

## Race Matters: Perceptions of Race and Racism in a Sickle Cell Center

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**Background.** Health care disparities based on race have been reported in the management of many diseases. Our goal was to identify perceptions of race and racism among both staff and patients/families with particular attention to provider attitudes as a potential contributor to racial healthcare disparities. **Procedure.** A confidential survey addressing issues of race and health care was given to all patients with sickle cell disease and their families upon arrival to clinic. The survey was made available online to all staff in the hematology/oncology program. Free text comments were obtained. **Results.** We received completed surveys from 112 patients/families. Surveys were completed by 135 of 158 staff members (85% return rate). The majority (92.6%) of patients/families

identified as black, while 94.1% of staff identified as white ( $P < 0.001$ ). More patients/families felt that race affects the quality of health care for sickle cell patients (50% vs. 31.6%,  $P = 0.003$ ). More staff perceived unequal treatment of patients, especially in the inpatient setting (20.9% vs. 10.9%,  $P = 0.03$ ). **Conclusions.** Provider attitudes contribute to continued racial health care disparities. We propose training health care providers on issues of race and racism. Training should provide critical thinking tools for improving medical providers' comfort and skills in caring for patients who are of a different race than their own. *Pediatr Blood Cancer* 2013;60:451–454. © 2012 Wiley Periodicals, Inc.

**Key words:** health care disparity; race; sickle cell disease

### INTRODUCTION

While many factors affect health care equity, disparities based on race 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 others [1–8]. According to the 2009 National Healthcare Disparities Report (NHDR), many of these discrepancies are not decreasing. Blacks receive worse care than whites for half of the core measures studied, and only 20% 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 socio-economic status, blacks still receive worse care than whites [9]. The 2010 NHDR showed little improvement [10]. A 2010 study reported that blacks in the Twin Cities of Minnesota have a significantly shorter life expectancy than whites, even after correcting for socio-economic status [11].

Although sickle cell disease (SCD) is a global issue affecting people of all races, in the United States patients are predominantly black. There are close to 100,000 people with SCD in the United States, with a prevalence of about 1 in 3,000 Americans and 1 in 500 black Americans [12].

Barriers to racial health care equity include the health care system (insurance, funding, majority white health care system), the patient (poor health literacy, fear, mistrust), the community (awareness, advocacy), and we the providers (unconscious bias, attitudes) [13–15].

Significant gaps exist in private and public funding for clinical care and research between diseases affecting blacks and whites in our country. For example, there is greater than eight times more support for persons with cystic fibrosis (CF) than that for persons with SCD [16]. In the United States, 98% of patients with SCD are black while over 90% of patients with CF are white [17,18]. This begs the question: Do race and racism factor in to this striking discrepancy in funding?

Mistrust may partially explain racial disparities as it may affect access to care. The long history of racial health care inequity may influence the level of trust that blacks have with respect to the health care system [19–21]. Although a health care provider may recommend standard of care, patients may not follow these recommendations partially because of mistrust.

Perceptions of staff can also affect the health care patients receive. SCD patients are perceived as being opioid dependent at twice the rate of other patients with pain [22]. Both staff and families in a sickle cell center perceived whites getting better service than blacks [23]. This was a small study involving face-to-face interviews. A larger, anonymous survey of 227 multidisciplinary 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 perceived race as an issue, whereas whites failed to see race as a factor in health care delivery [24]. Patients and families were not surveyed in this study. Much work has been done looking at patient–provider race concordance and health care quality. Given our geographic location and low ethnic diversity, issues of race may be particularly important in Minnesota. According to year 2010 U.S. Census Bureau Data, our nation's population is 72.4% white and 12.6% black. However, Minnesota is 85.3% white and only 5.2% black [25]. Furthermore, 88.1% of practicing physicians in Minnesota are white while only 2% are black [26]. Race concordance has been linked to patient adherence, continuity of care, and better clinical outcomes [27–30]. This is not just a concern in our state. Between 1978 and 2008, 75% of practicing physicians in the United States were white and 6.3% were black [31]. Given this substantial race discordance, the effect of race on health care delivery to people of color may be significant. Our goal was to identify perceptions of race and racism among both staff and patients/families with particular attention to provider attitudes as a potential contributor to racial healthcare disparities.

