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We all strive to provide quality health care to our patients and families. But what exactly is quality health care? The Institute of Medicine defines it as care that is timely, efficient, effective, safe, patient-centered, and equitable. Here we examine equity in health care, specifically for black Americans.

While many factors affect health care equity, disparities based on race that target communities of color are consistently reported in the management of many diseases. For example, blacks receive a lower standard of care than whites when being treated for breast cancer, orthopedic problems, cardiovascular disease, pain, and end-of-life care, among other conditions. According to the 2009 National Healthcare Disparities Report produced by the Agency for Healthcare Research and Quality, many of these discrepancies are not decreasing. Blacks receive worse care than whites for half of the core measures studied, and only about 20 percent of measures of disparities in quality of care improved over the study period of 2000–2007. Being uninsured was the single strongest predictor of quality of care. However, when correcting for uninsurance and socioeconomic status, blacks still receive worse care than whites.

Locally, a recent Wilder Foundation study reported similar results. Blacks in the Twin Cities have significantly shorter life expectancy than whites, even after correcting for socioeconomic status. (“The unequal distribution of health in the Twin Cities: a study commissioned by the Blue Cross and Blue Shield

Equity in health care

Examining the impact of racial bias

By Stephen Nelson, MD

of Minnesota Foundation,” October 2010)

These discrepancies raise the question: In what ways does racism shape disparities in health care, especially for blacks?

Background

For 18 years I have had the honor of caring for the majority of children with sickle cell disease (SCD) in Minnesota. About 100,000 Americans, including approximately 600 Minnesotans, are living with SCD. I have only recently begun to consider how, as a white male physician, my race may affect the health care delivery to our patients of color. This consideration is long overdue. Barriers to racial health care equity include the health care system (insurance, funding, white domination in provision of care), the patient (poor health literacy, fear, mistrust), the community (awareness, advocacy), and we the providers (bias, attitudes, expectations).

The vast majority of Americans with SCD are black. This might not be a concern if there were not significant gaps in private and public funding for clinical care and research between diseases affecting blacks and whites in our country. In 2004, the National Institutes of Health spent \$90 million on SCD and \$128 million dollars on cystic fibrosis (CF), a disease that predominantly affects whites—despite the fact that there are three times as

many Americans with SCD. When philanthropic support from the CF Foundation and the Sickle Cell Disease Association of America is considered, the per-capita support for patients with CF is \$5,074, compared to \$6 per person with SCD. These gaps are even more disconcerting when we consider that SCD is the most commonly detected disease in newborn screening programs in the U.S.

Patient perspective

From early medical experimentation on slaves, starting in the 17th century, to the Tuskegee experiments (1932–1972), to coerced sterilization of young black women (which was legal until 1974 in areas of the South), to present-day attitudes about AIDS contraction, the history of racism in medicine (and health care overall) toward black Americans has undoubtedly shaped this community’s lack of trust in the health care system. This legacy of racism and the resultant mistrust may partially explain racial disparities, as it may decrease black patients’ willingness to follow evidence-based recommendations made by (predominantly white) physicians.

Another patient-related issue reflecting this history and the race-class connection in the U.S. is decreased access to care based on socioeconomic status. For example, access issues such as health care literacy, time and physical availability to optimize

the most rigorous treatment plan, and even transportation to and from a clinic can dramatically affect the patient’s perspective on and experience of care.

Provider perspective

Medical staffs’ perceptions and awareness levels also affect the care patients receive. Several studies have shown race and sex to influence physicians’ management decisions. With respect to provider bias, SCD patients are perceived as being opioid-dependent at twice the rate of other patients with pain. In one study, both staff and families in a sickle cell center perceived whites getting better service than blacks. A larger study of more than 200 providers in a sickle cell center showed differing perceptions of the effect of race on the quality of health care delivery: Providers of color and women providers perceived race as an issue, whereas white male providers tended not to see race as a factor in health care delivery. In a recent study, white providers prescribed hydroxyurea (the only FDA-approved drug to treat SCD) less frequently than did black providers.

Identifying perceptions of race and racism

According to the 2000 U.S. Census Bureau data, our nation’s population was 75.1 percent white and 12.3 percent black. However, Minnesota’s population was 89.4 percent white and only 3.5 percent black. In 2010, the Minnesota black population had increased to 5.2 percent. Given the overwhelming majority of white providers in the health care system, the effects of institutional racism may be significant.

Lack of provider awareness of institutional racism and the resultant structural barriers that patients of color face are areas our center felt were important to examine. In 2009, we initiated research with the goal of identifying perceptions of race and racism among our staff and patients, with particular attention to provider attitudes as a potential contributor to racial health care disparities.

Methods. An 11-item survey was adapted from the Centers for Disease Control's 2008 Behavioral Risk Factor Surveillance System and the Sickle Cell Transfer Questionnaire, with specific questions regarding race, racism, and health care delivery. The target population was staff, patients, and families from the Sickle Cell Center at Children's Hospitals & Clinics of Minnesota.

Demographic data obtained included age, race, ethnicity, and gender. For staff, data were also collected about work position and work location (inpatient vs. outpatient). The survey was given to all patients with sickle cell disease >12 years of age and their families upon arrival to clinic. The survey was made available online to all staff in the hematology/oncology program.

