

# Unequal Treatment in the US: Lessons and Recommendations for Cancer Care Internationally

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**Summary:** Despite interventions that have improved the overall health of the majority of Americans, racial and ethnic minorities have benefited less from these advances. Research has shown that multiple factors contribute to racial and ethnic disparities in health, health care, and cancer care. The Institute of Medicine Report, "Unequal Treatment" provides a detailed examination of racial/ethnic disparities in health care in the U.S., highlighting three clinical contributors—poor provider-patient communication, stereotyping in clinical decisionmaking, and patient mistrust. Although the findings and recommendations in "Unequal Treatment" are broad in scope, they provide a blueprint for how to address disparities in health care in general—as well as cancer care—and have direct implications for clinical practice, both nationally and internationally. We propose a patient-based approach to cross-cultural care as a model to improve communication with racial and ethnic minorities, and cross-cultural populations in general. We also highlight the importance of community based interventions, such as those that use health care navigators to promote cancer screening. If we hope to provide effective cancer care around the world, we must be attentive to the factors that impact minorities and vulnerable populations, and be prepared to address them.

**Key Words:** disparities, culture, cancer

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## BACKGROUND

Despite interventions that have improved the overall health of the majority of Americans, racial and ethnic minorities (African Americans, Hispanics, Native Americans/Alaska Natives, and Asian/Pacific Islanders) have benefited significantly less from these advances. National data indicates that minority Americans have poorer health outcomes (compared with whites) from preventable and treatable conditions such as cardiovascular disease, diabetes, asthma, cancer, and HIV/AIDS, among others.<sup>1–2</sup> These issues will be magnified in the future as the United States continues to become more diverse. For example, in the United States, the minority population increased from 86.9 million to 111.9 million between 2000 and 2010, indicating a growth of 29%.<sup>3</sup> This increasing diversity is also seen globally, and disparities have also been found in international settings as well.<sup>4</sup>

Multiple factors contribute to racial and ethnic disparities in health. First, research has demonstrated that social determinants such as lower levels of education, overall lower socioeconomic status, inadequate and unsafe housing, racism, and living in close proximity to environmental hazards disproportionately impact minority populations and thus contribute to their poorer health outcomes.<sup>5–9</sup> Second, lack of access to care also takes a toll, as uninsured individuals are less likely to have a regular source of care, are more likely to report delaying seeking care, and are more likely to report that they have not received needed care—all resulting in avoidable hospitalizations, emergency hospital care, and adverse health outcomes.<sup>10–12</sup> This is especially important for minority populations who are more likely to be uninsured than their white counterparts.<sup>13</sup> Finally, there is also evidence of racial and ethnic disparities in healthcare. Research has shown that minorities receive a lower quality of care when they are in the healthcare system, even when controlling for social determinants and insurance status. For example, rates of colorectal cancer screening are particularly low in ethnic minorities, non-English speakers, and low-income individuals,<sup>14–18</sup> similar findings have been documented for breast cancer screening.<sup>19</sup> In regard to cancer treatment, evidence has shown disparities in lung cancer (Blacks 34% less likely to receive timely surgery, chemotherapy, or radiation for stage III nonsmall cell lung cancer relative to whites; African Americans receiving less curative surgery than whites for nonsmall cell lung cancer),<sup>20,21</sup> breast cancer (Hispanics and blacks less likely to receive radiation therapy than whites),<sup>22</sup> and in the area of pain management (minorities less likely to receive same amount of pain medication for cancer treatment).<sup>23</sup>

## THE INSTITUTE OF MEDICINE REPORT "UNEQUAL TREATMENT"

As a result of this research, the United States Congress commissioned the Institute of Medicine (IOM) in 1999 to further study racial/ethnic disparities in the healthcare system. The final report, entitled "Unequal Treatment: Confronting Racial/Ethnic Disparities in Health Care"<sup>24</sup> was released in 2002 and found that racial and ethnic disparities in healthcare exist and are associated with worse health outcomes. They occur in the context of broader historic and contemporary social and economic inequality, and are evidence of persistent racial and ethnic discrimination in many sectors of American life. Many sources—including health systems, healthcare providers, and patients—may contribute to racial and ethnic disparities in healthcare. Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare as well—and although a small number of studies suggest that

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certain patients may be more likely to refuse treatments, these refusal rates are generally small and do not fully explain healthcare disparities.

### KEY CLINICAL LESSONS FROM “UNEQUAL TREATMENT”

Three key areas were identified as having clinical relevance and contributing to racial/ethnic disparities in healthcare: provider-patient communication, clinical decision-making, and mistrust.

