparities at their own organizations.



Challenges Navigating the Health Care System

Once a patient has recognized the need for medical care and has some form of insurance coverage (both potential sources of disparities outside the health care system), he or she must navigate through a very complex health care system to obtain needed care. Multiple barriers come into play in this first step in our model that may prevent immigrants, patients with limited-English proficiency or low health literacy, and minorities from getting timely, effective care, thus leading to disparities in care.

Patients may:

- Not trust the hospital or its providers.[104]
- Be afraid to seek care due to language barriers and embarrassment or cultural differences.[105-107]
- Not be familiar with the use of primary care services, relying instead on urgent care or emergency services.[104]
- May not understand how to prepare for a procedure, how to access specialty care, or where to go to follow up on an abnormal test result.[108]
- Have as their only accessible source of care hospitals with limited resources that serve a higher proportion of minority patients. These hospitals may have less availability of provider visits, less access to specific health care services, and lower quality of care.[14, 109]

Massachusetts General Hospital identified disparities between Hispanic/Latino patient and white non-Hispanics in colorectal cancer screening rates and diabetes control. Culturally competent coaching and navigator programs were implemented to help patients manage the complexities of their illness and of the health care system, and these have led to decreased disparities in these areas.

For these primarily health system-level factors, hospitals can play a major role in addressing disparities by improving their systems to provide more accessible, high quality care to diverse patient groups. Approaches include making the environment more culturally and linguistically responsive (translated signage, maps and other materials, diverse workforce, etc.), emphasizing “medical homes,” educating patients on how to manage the system, and use of patient navigators to help patients with particularly complex conditions or procedures (see Chapter 5 “What Can You Do?”).

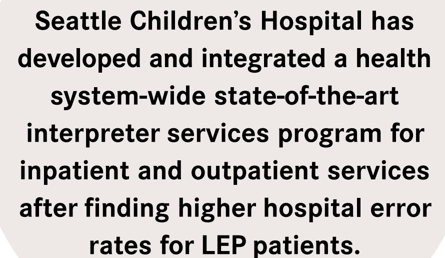
Barriers to Communication and Rapport

Even once a patient is able to navigate through the health care system to reach the appropriate services, he or she may be more challenged to effectively communicate and build rapport with providers. Good communication and trust between patient and providers are essential to effective delivery of health care services. Several studies show that providers communicate less effectively with minority patients and those with language barriers, and are less likely to

build trusting relationships.[110, 111] For example, a national survey by the Commonwealth Fund showed that Hispanics were twice as likely as whites to report one or more communication problems such as not understanding their doctor, feeling their doctor did not listen to them, or feeling afraid to ask questions (a third of Hispanics and a quarter of African-Americans and Asian-Americans experience these communication problems).[104]

Poor communication and rapport due to language barriers or cultural differences can lead to:

- Dissatisfied, mistrustful patients when providers do not understand their unique perspectives and values.[112-114]
- Patients misunderstanding their illness and treatment plan.[115]
- Clinical uncertainty and misdiagnosis, or over-reliance on objective testing such as CT scans in the emergency department.[2, 6]



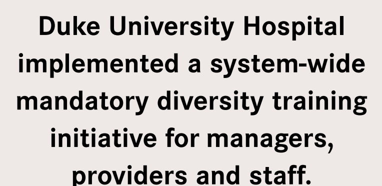
These *care-process variables* are another important area for hospitals to focus on in order to make an impact on disparities in care.

- Improving the cultural competency of health care providers and other staff through ongoing training and feedback can improve their ability to communicate well with patients across cultures, improve rapport, and enhance patient understanding and follow-up.[2, 116]
- In addition, improving the cultural competency of the hospital's care delivery system more broadly, can make patients of all cultural backgrounds feel more satisfied with the care the hospital provides.