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**PROCEDURE**

An 11-item survey was adapted from the Centers for Disease Control’s 2008 Behavioral Risk Factor Surveillance System (BRFSS) and the Sick Cell Transfer Questionnaire with specific questions regarding race, racism, and health care delivery [32,33]. The three items within the racism domain are original questions, as we wanted to get a feel for respondents’ understanding of race and racism in our society. Thus, we purposely did not define racism for respondents. All items within the racial awareness domain and two of the items within the health care delivery domain were adapted from the BRFSS [33]. We used the three-item Influence of Patient Race on Provision of Health Care Services Index (IPR-PHCSI) from the Sick Cell Transfer Questionnaire developed by Telfair et al. [24,32].

The target population included staff, patients, and families from the Sick Cell Center at Children’s Hospitals & Clinics of Minnesota. We care for more than 90% of children with SCD statewide. All participants completed an identical survey. Demographic data obtained included age, race, ethnicity, and gender. For staff, data was 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. This included physicians, nurses, nurse practitioners, physician’s assistants, health unit coordinators, medical assistants, nursing assistants, child life specialists, psychologists, social workers, chaplains, and research assistants. Both inpatient and outpatient staffs were surveyed on both of our Minneapolis and St. Paul campuses. The Institutional Review Board exempted the study from obtaining written informed consent and the Minnesota Nurses Association approved the study.

We asked participants to rate how much they agreed or disagreed with each statement on the survey using the five-point Likert scale ranging from strongly agree to strongly disagree. In the survey domain pertaining to racism we used statements such as “Racism is a problem in the U.S.” and “Racism is a problem at Children’s.” In the section addressing racial awareness we asked questions such as “How often are you reminded of your race?” and “When at Children’s, you’ve had an emotional response because of how you were treated based on your race.” In the survey domain addressing health care delivery we used statements such as “The health care sickle cell patients receive is influenced by the fact that most patients are black/African-American” and “Sickle cell patients are treated the same as other patients while admitted to the hospital.” An opportunity was given for open-ended comments at the end of the survey.

Responses of agree/strongly agree or disagree/strongly disagree were combined and compared. Odds ratios (OR) and associated *P* values are reported using chi square and Fisher exact probability tests. We also compared our results on the IPR-PHCSI with those previously reported [24].

**RESULTS**

We received completed surveys from 112 patients/families. Fourteen patients or family members refused to complete the survey (11%). The demographics of this convenience sample matched those of our total population of 200 children with SCD. Surveys were made available online to 158 staff members

and 135 were completed (85% return rate). Both staff and families were predominately female (90.3% vs. 73.6%, *P* < 0.001). The majority of patients/families identified themselves as black (92.6%), while 94.1% of staff identified themselves as white (*P* < 0.001). Staff tended to be older with 73.5% of staff being >30 years of age versus 58.2% of patients/families (*P* = 0.01; Table I). Nurses comprised 51.1% of staff respondents while 19.5% were providers (physician, nurse practitioner, or physician’s assistant). The remaining 30% were equally represented by clinical research assistants, medical assistants, health unit coordinators, pharmacy staff, inpatient nurses’ aides, and psycho-social staff (child life, social work, and psychology). Almost half (45%) of staff worked solely in the inpatient setting, 30% in the outpatient setting, and 25% equally in both settings.

Within the health care delivery domain, more patients/families felt that race affects the quality of health care for sickle cell patients (50% vs. 31.6%, *P* = 0.003, OR 2.1). More staff perceived unequal treatment of patients at our institution, especially in the inpatient setting (20.9% vs. 10.9%, *P* = 0.03, OR 0.46). An equally small number of patients and families perceived being treated differently because of race in the outpatient and inpatient settings (11% vs. 10.9%). The minority of staff and patients perceived differences in pain management based on race (13.3% vs. 15.6%, *P* = 0.38). Under the racial awareness domain patients/families showed a greater awareness of race as more of them had emotional responses because of race while at the hospital (56.6% vs. 27.5%, *P* < 0.001, OR 3.43). They also perceived race affecting interpersonal relationships with caregivers more than did staff (47.5% vs. 29.2%, *P* = 0.005, OR 2.13).

Within the survey domain addressing racism both staff and patients/families agreed that racism is a problem in the United States. However, most felt this was not an issue at our institution. More staff perceived racism as a problem nationally when compared to patients/families (83.9% vs. 72%, *P* = 0.02, OR 0.49).

