

Does Race Influence the Provision of Care to Persons with Sickle Cell Disease? Perceptions of Multidisciplinary Providers

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Abstract: This study examined whether multi-disciplinary health care providers (HCPs) perceived race of persons with sickle cell disease (SCD) as an influence in the delivery of health care. A total of 227 multidisciplinary HCPs completed the three-item Influence of Patient Race on Provision of Health Care Services Index (Cronbach's alpha = 0.77). Results suggest that African American HCPs were more likely to perceive race as an influence along all scale items, whereas Caucasian and other race HCPs did not. Female HCPs and those who serve adults were more likely than male HCPs and those who serve children to perceive race as having an influence on the quality of health care. Findings suggest a need for the examination of the health care delivery systems in which persons with SCD receive care to determine if race does, in fact, affect the delivery of health care and to explain the discrepancies in the perceptions of the HCPs.

Key words: Race, cultural competency, discrimination, sickle cell disease, health care delivery.

Article:

One of three overarching goals for the nation outlined in *Healthy People 2000*¹ is to reduce health disparities among Americans. Since the United States began to collect race-specific health data 50 years ago, health differences between African Americans and other Americans have been noted. An often, discussed but rarely studied clinical issue is how the race of persons with sickle cell disease (SCD) influences the type and quality of care they receive. Epidemiological studies examining these differences have concluded that race is a major risk factor even after other socioeconomic factors are controlled. Evidence also indicates that characteristics ascribed to being African American, such as being poor or violence prone, influence provider decision making and behaviors.^{2,3}

The discrimination in the health care system faced by African Americans is a function of biases against poverty and race.⁴⁻⁵ Chamberlain⁶ argues that that the majority group's views are based on negative "implied causes" that are stereotypical misconceptions about the social and health practices of African Americans. These views have led to institutionalized racism and classism. Gamble⁷ notes that medicine is not a value-free discipline; rather, it reflects and reinforces the beliefs, values, and power dynamics of the wider society in both its policies and practices. Such practices serve to reinforce the constellation of mistrustful attitudes and beliefs about the medical care system generally held by people of color.³⁻⁵ These attitudes have contributed to the negative health and medical care of many people of color within the health care system, which in turn influence their health behavior.⁸⁻¹⁰ For example, persons who are ethnically and culturally different from health and medical care providers often do not follow through on prescribed medical regimens they do not trust.¹¹⁻¹³

A related problem is the belief among many people of color that health and medical care providers are not really interested in them or their health.¹³ Blendon and colleagues¹⁴ found that that African Americans were more likely than whites to report that during their most recent visit their doctor did not inquire sufficiently

about their pain or symptom, tell them how long it would take for prescribed medicine to work, explain the severity of the illness, or discuss examination findings.

Because SCD occurs most often in African Americans in the United States, the role of race in the delivery of care to persons with this condition is an important issue.¹⁵ Currently, about 65,000 individuals with SCD reside in the United States.¹⁶ It is the most common genetic disorder within a specific population, having an incidence of 1 in every 500 live blackbirths.¹⁷⁻¹⁸ Recent results from the Cooperative Study of Sickle Cell Disease (CSSCD) show that for individuals with the most common and severe form of SCD (hemoglobin SS), the median age of death was 42 years for males and 48 years for females; and, for those with the second most common and milder form (hemoglobin SC), the median age of death was 60 years for males and 68 for females (similar to the general population of African Americans).¹⁵⁻¹⁸

Many persons with SCD must deal with lack of knowledge and understanding of their condition by providers and the general public, the stereotype of being socially dysfunctional as a result of having a chronic condition, and the stigmatization of their condition as the "black disease."¹⁵ In addition to managing a chronic condition like SCD, these individuals must also struggle with issues related to being African American, as well as being a member of a racial group with high rates of poor health and social outcomes (e.g., violence, school dropout and teenage pregnancy).¹⁹⁻²¹

Anecdotal evidence suggests that it is the association with being African American and the chronicity of SCD that may account for much of the disparity in type and quality of care received by persons with SCD. However, the evidence also indicates that there is not consensus among SCD and other providers that patient race affects the delivery of care. Because this important issue has not been addressed in the research and clinical practice literature, many questions remain unanswered. The research presented in this article attempts to address these questions. Specifically, it asks the following: (1) Are there specific clinical care areas in which race of the person influences the type and quality of care as perceived by health care providers? and (2) What characteristics of the provider are associated with the perception that the race of the persons with SCD influences the type and quality of care?