Biases in Clinical Decision-Making

Despite the best intentions of clinicians, research has shown that a wide range of non-medical factors may have as much influence on clinical decisions as the actual signs and symptoms of disease.[117, 118] Clinical decisions are influenced by characteristics of the patient (including age, gender, socioeconomic status, race/ethnicity, language proficiency, and insurance status), characteristics of the doctor (including the specialty, level of training, clinical experience, age, gender, and race/ethnicity) and features of the practice setting (including location, organization of practice, form of compensation, performance expectations, and incentives).[37, 103, 119-127] The challenge is that if left unchecked, stereotyping may lead to lower quality of care for certain groups of patients.[2]

- Conscious, or more likely unconscious stereotypes, judgments or preconceptions about patients based on personal characteristics can lead to disparities in care.
- Even when clinicians have the best intentions, unconscious biases may come into play about what a patient is capable of understanding, whether they would want a procedure or treatment, or how much effort it is worth spending to overcome communication barriers.
- For example: studies show that minority patients are:
    - Less likely to receive adequate pain medication in the emergency setting (potentially due to stereotypes that they are drug-seeking).[128]
    - Less likely to be treated with highly active antiretroviral therapy for HIV (due to stereotypes about inability to adhere to therapy).[120]



Hospitals can address issues of stereotypes and biases in clinical decision-making in at least two main ways.

- Cultural competence training for health care professionals and other staff can increase awareness of unconscious biases and the impact on clinical decisions.[2, 129] This must be done through a non-judgmental approach.
- Systems can be set up to minimize the impact of biases through enforcement of evidence-based practice guidelines and report cards to providers stratified by race/ethnicity, language, etc.[2, 130, 131]

Lack of Follow-Through with Provider Recommendations

Whether or not a patient will accept and follow through with a provider's recommendations depends on a balance of key factors:

Mistrust

A survey by the Kaiser Family Foundation found that 65% of African-Americans and 58% of Hispanics (compared to 22% of whites) were afraid of being treated unfairly when accessing health care services based on their race/ethnicity.[78] This lack of trust can result in inconsistent care, doctor shopping, self-medicating, and an increased demand for referrals and diagnostic tests by patients.[132]

Cultural beliefs

Sometimes patients have a completely different understanding of their condition or its treatment. For example, some patients are afraid to have surgery for cancer because of fear of spreading the tumor.[133] If these beliefs aren't explored and taken into consideration, patients may be less likely to follow through with recommendations.

Poor understanding of the management plan due to communication barriers

Patients with language barriers who are discharged from the emergency room are less likely to understand their diagnosis, prescribed medications, instructions, and plans for follow-up care.[134] Further, they are less likely to be satisfied with their care or willing to return if they had a problem; more likely to report problems with their care;[135] and less satisfied with the patient-provider relationship.[135]

Once again, both communication and trust are potentially amenable to approaches that aim to increase the cultural competence of health care providers. This should include clinicians at all levels, as well as hospital staff who interact with patients, and can contribute to an environment of acceptance and customer service for diverse patients. Innovative programs such as culturally and linguistically competent navigators, health coaches, and educators, as well as information technology-based interventions, can extend the influence of the medical system to help patients follow through with recommendations, improve health outcomes, and reduce disparities.

Given the multiple causes of disparities, it is clear that there are no simple solutions for addressing them, just as there are no simple solutions for improving health care quality overall. Although the relative contribution of each these factors has not been calculated, the overall model can provide some direction and areas of focus for potential interventions. Strategies to address disparities will require a multidisciplinary, multi-method, step-wise approach and will be discussed further in this guidebook.

A Tale of Two Patients

Just as the Joint Commission uses "patient tracers" to assess whether hospitals are meeting certain standards, we will use two simulated cases to walk through the various steps to obtaining high quality health care. At each step problems may arise, particularly for racial and ethnic minority patients that can lead to disparities. We will focus on two cases – Mr. P and Mrs. L – which exemplify these steps. We have intentionally left out the patient's race/ethnicity, given that these are cross-cutting issues that can affect any patients.

Disparities Simulation Case 1 – Mr. P

Mr. P is a 55 year-old man who has lived in the U.S. for 5 years and speaks just enough English to get by. He is college educated, works as a mechanic, and has insurance through his employer. He has type II diabetes and hypertension, both in poor control. He missed his last appointment with his primary care physician (PCP) and has been without medication since. When he developed a problem with his vision, he waited 6 weeks before going to an urgent care center.

Navigating the Health Care System

Mr. P was afraid to seek care due to language barriers and embarrassment. He was not familiar with how to access his PCP and instead relied on costly urgent care or emergency services.