**TABLE I. Respondent Demographics**

	Patient/family		Staff	
	n	%	n	%
Gender				
Male	28	26.4	13	9.7
Female	78	73.6	121	90.3
Culture/ethnicity				
African	40	36.4	1	0.8
African-American	60	54.6	2	1.6
European-American	3	2.7	107	85.6
Caribbean	3	2.7	0	0.0
Latino/Latina	1	0.9	0	0.0
Other	3	2.7	15	12.0
Race				
White	4	3.7	127	94.1
Black or African-American	100	92.6	3	2.2
Hispanic or Latino	1	0.9	0	0.0
Other	3	2.8	5	3.7
Current age				
12–20	28	27.2	0	0.0
21–30	15	14.6	35	26.5
31–40	28	27.2	31	23.5
41–50	19	18.4	34	25.8
>50	13	12.6	32	24.2

Of respondents who felt there was racism at the hospital, again more staff than patients and families perceived this to be an issue (23.7% vs. 9%,  $P = 0.002$ , OR 0.31; Table II).

## DISCUSSION

Race affects health care delivery and is an independent factor in health care disparities [9–11]. However, physicians often fail to see this. Surveys by the Kaiser Family Foundation showed that only 29% of physicians felt that our health care system treats people unfairly based on race, while 47% of the public felt this way. This is especially true among white physicians. Only 4% of white physicians felt that our health care system frequently treats people unfairly based on race, while 41% of black physicians felt this way [34,35].

Similarly, in our survey half of patients and families saw race as affecting health care, but less than one-third of staff perceived this. This was less of an issue with our patients and families who identified as African when compared to our African-American families. More African respondents than African-Americans disagreed with the statement that race influences the quality of health care (38.4% vs. 14.2%,  $P = 0.009$ , OR 3.4). This is likely related to the amount of time a person of color has lived in our racialized society. As suggested by Appiah-Kubi and Lipton [36], recent immigrants may have less mistrust of the health care system.

When looking at responses to the three-item IPR-PHCSI, our results are strikingly similar to those previously reported [24]. Among white providers, Telfair's group showed that only 35% felt that race affects health care quality, 37% felt race influences relationships between patients and providers, and 16% felt that race affects pain management. The results from our almost all-white staff were 32%, 30%, and 13% respectively. Provider attitudes and perceptions have not changed significantly in over a decade.

Provider attitudes may contribute to continued racial health care disparities. This can be illustrated by the following comments from staff. "Sickle cell patients often have behaviors that elicit negative reactions. . . I don't think it's a racial issue." "I do not feel sickle cell patients are treated different due to race. If

anything. . . it is their behavior [that causes different treatment]." "[Sickle cell] patients are challenging because of their lack of support systems, not because of race."

There were two primary limitations of our study. The first was with regard to the range of provider social identities and the potential influence of these identities on provider bias and provider awareness of systemic racism and its impact on patients. For example, a majority of the staff were female and as such, their potential experiences with sexism may have made them more sensitive to discrimination of any kind. Age may have also been a factor. The staff was significantly older than patients/families and that may have informed how staff related to the current racial realities of patients. We did not ask respondents about the significance of their racial identity, which could have an impact on the degree to which they understand and identify racism in their lives. Issues of race may not be as salient or impactful for some of the younger respondents. And finally, the fact that the providers are health care workers may inform their level of sensitivity regarding racial issues more than those in other fields.

Secondly, we were surprised to find that patients and families often perceived race to be less of an issue than did staff. For patients and families, perhaps their daily experiences with racism had them perceive our institution as less racist when compared to other areas of their lives. As such, it might have been helpful to ask how their experiences at our hospital compared to their experiences elsewhere. This is an important question for future studies.

Our results suggest that race still matters in health care delivery and that provider attitudes are not changing. Although not the sole issue, health care provider attitudes must change in order to help improve racial health care disparities. In 2009, the US Department of Health and Human Services recommended that in order to accelerate the pace of improvement we must train providers [9]. To that end, we have developed a training module 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. One goal of the training is to improve medical providers' comfort and skills in caring for patients who are of a different race than their own. We plan to assess the efficacy of the training module through pre- and post-surveys of