To address these questions, a cross-sectional study was carried out in 1993 by a multidisciplinary team of clinicians and researchers at the University of North Carolina at Chapel Hill (UNC). The purpose of this study was to examine whether multidisciplinary health care providers perceive the race of persons with SCD as influencing their health and medical care. This study was part of a larger study examining the issues, concerns, and expectations of health care providers with regard to the problem of transition of adolescents and young adults to adult care.²²

Methods

A total of 227 multidisciplinary health and medical care providers completed the provider version of the Sickle Cell Transfer Questionnaire (SCTQ) (discussed elsewhere²²). All SCTQ questions were developed specifically for the larger study and were based on patient/parent clinical concerns expressed in individual clinic encounters, three focus group sessions with direct health care providers (psychosocial and biomedical) over a two-year period, and concerns expressed by a cadre of 12 clinicians and researchers from the Duke/UNC Comprehensive Pediatric and Adult SCD Programs and their community-based affiliates. Although the SCTQ was primarily concerned with issues of adolescent transition, the three items examined in this article were asked about the SCD population as a whole. Multidisciplinary health care providers who participated in the study were recruited from the Duke/UNC Comprehensive Sickle Cell Program and its satellites and community-based affiliates; a random sample of private providers from the state of North Carolina, who, because of their specialty area (e.g., internal medicine) had the potential of treating persons with SCD; and a national sample of providers who treat persons with SCD (taken from the National Heart, Lung and Blood Institute roster of SCD providers) (see Table 1).

The provider version of the three-item Influence of Patient Race on Provision of Health Care Services Index (IPR-PHCSI, developed specifically for this study) was included in the SCTQ. Using methods discussed by Spedor²³ and DeVellis²⁴ the IPR-PHCSI assessed participants' underlying perceptions about the influence of race on the provision of care. It also allowed for a clearer examination of the tendency of responses to the three items to be highly correlated in the initial bivariate analysis. The participants were asked to agree (scored as 1) or disagree (scored as 0) with three critical questions about (1) the quality of health care provided to persons with SCD, (2) decisions about the administration of pain medication to persons with SCD, and (3) the quality of interpersonal relations between health care providers and persons with SCD (see the appendix). The lowest possible score for the IPR-PHCSI was 0, and the highest possible score was 3.3. Internal consistency of the IPR-PHCSI, as assessed by Cronbach's alpha, was 0.77. The present study is an examination of the three individual items and the overall index.

TABLE 1
DEMOGRAPHIC CHARACTERISTICS
OF THE PROVIDER SAMPLE

<i>VARIABLE</i>	<i>n</i>	<i>PERCENT OF SAMPLE</i>
Gender		
Female	138	61
Male	89	39
Race		
African American	66	29
Caucasian	141	62
Other	20	9
Population served		
Child/adolescent	138	61
Adult	38	17
Both	51	23
Primary specialty		
Hematologist	37	16
General/family practitioner	20	9
Internist	11	5
Pediatrician	44	19
Nurse practitioner/physician assistant	75	33
Social worker/counselor	40	18
Region		
Urban	174	77
Rural	53	23
Total	227	100

Analyses were conducted at both univariate and bivariate levels. Simple bivariate statistics were used to examine between- and within-group associations of key descriptive and categorical variables (e.g., race, age, gender, and specialty type, respectively). Because it was important to ascertain the perceived level of agreement among providers by category, dummy variables (e.g., 1 = pediatrician, 0 = nonpediatrician) representing the key provider characteristics of race, gender, primary specialty population served and regional location were developed and used in the bivariate analysis

As indicated in Hosmer and Lemeshow,²⁵ because of the sample size and dichotomous outcome variable (perception of race as an influence), multivariate logistic regression analyses of the individual items were conducted. Based on the same rationale, multiple linear regression of the overall index was conducted. The purpose of these analyses was to determine the strongest predictors (independent variables) that best clarify the statistically significant ($p < 0.1$) bivariate results. All analyses were carried out using SPSS/PC+.²⁶

TABLE 2
ASSESSMENT: PROVIDERS' PERCEPTION OF THE
INFLUENCE OF RACE ON THE DELIVERY OF HEALTH
CARE TO AFRICAN AMERICANS WITH SCD (N = 227)

VIEW	PERCENTAGE AGREE	PERCENTAGE DISAGREE
Quality of health care influenced by fact of being African American	49	52
Pain medication decisions influenced by fact of being African American	23	77
Quality of interpersonal relations influenced by being African American	49	52

Results

Demographic characteristics of the sample are listed in Table 1. Individual item results at the univariate level indicate that health care providers generally disagreed that race influences the delivery of health care to individuals with SCD (Table 2).