#### Provider-Patient Communication

Socio-cultural differences between patient and provider influence communication and clinical decision-making, and are especially pertinent given the evidence that links provider-patient communication to patient satisfaction, adherence, and subsequently, health outcomes.<sup>25,26</sup> These include variations in recognition of symptoms, thresholds for seeking care, comprehension of management strategies, expectations of care (including preferences for or against diagnostic and therapeutic procedures), and adherence to preventive measures and medications. When socio-cultural differences between patient and provider are not appreciated, explored, understood, or communicated effectively in the medical encounter, patient dissatisfaction, poor adherence, poorer health outcomes, and racial/ethnic disparities in care may result.<sup>27</sup> Provider-patient communication without an interpreter, even in the setting of a minimal language barrier, is recognized as a major challenge to effective healthcare delivery.<sup>28–32</sup> In addition, a survey of 6722 Americans aged 18 and older found that 19% of all patients had trouble understanding the doctor, felt the doctor did not listen, or had medical questions they were afraid to ask.<sup>33</sup> Whereas whites experienced these barriers 16% of the time, African Americans experienced them 23% of the time, Hispanics 33% of the time, and Asian Americans 27% of the time. This also affects end-of-life (EOL) communication. For example, one study found that do not resuscitate (DNR) orders among African American patients with cancer did not reduce the likelihood of life-prolonging care or increase the likelihood of receipt of care consistent with baseline preferences. Further, EOL discussions were associated with EOL care outcomes among whites, but not among African Americans.<sup>34</sup> Given the importance of effective communication in the clinical encounter and the link to health outcomes, it is obvious that minorities are disproportionately affected. Therefore, provider-patient communication may likely contribute to racial/ethnic disparities in healthcare.

#### Clinical Decision-making

Nonmedical factors, ranging from the patient's physical appearance to the organizational setting in which medical care is delivered, may have as much influence on clinical decisions as the actual signs and symptoms of disease.<sup>35,36</sup> Clinical decisions, in addition to being shaped by symptoms and probability of disease, are shaped by characteristics of the patient (including patient age, sex, socioeconomic status, race/ethnicity, language proficiency, and insurance status), characteristics of the doctor (including the specialty, level of training, clinical experience, age, sex, and race/ethnicity), and features of the practice setting (including location, organization of practice, form of compensation, performance expectations, and incentives).<sup>25,37–46</sup> The literature on social cognitive theory also reveals how natural tendencies to

stereotype might influence clinical decision-making. We all share the subconscious strategy of attempting to simplify our decision-making process and lessen our cognitive effort by using “categories” or “stereotypes” in which we apply beliefs and expectations about groups of people to individuals from that group.<sup>47–49</sup> It is important to underscore that stereotyping often occurs subconsciously, unlike prejudice or discrimination, both conscious processes.<sup>47</sup> However, if left unchecked, stereotyping has a detrimental clinical effect on certain groups who fall into specific categories deemed as less worthy of diagnostic or therapeutic procedures or resources.<sup>50,51</sup> A recent study found that when physicians who reported no explicit preference for white versus black patients were given the Implicit Association Test, they demonstrated a preference for white Americans and had implicit stereotypes of African Americans as less cooperative with medical procedures and less cooperative in general.<sup>52</sup> Although stereotyping is natural and expected, evidence is demonstrating its effect on clinical decision-making and racial and ethnic disparities in healthcare.

#### Mistrust

Trust is a crucial element in the therapeutic alliance between patient and healthcare provider. It facilitates open communication and is directly correlated with adherence to physician recommendations and patient satisfaction.<sup>53</sup> Patients who mistrust their healthcare providers are less satisfied with the care they receive<sup>54</sup> and mistrust of the healthcare system greatly affects patient's use of services. On the basis of historical factors of discrimination, segregation, and medical experimentation, African Americans in particular may be especially mistrustful of providers.<sup>55</sup> A national telephone survey found that there is significant mistrust of the healthcare system among minority populations. Of the 3884 individuals surveyed, 36% of Hispanics and 35% of African Americans (compared with 15% of whites) felt they were treated unfairly in the healthcare system in the past based on their race and ethnicity. Perhaps even more alarming—65% of African Americans and 58% of Hispanics (compared with 22% of whites) were afraid of being treated unfairly in the future based on their race/ethnicity.<sup>56</sup> This mistrust may impact patient decision-making in various ways, particularly in critical situations. For example, a recent survey found that African American patients were more likely than whites to prefer life-sustaining treatment even after controlling for the extent of illness and mental incapacitation.<sup>57</sup> Researchers hypothesize that African American patients in this study may be requesting more aggressive treatment at EOL because they are mistrustful of healthcare provider's efforts to “withdraw” any type of treatment—even if it may not benefit them—because of their previous experience with discrimination. Any effort to eliminate barriers that contribute to disparities in clinical practice will surely have to take into account the importance of addressing mistrust—and building trust—in the medical encounter.