Mr. P spoke to a nurse practitioner (NP) in English at the urgent care center and described his symptoms as best he could. The NP had a difficult time understanding him and did not have time to call an interpreter. Somewhat frustrated, he gave Mr. P a referral to an ophthalmologist and told him to follow up with his PCP. Two weeks later Mr. P presented to the Emergency Department with weakness of his right leg from a carotid territory stroke. In the hospital his PCP was able to get his diabetes and hypertension in fair control. However, their communication was limited due to the language barrier, and it wasn't clear how much he understood about the importance of tight control.

Communication and Rapport

- Mr. P was upset and embarrassed and was reluctant to return to see his PCP until after he already had suffered a stroke, a potentially avoidable medical error and liability issue.
- Mr. P didn't have an opportunity to learn about diabetes and hypertension management in a way he could understand. This may lead to poor adherence to medications, diet, etc. and poor quality care.

Mr. P's PCP did not believe that he was likely to adhere to the regimen. In her view, Mr. P didn't really understand the importance of managing his diabetes and hypertension, and she in turn didn't understand his motivations. She opted against starting him on insulin because she felt that he would not be able to manage the complexity of insulin administration and he wouldn't want it anyway. She maximized his oral medications and did not refer him to an endocrinologist.

Clinical Decision-Making

- Mr. P's doctor assumed many things about him that were unfounded. Had she been able to communicate with him better she may have understood that he is intelligent, well educated, and motivated to improve his health. He had no major concerns about taking insulin.

Mr. P did not fully trust his PCP, and also had difficulty affording co-payments for brand-name medications. When he began to develop some dizziness from the medications he called his PCP's office to report this and was told he should go to the emergency department given his stroke history. Fearing another hospitalization, he instead stopped taking the medication and missed his follow-up appointment.

Follow-Through with Provider Recommendations

- Mr. P never developed much rapport or trust with his PCP and did not feel comfortable with her recommendations.
- Mr. P didn't really understand the management plan due to his limited-English proficiency and thus he didn't follow through as he was supposed to.

Disparities Simulation Case 2 – Mrs. L

Mrs. L is a 53 year-old female with a past medical history of mild asthma and iron deficiency anemia who saw her doctor recently for some chest discomfort – or "atypical chest pain". She was thought to have gastroesophageal reflux (GERD), and was given a prescription for an antacid medication. Four weeks later her symptoms have worsened. She is scheduled for an upper endoscopy and is sent information on the procedure. However, she doesn't fully understand the printed materials as they are written in complicated language. When she shows up to get it done, she is sent home and told to reschedule because she ate breakfast. She gets the procedure done at a later date, and it is normal. Two days later she presents to the emergency room with a small myocardial infarction.

Navigating the Health Care System

- Mrs. L has trouble reading in general but especially the complicated language used to described health related concepts such as preparing for an upper endocscopy (low health literacy). This led to a delay in her receiving the endoscopy.

Clinical Decision-Making

- Patients from different cultural backgrounds may present their symptoms differently than what is described in medical textbooks, which generally base their descriptions of symptoms on white male patients. There is also a tendency to under-appreciate the risk of coronary artery disease in women. Understanding this may have heightened the physician's suspicion of coronary artery disease and led to a more timely work-up of her heart rather than her upper GI tract.

Mrs. L is admitted to the hospital and told she needs to have a cardiac catheterization. She says she wants to discuss this with her sister tomorrow when she arrives from out of town, but is told that the situation is urgent and she needs to decide. She has trouble understanding why this is the case, and feels particularly mistrustful of the hospital physician. The next day she speaks to her sister and agrees to get the procedure, but unfortunately she has missed her turn and ends up waiting two more days. On the night prior to the procedure she is found to be too anemic to undergo the catheterization (she has underlying anemia and had a significant amount of blood drawn) and she is told she needs a blood transfusion. When the doctor tries to get informed consent, he finds out she is a Jehovah's Witness and cannot accept blood products. She is treated with a red blood cell stimulation medication, blood draws are minimized, and she gets the catheterization five days later.

Communication and Rapport

- Like Mr. P, Mrs. L never developed much rapport or trust with the physician caring for her, though in this case there were no language barriers. She perceived a lack of respect for her concerns, which contributed further to this mistrust.
- Better communication with Mrs. L could have opened up a discussion about her religious restrictions on blood products. This may have improved her care and shortened her hospital stay.