Health care providers especially did not agree (77 percent) that decisions about pain medications are influenced by the race of their patients. However, the bivariate results indicate that responses to these questions varied by the provider characteristics of race, gender, specialty, population served, and regional location (Table 3). Bivariate results comparing responses to these questions of providers who had a primary treatment focus on persons with SCD (comprehensive centers [44percent] versus those who did not have this focus, e.g., private practice, health departments, etc. [66 percent]), and results comparing providers who were in hospital inpatient/outpatient settings [56 percent] versus those in community-based settings were not statistically significant and, therefore, will not be discussed here or listed in Table 3).

Provider race-ethnicity. Bivariate results indicated that African American providers were more likely to agree with all questions than were both Caucasians and non-African Americans. African American providers were significantly more likely to agree that race is an influence on quality (76 percent, $p < 0.00$), whereas Caucasians were less likely to agree that race is an influence on quality (35 percent, $p < 0.00$) in the provision of healthcare care services for African Americans with SCD (Table 3).

Gender of provider. The bivariate results also reveal that gender is a factor influencing provider perspectives on these questions. Female health care providers were significantly more likely than male providers to agree with all three statements regarding race as an influence on the provision of health care for African Americans with SCD (30 to 54 percent females vs. 12 to 37 percent males, $p = 0.01$ or less) (Table 3).

Provider specialty. Table 3 indicates that with regard to the question of the effect of race on the quality of health care received by African Americans, internists were more likely to agree that race is an influencing factor (72 percent, $p < 0.09$) than were their colleagues. Pediatricians, on the other hand, were more likely than other types of providers to disagree that the quality of health care is affected by race (66 percent, $p < 0.07$). The bivariate results confirmed the univariate results that regardless of specialty, providers tended to disagree that decisions about pain medication are influenced by the fact that patients are predominantly African American. Pediatricians were significantly less likely to agree (9 percent, $p < 0.02$), whereas social workers/counselors were significantly more likely to agree than other health care providers (37 percent, $p < 0.01$). Similarly, on the question of the effect of race on the quality of interpersonal relations between providers and patients, pediatricians were again least likely to agree (29 percent, $p < 0.01$) than other health care providers, whereas social workers/counselors were more likely to agree (60 percent, $p < 0.06$).

TABLE 3
UNIVARIATE AND BIVARIATE ANALYSIS OF
IPR-PHCSI ITEMS BY PROVIDER CATEGORY

	QUALITY OF HEALTH CARE			PAIN MEDICATION DECISIONS			QUALITY OF RELATIONSHIPS		
	% AGREE	χ^2	p	% AGREE	χ^2	p	% AGREE	χ^2	p
Primary specialty									
Hematologist	49	0.560	0.81	24	0.052	0.82	46	0.009	0.92
General/family practitioner	30	2.91*	0.09	1	2.23*	0.13	45	0.077*	0.78
Internist	72	2.72	0.09	27	0.090	0.76	54	0.200	0.65
Pediatrician	34	3.23*	0.07	9	5.65*	0.02	29	6.01*	0.01
Nurse/physician assistant	5	0.647	0.42	25	0.378	0.53	49	0.323	0.57
Social worker/counselor	55	0.904	0.34	37	5.86	0.01	60	3.49	0.06
Population served									
Child-adolescent	44	1.57*	0.21	19	3.51*	0.06	42	2.98*	0.08
Adult	63	4.93	0.03	39	6.48	0.01	60	2.90	0.08
Both populations	43	0.274*	0.60	22	0.012*	0.91	49	0.235	0.63
Gender									
Male	37	6.68*	0.00	12	9.89*	0.00	37	6.41*	0.01
Female	54	6.68	0.00	30	9.89	0.00	53	6.41	0.01
Race-ethnicity									
African American	76	32.25	0.00	42	20.47	0.00	71	21.86	0.00
Caucasian	35	23.53*	0.00	16	11.18*	0.00	37	13.40*	0.00
Other	40	0.591*	0.44	1	2.23*	0.13	35	1.48*	0.22
Region									
Rural	38	2.57*	0.11	11	5.10*	0.02	40	1.56*	0.21
Urban	50	2.57	0.11	26	5.10	0.02	49	1.56	0.21

Note: IPR-PHCSI-Influence of Patient Race on Provision of Health Care Services Index.
*Indicates an inverse relationship; that is, those who mostly disagreed.