### KEY RECOMMENDATIONS OF UNEQUAL TREATMENT

The IOM Report “Unequal Treatment” provided a series of recommendations to address racial and ethnic disparities in healthcare targeted to a broad set of stakeholders.

- Increase Awareness of Racial/Ethnic Disparities in Healthcare

*It is important to increase awareness of disparities among healthcare leaders and providers so they can take action to address them.*

- **Collect and Report Healthcare Access and Utilization Data by Patient's Race/Ethnicity**  
*By collecting patient race and ethnicity data, we can identify disparities locally, and then implement strategies to monitor and eliminate them as part of quality improvement and performance measurement efforts.*
- **Encourage the Use of Evidence-based Guidelines and Quality Improvement**  
*The adoption and implementation of evidence-based guidelines for all patients will address variations in care that might lead to racial and ethnic disparities.*
- **Support the Use of Language Interpretation Services in the Clinical Setting**  
*The use of interpreter services is critical in the effective care of patients with limited English proficiency.*
- **Increase the Proportion of Underrepresented Minorities in the Healthcare Workforce**  
*Minorities are underrepresented in the healthcare workforce, and efforts to improve diversity may improve quality of care for racial and ethnic minorities.*
- **Integrate Cross-cultural Education Into the Training of All Healthcare Professionals**  
*Improving healthcare providers' capacity to communicate and care for diverse populations will improve the quality of care patients receive, and address disparities in care.*

### Cross-Cultural Care: A Patient-Based Approach

Healthcare providers can acquire a set of tools and skills that can help them improve communication, build trust, and better understand and care for diverse patient populations. This should help improve quality and address disparities. In previous work, we have described the patient-based approach to cross-cultural care as a model to improve communication with racial and ethnic minorities, and cross-cultural populations in general.<sup>58</sup> In brief, this approach consists of 4 steps: (1) assess core cross-cultural issues; (2) explore the meaning of the illness; (3) determine the social context; and (4) engage in negotiation.

#### Assess Core Cross-Cultural Issues

Interactions between patients and healthcare professionals often lead to misunderstandings that reflect inherent differences in cultural values and expectations. These misunderstandings can originate from healthcare providers being inattentive to "hot-button" issues that can lead to outcomes ranging from mild discomfort, to noncooperation, to a major lack of trust that disintegrates the therapeutic relationship. Fortunately, certain core cross-cultural issues tend to recur across cultures. Rather than attempt to learn an encyclopedia of culture-specific issues, a more practical approach is to explore the various types of problems that are likely to occur in cross-cultural medical encounters, and to learn to identify and manage these as they arise. Listed below are 5 core cross-cultural issues that should be taken into account to avoid cross-cultural misunderstandings:

- **Styles of Communication**—Providers should get a sense for their patients' communication style and adapt the communication style accordingly, pay attention to cultural differences, and determine how the patient prefers to receive bad news.
- **Mistrust and Prejudice**—Providers should be encouraged to discuss mistrust openly, understand the patients'

perspective, provide focused reassurance with patients, and build a partnership with patients.

- **Decision-making and Family Dynamics**—Providers should ask directly if the patient is an autonomous decision-maker or would prefer the family or someone else in particular to be involved.
- **Traditions, Customs, and Spirituality**—Patient expressions of spirituality should be discussed when appropriate and relevant to the clinical interaction.
- **Sexual and Gender Issues**—Providers should keep sexual and gender issues in mind and be aware of the different ways that patients and families view gender roles and try to accommodate when feasible.

### Explore the Meaning of the Illness

When patients seek care for a medical issue, they generally come with certain beliefs about the cause of their symptoms, concerns about their illness, and expectations about potential treatment. The overall conceptualization of the illness experience has been called the patient's explanatory model.<sup>59</sup> This represents the "meaning of the illness" for the patient—or how they understand and explain their condition. Exploring and understanding these can be extremely useful with all patients, but particularly for patients whose cultural backgrounds and perspectives on health and illness may differ significantly from the Western model of biomedicine. Simple and straightforward questions can be used to explore the patients' perspective of the meaning of illness (eg, what do you think caused the problem? What do you call the problem? What do you know about illness and how it works?).