Results. We received completed surveys from 112 patients/families. Surveys were made available to 158 staff members and 135 were completed (85 percent return rate). This very high return rate speaks to the deep interest in this topic. Not surprisingly, 92.6 percent of patients/families identified as black, while 94.1 percent of staff identified as white ($P<0.001$).

Among the significant findings were the following:

- More patients/families than staff felt that race affects the quality of health care for sickle cell patients (50 percent vs. 31.6 percent, $P=0.003$, OR 2.1).
- More staff than patients/families perceived unequal treatment of patients at our institution, especially in the inpatient setting (20.9 percent vs. 10.9 percent, $P=0.03$, OR 0.46).
- Patients/families showed a greater awareness of race than staff, as measured by self-reports of emotional responses because of race while at the hospital (56.6 percent vs. 27.5 percent, $P<0.001$, OR 3.43).

- Patients/families perceived race affecting interpersonal relationships with caregivers more than did staff (47.5 percent vs. 29.2 percent, $P=0.005$, OR 2.13).
- Though the majority of staff and patients/families agreed that racism is a problem in the U.S., most respondents felt this was not an issue at our institution.
- More staff than patients/families perceived racism as a problem nationally (83.9 percent vs. 72 percent, $P=0.02$, OR 0.49).
- Of respondents who felt there was racism at our hospital, more staff than patients/families perceived this to be an issue (23.7 percent vs. 9 percent, $P=0.002$, OR 0.31).

Discussion of results

As expected, patients/families showed a greater awareness of race than did staff and felt that race affected the quality of care they received. This was less of an issue with our more recent West African immigrant families as compared to our African American families.

More staff than patients/families perceived racism as a problem in our institution. Staff also perceived unequal treatment of sickle cell patients based on race, especially in the inpatient setting. We were surprised to find perceptions of racial issues being more prevalent among staff. Perhaps the female-majority staff is more sensitive to discrimination of any kind because of personal experiences with sexism. Other factors that may have contributed to these findings:

- Our staff was significantly older than patients/families.
- Health care workers may be more sensitive than those in other fields.
- Our work in healing fellow humans may help make us more aware of inequities.
- Perhaps because of the nature of their daily experiences with racism, patients and families perceive our institution as less racist when compared to other areas of their lives. It might have been better to ask how Children's compares to their experiences with racism in other areas of their lives.

The survey gave us insight into how provider attitudes may contribute to continued racial

health care disparities. For example, one provider commented that "[sickle cell] patients are challenging because of their lack of support systems, not because of race." This provider's separation of systemic issues such as support structures from the realities of race and racism in the U.S. is a powerful indicator of the lack of knowledge and awareness of how racism operates in our country.

Given that typically there is no intentional or direct training regarding racism in nursing or medical schools, and given that there has been no direct training at our institution about these issues to mitigate the presence of societal racism, it is not surprising that providers have very little understanding of the complexities of racism and its manifestations in provision of health care or in society as a whole. A recent survey of physicians at Children's revealed that they had received an average of 5.3 hours of "racism training" during 1,200 person-years of practice. Further questioning revealed that this training actually represented diversity and cultural competency training, and not training specific to issues of race, racism, and whiteness.

Next steps

Clearly, health care provider attitudes must change in order to reduce health care disparities associated with race. In 2009, the U.S. Department of Health and Human Services recommended that in order to accelerate the pace of improvement, we must train providers.

Diversity and cultural competency trainings are already in place at many institutions, including our own. While they have been shown to be successful in fostering an appreciation and awareness of difference, as well as developing tools for cross-cultural communication, they have not addressed the core of racism and, therefore, fall short of being able to truly effect change in racial disparity in patient care.

After analyzing the results of our survey, we recommended social justice/anti-racist trainings in addition to the diversity and cultural competency trainings. To that end, we have developed a training module for staff to help providers address individual racial bias, the role of racism in

evidence-based medical protocols, and the realities of systemic racism and its impact on patients. The ultimate goal is to improve provider attitudes and provider confidence in caring for patients and families of color.

We hope to take the training module hospital-wide following our initial pilot study, and then offer it to other institutions. We have developed a half-day and a full-day workshop, depending upon the needs of the organization. The training module will:

- Address the definition of race/racism and history of the social construction of race
- Differentiate among diversity, cultural competency, and social justice
- Explore our current health care system (racial make-up of providers, how insurance became tied to employment, what we're taught/not taught in school, evidence-based medicine, racial disparities)
- Examine racism/whiteness in our society, including examples of racism/whiteness in medicine
- Examine how race affects each of the Institute of Medicine's six measures of quality care, and provide trainees tools for understanding these effects
- Introduce critical thinking tools for improving medical providers' comfort and skills in caring for patients of color

We are currently developing a longer training experience (six half-day sessions over four to six months) for those who desire more in-depth exploration.

Although our study focused on white providers and black patients, the findings and future directions can be applied across all aspects of health care delivery. Dismantling racism and provider bias will remove at least one of the barriers to racial equity in health care. We physicians have the greatest ability to affect change in this area. Until racial issues are addressed honestly by members of the health care team, it is unlikely that we will see significant improvements in racial health-care disparities for Americans.

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