**TABLE II. Survey Results**

	Patient/family (N)	Staff (N)	P	OR
<b>I. Racism domain</b>				
Every American has the same opportunities for success and happiness, regardless of race	72 (64.3%)	52 (44.1%)	0.001	2.2
Racism is a problem in the U.S.	80 (72%)	99 (83.9%)	0.02	0.5
Racism is a problem at children's	10 (9%)	28 (23.7%)	0.002	0.3
<b>II. Racial awareness domain</b>				
How often are you reminded of your race? (once a day + constantly/all the time) <sup>a</sup>	23 (21.5%)	17 (14.5%)	0.11	1.6
At children's, you've had an emotional response because of treatment based on your race (yes) <sup>a</sup>	60 (56.6%)	30 (27.5%)	<0.001	3.4
How frequent are these responses? (once per week + every time at children's) <sup>a</sup>	31 (51.7%)	6 (20%)	0.003	4.3
<b>III. Health care delivery domain</b>				
Quality of care for SCD patients is influenced by the fact that most patients are black <sup>b</sup>	54 (50%)	37 (31.6%)	0.003	2.1
Race affects pain management <sup>b</sup>	17 (15.6%)	51 (13.3%)	0.38	1.2
SCD patients are treated the same as other patients when in clinic <sup>a</sup>	84 (77.1%)	77 (68.1%)	0.09	1.6
SCD patients are treated the same as other patients when admitted to the hospital <sup>a</sup>	80 (72.7%)	66 (57.4%)	0.01	2.0
Race affects relationships between caregivers and patients (yes) <sup>b</sup>	48 (47.5%)	34 (29.8%)	0.005	2.1

Results include responses of agree + strongly agree except where indicated. Note that each question was skipped by a variable number of respondents. OR, odds ratio. <sup>a</sup>Adapted from Behavioral Risk Factor Surveillance System. <sup>b</sup>Three-item Influence of Patient Race on Provision of Health Care Services Index from the Sickle Cell Transfer Questionnaire.

participants and report these results. If effective, we would advocate for widespread training of health care providers including early training in medical and nursing schools.

Our study focused on white health care staff and black patients, and it is unclear if our results will be generalizable across other areas within our health care system. But, regardless of the racial dynamic between provider and patient, dismantling unconscious provider bias may remove at least one of the barriers to racial equity in health care. More study is needed in order to address perceived disparities and to identify potential solutions to these challenges. Until racial issues are satisfactorily addressed by members of the healthcare team, it is unlikely that we will see significant improvements in racial healthcare disparities for Americans.