### Determine the Social Context

The manifestations of a person's illness are inextricably linked to those factors that make up the individual's social environment.<sup>8</sup> This social context is not limited to socioeconomic status, but also encompasses migration history, social networks, literacy, and other factors. The social context can be broken down into 3 specific areas with particular relevance to the clinical encounter: environment change (such as migration); language and literacy; and life control, social stressors, and supports.

#### Environment Change

Understanding the patient's unique migration experience can help the healthcare provider to build rapport and trust, allay certain concerns (such as fear of deportation), acknowledge a source of distress, which may be causing psychological or psychosomatic problems, and focus on interventions, which facilitate the patient's transition.

#### Language and Literacy

Assessing a patient's language proficiency, and assuring that there are appropriate interpreter services available (either trained interpreter or telephone interpreter service) is an essential component of delivering care to immigrant populations.

#### Life Control, Social Stressors, and Support

Providers should be encouraged to ask patients directly about possible life stressors, support networks available, and other basic necessities such as affording food, medication, and medical expenses.

## Engage in Negotiation

Healthcare providers and patients rarely see things in exactly the same way. Cross-cultural interactions add additional layers of complexity to this situation that may be especially pronounced when caring for patients from diverse socio-cultural backgrounds. Although there is no simple answer to this question, we can often turn to the process of cross-cultural negotiation for some guidelines. This can be done in an efficient, effective way by considering the following steps:

- Step 1: Explore the Patient's Perspective—This may involve asking open-ended questions about the patient's understanding and concerns about the illness and its treatment.
- Step 2: Explain Your Perspective—This requires providing the patient with an explanation in terms that are understandable and familiar, including explaining why you think it is in their best interest.
- Step 3: Acknowledge the Difference in Opinion—Do this in a way that is nonjudgmental and accepting of difference.
- Step 4: Create Common Ground—This may mean offering a compromise or asking the patient what they are willing to do, and often requires some back and forth discussion in an environment where the patient feels they can be open with you.
- Step 5: Settle on a Mutually Acceptable Plan—Once a plan is developed, check in with the patient again to make sure that it is acceptable. Look for any sign of hesitation on the part of the patient and discuss this openly.

## PUTTING CROSS-CULTURAL CARE INTO ACTION

### The MGH Colon Cancer Navigation Project

Many hospitals and health centers have implemented community-based health interventions that often include health navigators who are bilingual and use cross-cultural communication skills to bridge differences, improve care, and address disparities. For example, at the Massachusetts General Hospital's Chelsea Healthcare Center it was determined that Latinos were significantly less likely than whites to receive colorectal cancer (CRC) screening. As a result, a program was developed where navigators, who are also outreach workers and interpreters at the health center, are able to target patients who haven't had CRC screening and contact them to: (1) provide education on CRC screening; (2) address patient-specific barriers and develop solutions to overcome barriers; and (3) schedule appointments, translate, and accompany patients (if needed) to CRC screening appointments. Results from a randomized control trial showed that patients in the intervention group (receiving navigator services) were more likely to undergo CRC screening than patients receiving usual care services (27% vs. 12% for any CRC screening,  $P < 0.001$ ; 21% vs. 10% for colonoscopy completion,  $P < 0.001$ ). The higher screening rate resulted in the identification of 10.5 polyps per 100 patients in the intervention group versus 6.8 for those receiving usual care ( $P = 0.04$ ).<sup>60</sup>

## CONCLUSION

"Unequal Treatment" provides a detailed, systematic examination of racial/ethnic disparities in healthcare in the United States, but also has implications for cancer care

internationally. From this exploration emerge 3 particular barriers that contribute to disparities in clinical practice—poor provider-patient communication, stereotyping in the clinical decision-making process, and patient mistrust. Although the recommendations in "Unequal Treatment" are broad in scope, they provide a blueprint for how to address disparities in healthcare in general—as well as cancer care in particular—and have direct implications for clinical practice, both nationally and internationally. Interventions such as those that affect health systems, as well as those related to healthcare professionals—increasing awareness, providing cross-cultural education, and minority recruitment—should help address disparities that arise from the clinical encounter. Community-based programs, such as navigators, will also help us address the barriers that minority and diverse patients face in their efforts to obtain high-quality care. Ultimately, if we hope to provide effective cancer care around the world, we must be attentive to the factors that impact minorities and vulnerable populations, and be prepared to address them.

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