Type of population served. Results in Table 3 show that that providers who serve adults were much more likely than those who serve children to agree that race influences the quality of health and medical care (63 percent, $p = 0.3$), the administration of pain medications (39 percent, $p = 0.01$), and the quality of provider/patient relations.

Regional location. Results in Table 33 show that providers in urban and rural areas differed only on the question of the administration of pain medication. Providers in urban locations were more likely than providers in rural areas to agree that race of the patient influences pain medication decisions (26 vs. 11 percent, $p < 0.02$).

In summary, providers who were African American, were female, were not pediatricians, treated adult patients only, and worked in urban areas were more likely to perceive race as an influence in the provision of health and medical care to persons with SCD. Multivariate analyses were conducted to clarify which provider characteristic(s) had the greatest influence on the respondents' beliefs. Given the study's small sample size, all of the provider characteristics that were statistically significant at the bivariate level ($p < 0.1$) were entered into a set of multiple regression models to avoid omitting important variables. Logistic regression models²⁵ were used to examine agreement or disagreement with each of the three individual index items, items, whereas multivariate linear regression models²⁷ were used to assess the overall response trend of providers (the index score) (Table 4A).

Race of the provider (African American) remained significantly related to all three questions ($p < 0.00$). For quality of health and medical care received, received, population served (adults) also remained significant ($p = 0.05$). For pain medication administration decisions, both population served (adults) and gender (female) remained significant ($p < 0.05$, respectively) (Table 4). For all individual items, provider race (African American) was the strongest single predictor of the likelihood of agreement that race was an influence ($p <$

0.00), whereas provider race (African American) and provider gender (female) were the strongest overall (index score) predictors of agreement ($p \leq 0.02$) (Table 4B)

**TABLE 4A
RESULTS OF MULTIPLE LOGISTICS REGRESSION
MODEL FOR INDIVIDUAL ITEMS AND PRACTITIONER
CHARACTERISTICS OF MOSTLY AGREE**

<i>QUESTION</i>	<i>CHARACTERISTICS</i>	β <i>COEFFICIENT</i>	<i>STANDARD ERROR</i>	<i>ODDS RATIO</i>	<i>95 PERCENT CONFIDENCE INTERVAL</i>
Quality of health care	Adults served	0.7666	0.4036	2.2	0.98-4.75*
	Female	0.4087	0.3065	1.5	0.83-2.74
	African American	1.7231	0.3543	5.6	2.80-11.22***
Pain medication decisions	Social worker/counselor	0.5568	0.4161	1.8	0.077-3.94
	Adults served	1.0012	0.4201	2.7	1.19-6.20**
	Female	0.7662	0.4040	2.2	0.97-4.75*
	African American	1.1263	0.3553	3.1	1.54-6.19***
	Urban	0.6808	0.4987	2.0	0.74-5.25
Quality of relationship	Female	0.4222	0.2978	1.5	0.85-2.73
	African American	1.3500	0.3308	3.9	2.02-7.38***

Note: 1 = provider category, 0 = all others.
* $p < 0.05$. ** $p < 0.05$. *** $p < 0.001$.

**TABLE 4B
RESULTS OF MULTIPLE REGRESSION MODEL
FOR OVERALL INDEX AND PRACTITIONER
CHARACTERISTICS OF MOSTLY AGREE**

<i>CHARACTERISTIC</i>	<i>REGRESSION COEFFICIENT</i>	<i>p</i>
Urban	0.20	0.25
Adults	0.44	0.02
African American	0.86	0.00
Social worker/counselor	0.15	0.14
Female	0.54	0.00

Note: For the multiple regression model, $R^2 = 0.19$, $F = 10.34$, $p = 0.0000$.

Finally, it is important to note that the IPR-PHCSI items were worded in such a way as not to imply either a negative or positive influence of race but to allow for individual interpretation by the respondent. Anecdotal provider comments indicated that they perceived the race of the person as negatively influencing the provision of care. Examples of these comments are as follows: "Overall I agree; however, it depends a lot on caregivers individually"; "These factors should not be true—it is most unfortunate they're due to ignorance"; "I do not feel that these issues apply to our clinic; however, unfortunately I do feel that throughout the house staff, some of these [statements] may in fact be true"; and "In our program, in ERs, other hospitals, and so on, I would 'agree' to all three [statements]." The following discussion will take these comments and the interpretation of patient race as a negative influence into account.