## REFERENCES

1. Esnaola NF, Knott K, Finney C, et al. Urban/rural residence moderates effect of race on receipt of surgery in patients with nonmetastatic breast cancer: A report from the South Carolina Central Cancer Registry. *Ann Surg Oncol* 2008;15:1828–1836.
2. Press R, Carrasquillo O, Sciacca RR, et al. Racial/ethnic disparities in time to follow-up after an abnormal mammogram. *J Womens Health* 2008;17:923–930.
3. Levinson W, Hudak PL, Feldman JJ, et al. "It's not what you say..." Racial disparities in communication between orthopedic surgeons and patients. *Med Care* 2008;46:410–416.
4. Brown CP, Ross L, Lopez I, et al. Disparities in the receipt of cardiac revascularization procedures between blacks and whites: An analysis of secular trends. *Ethn Dis* 2008;18:112–117.
5. Greenberg CC, Weeks JC, Stain SC. Disparities in oncologic surgery. *World J Surg* 2008;32:522–528.
6. Esnaola NF, Gebregziabher M, Knott K, et al. Underuse of surgical resection for localized, non-small cell lung cancer among whites and African Americans in South Carolina. *Ann Thorac Surg* 2008;86:220–226.
7. Bigby J, Ashley SW. Disparities in surgical care: Strategies for enhancing provider–patient communication. *World J Surg* 2008;32:529–532.
8. Cohen LL. Racial/ethnic disparities in hospice care: A systematic review. *J Palliat Med* 2008;11:763–768.
9. 2009 National Healthcare Disparities Report. U.S. Department of Health and Human Services, AHRQ Publication No. 10-0004 March 2010 Available at [www.ahrq.gov/qual/qdr09.htm](http://www.ahrq.gov/qual/qdr09.htm). Accessed July 21, 2010.
10. 2010 National Healthcare Disparities Report. U.S. Department of Health and Human Services, AHRQ Publication No. 11-0005 Health and Human Services, AHRQ Publication No. 11-0005 March 2011. Available at [www.ahrq.gov/qual/qdr10.htm](http://www.ahrq.gov/qual/qdr10.htm). Accessed March 16, 2012.
11. The unequal distribution of health in the Twin Cities. Blue Cross Blue Shield of Minnesota Foundation, October 2010. Available at [www.bcbsmnfoundation.org/objects/Publications/F9790\\_web%20-%20Wilder%20full%20report.pdf](http://www.bcbsmnfoundation.org/objects/Publications/F9790_web%20-%20Wilder%20full%20report.pdf). Accessed March 16, 2012.
12. Hassell KL. Population estimates of sickle cell disease in the U.S. *Am J Prev Med* 2010;38:S512–S521.
13. Schulman KA, Berlin JA, Harless W, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *N Engl J Med* 1999;340:618–626.
14. Burgess DJ, Fu SS, van Ryn M. Why do providers contribute to disparities and what can be done about it? *J Gen Intern Med* 2004;19:1154–1159.
15. van Ryn M, Burgess DJ, Dovidio JF, et al. The impact of racism on clinician cognition, behavior, and clinical decision-making. *DuBois Rev* 2011;8:199–218.
16. Smith LA, Oyeku SO, Homer C, et al. Sickle cell disease: A question of equity and quality. *Pediatrics* 2006;117:1763–1770.
17. American Red Cross. Blood Facts and Statistics. Available at [www.redcrossblood.org/learn-about-blood/blood-facts-and-statistics](http://www.redcrossblood.org/learn-about-blood/blood-facts-and-statistics). Accessed August 10, 2012.
18. American Lung Association. State of Lung Disease in Diverse Communities 2010. Available at [www.lung.org/assets/documents/publications/lung-disease-data/solddc\\_2010.pdf](http://www.lung.org/assets/documents/publications/lung-disease-data/solddc_2010.pdf). Accessed August 10, 2012.
19. Randall VR. Slavery, segregation and racism: Trusting the health care system ain't always easy! An African American perspective on bioethics. *St Louis U Pub Law Rev* 1995;15:191–235.
20. Dula A. African American suspicion of the healthcare system is justified: What do we do about it? *Camb Q Healthc Ethics* 1994;3:347–357.
21. Clark PA. A legacy of mistrust: African-Americans, the medical profession, and AIDS. *Linacore Q* 1998;65:66–88.
22. Waldrop RD, Mandry C. Health professional perceptions of opioid dependence among patients with pain. *Am J Emerg Med* 1995;13:529–531.
23. Chestnut DE. Perceptions of ethnic and cultural factors in the delivery of services in the treatment of sickle cell disease. *J Health Soc Policy* 1994;5:215–242.
24. Telfair J, Myers J, Drezner S. Does race influence the provision of care to persons with sickle cell disease? *J Health Care Poor Underserved* 1998;9:184–195.
25. U.S. Census Bureau. United States Census 2010 data. Available at <http://2010.census.gov/2010census/>. Accessed November 1, 2011.
26. Minnesota physicians facts and data 2008. Minnesota Department of Health. Available at <http://www.health.state.mn.us/divs/orhpc/pubs/workforce/phys08.pdf>. Accessed May 21, 2012.
27. Hall JA, Horgan TG, Stein TS, et al. Liking in the physician–patient relationship. *Patient Educ Couns* 2002;48:69–77.
28. Hall JA, Roter DL, Katz NR. Meta-analysis of correlates of provider behavior in medical encounters. *Med Care* 1988;26:657–675.
29. Kaplan SH, Greenfield S, Gandek B, et al. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med* 1996;124:497–504.
30. Stewart MA. Effective physician–patient communication and health outcomes: A review. *Can Med Assoc J* 1995;152:1423–1433.
31. Association of American Medical Colleges. Diversity in the Physician Workforce: Facts and Figures 2010. Available at [www.aamc.org/factsandfigures](http://www.aamc.org/factsandfigures). Accessed February 1, 2012.
32. Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: Adolescent, adult, and parent perspectives. *J Adolesc Health* 1994;15:558–565.
33. Centers for Disease Control. 2008 Behavioral Risk Factor Surveillance System. Available at [www.cdc.gov/BRFSS/questionnaires/english.htm](http://www.cdc.gov/BRFSS/questionnaires/english.htm). Accessed March 1, 2009.
34. Survey of race, ethnicity and medical care: Public perceptions and experiences. Kaiser Family Foundation. October 1999. Available at [www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13294](http://www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13294). Accessed February 3, 2012.
35. National survey of physicians. Kaiser Family Foundation. March 2002. Available at [www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13955](http://www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13955). Accessed February 3, 2012.
36. Appiah-Kubi A, Lipton JM. The long road to the cure of sickle cell anemia: Reflections on race and medicine in America. *Pediatr Blood Cancer* 2012;58:485–486.