Discussion

Data from this study suggest that while providers in general do not view race as influencing the delivery of health and medical care to persons with SCD, there are clear indications that particular groups do feel this way, and as the anecdotal evidence indicates, this influence is perceived as negative. The exception was the strong agreement on the delivery of pain medications. Pain is related to technical decision making about the delivery of prescribed care. It can be argued that it is less individualized and more routinized, thus higher levels of agreement would be found, particularly among specialists. However, with regard to the quality of

care and interpersonal relations between provider and patient, some variation maybe expected because of the potential effect of personal biases, individual beliefs, and social influences on decision making and beliefs about the population. Furthermore, these factors require a deeper level of listening, communicating, and empathy that that are also subject to personal and social influences. The extent of these variations has significant implications for the delivery of care to persons with chronic conditions like SCD, because care of this population requires not only technical expertise but a need to maintain a long-term interpersonal relationship, the monitoring of a regimen of comprehensive (quality) care, and for the provider to demonstrate an adequate level of cultural competence.

Of all the provider characteristics, African American and Caucasian health and medical care providers had opposing views about the effect of race on the delivery and quality of health care for African Americans with SCD. This suggests a lack of understanding and communication between the two groups, as well as their differential health and medical care experiences. African American and female health care providers (of all races) were more likely to believe that race has an influence on the quality of care received, pain medication decisions, and interpersonal relations. But the group that that most often serves individuals with SCD—namely, Caucasian and male health care providers—were less likely to believe that race influenced the delivery of health and medical care. Thus, providers who historically have experienced discrimination are more likely to perceive that race negatively influences care. This is most likely due to the African American and female providers' heightened sensitivity to discrimination as practiced in the health and medical care systems. Furthermore, given the tone of the anecdotal remarks, it is most likely true that providers who have chosen to work with this population have made a conscious decision to work with a predominantly African American population and therefore do not view the race of the patient as a personal issue but they are aware that it is a problem outside of their practice. Interestingly, pediatricians were least likely to view race as an influence in the provision of health and medical care to persons with SCD. This is most likely due to their overall orientation and training, as well as many of the reasons already discussed.

Because of the cross-sectional nature of this study, the overrepresentation of female providers, and the sample size, results of this study must be seen as preliminary. Future research should use a more representative and randomly selected sample of respondents, especially adult and rural providers. Furthermore, it is believed that this study would have been strengthened methodologically if responses had been sought to a series of situational questions or scenarios specifically focusing on the relationship between patient race and service delivery. Therefore, to determine if race in fact affects the delivery of medical care and to explain the discrepancy in the perceptions of female, African American, and Caucasian health care providers according to sex and race,⁵ a logical next step would be a rigorous and systematic study using a series of situation-specific questions that examine the actual quality and type of care offered by providers who serve persons with SCD.

Despite limitations, these findings are consistent with other reports^{1-4,6} and provide support for the anecdotal evidence that suggests that race of persons with SCD influences the type and quality of care they receive. Even these preliminary findings suggest that physicians, nurses, nurses, physician assistants, and other multidisciplinary providers caring for persons with SCD can play a major role in addressing these issues by participating in the development and implementation of continuing education programs that increase providers' awareness of their own disease, race, ethnic background, gender beliefs, and prejudices. Providers can also work with others to build and maintain a culturally diverse and aware staff (inducting scientists and administrators) who are sensitive to the disease management issues of persons with SCD and develop mechanisms that facilitate understanding and communication between patients from diverse cultural and ethnic backgrounds and the health care providers who serve them.

It is essential that health and medical care providers and researchers who care for and study African Americans with SCD take into account and address the ramifications of race, culture class gender, and the chronicity of the condition as factors affecting health, care delivery. This is particularly important because

the majority of researchers and physicians providing care for individuals with SCD are Caucasian and male and the majority of individuals with SCD are African American.

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APPENDIX

Influence of Patient Race on the Provision of Health Care Services Index

	AGREE	DISAGREE
A. The quality of the health care SCD patients receive is influenced by the fact that most patients are African American	<input type="checkbox"/>	<input type="checkbox"/>
B. The decisions to administer pain medications to SCD patients are influenced by the fact that most patients are African American	<input type="checkbox"/>	<input type="checkbox"/>
C. The quality of the interpersonal relationships in the treatment process of SCD patients are affected by the fact that most patients are African American		

Note: The response pattern for the set of items in Appendix was dichotomized (0 = disagree, 1 = agree) to facilitate the process of answering questions.

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