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Perceived Discrimination in Health Care is Associated with a Greater Burden of Pain in Sickle Cell Disease

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Abstract

Context—Perceived discriminatory experiences in society have been associated with a higher burden of pain among some minority patient populations.

Objectives—To describe the extent to which patients with sickle cell disease (SCD) perceive discrimination from health care providers, and to examine the association of these experiences with the burden of chronic SCD pain.

Methods—Cross-sectional analysis of data collected at baseline of a prospective cohort study of SCD patient experiences of care (n = 291). Perceived race-based and disease-based discrimination from health care providers were measured using subscales adapted from the Interpersonal Processes of Care Survey. Discrimination scores were examined for their association with patient characteristics and measures of pain burden using descriptive, bivariate, and multivariate analytic techniques.

Results—Respondents reported a greater burden of race-based discrimination from health care providers than has been previously reported by African Americans, and they reported a greater amount of disease-based versus race-based discrimination. While age and having difficulty persuading providers about pain were the only patient characteristics independently associated with race-based discrimination, older age, greater emergency room utilization, having difficulty persuading providers about pain, daily chronic pain, fewer “good days” during a week, and a higher severity of pain on their “good days” were independently associated with greater disease-based discrimination.

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Disclosures

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Conclusion—Perceived disease-based, but not race-based, discrimination was found to be associated with a greater range of self-reported pain among patients with SCD. If causal, this finding could signal an important new approach to mitigating the burden of pain experienced by persons with SCD.

Keywords

Discrimination; patient-provider communication; health care quality; sickle cell disease; chronic pain

Introduction

Racial and ethnic disparities in the burden of pain and in the quality of pain treatment are a significant public health problem in the U.S.¹ A full understanding of the causes of these disparities is required for their effective mitigation. Racial and ethnic discrimination is hypothesized to play an important role in the development and maintenance of health disparities.² Individual perceptions of experiences with racial discrimination have been associated with a number of adverse health behaviors and outcomes, including worse physical and mental health.³ A growing body of research has begun to explore the impact of racial discrimination as a contributing factor to the higher burden of pain experienced by racial and ethnic minorities. In one study, Edwards found that the lifetime experience of racial discrimination was the strongest predictor of the report of back pain among a sample of African Americans, even after accounting for a number of demographic, physical, and mental health-related factors.⁴ Similarly, Burgess et al. found that perceived racial discrimination was associated with greater bodily pain among a sample of older African American men.⁵ While these studies suggest an important potential cause of the high burden of pain typically experienced by African Americans, their design raises questions about generalizability to other African American patient populations. Additionally, both prior studies examined patient experiences of racial discrimination from a wide array of potential sources in society (e.g., school, employment, daily experiences, etc.) but failed to examine discrimination from health care providers. The extent to which perceived discrimination is experienced in health care is an important area of inquiry since it is within this context that health care organizations and health policy-makers might exert their greatest level of influence in ameliorating the health effects of discrimination.

The current study seeks to address these two important gaps in our knowledge by examining perceived discrimination in health care among patients with sickle cell disease (SCD). In the U.S., African Americans have the greatest incidence of SCD at 1 per every 400 African American births.⁶ The disease has a significant impact on the health of the affected individual as it is the cause of early mortality and a great degree of morbidity, including frequent episodes of severe acute pain and a high burden of chronic pain.^{7, 8}

The characteristics of SCD, unfortunately, make it an ideal patient population for the study of the relationship between discrimination and pain. Many health care providers have been shown to possess negative attitudes about SCD patients that serve as significant barriers to the delivery of appropriate pain management in SCD.^{9–15} These attitudes contribute to

many problems in the interpersonal quality of care delivered to SCD patients.^{16–19} Nevertheless, the extent to which SCD patients perceive discrimination from health care providers, and the extent to which this perceived discrimination is independently associated with the burden of SCD pain, is not known. The aims of the current study were twofold: 1) To describe the extent to which patients with SCD perceive discrimination from health care providers, and 2) To examine the association between perceived discrimination and the burden of chronic SCD pain.

Methods

Study Design, Subjects and Setting

Our study was conducted using data collected as part of the Improving Patient Outcomes with Respect and Trust (IMPORT) study. The IMPORT study is a federally funded observational cohort study of SCD patient experiences with health care taking place at two academic medical centers in the Baltimore/Washington D.C. metro area.

Eligibility criteria for the IMPORT study were: 1) age 15 years or older, 2) diagnosed with any of the following sickle hemoglobinopathies: HbSS, HbSC, Hb SB-thalassemia or Hb SS/a-thalassemia, 3) no reported plans to move in the next three years, and 4) expressed willingness to adhere to study procedures. Research assistants recruited eligible patients from waiting rooms of adult and pediatric SCD clinics at the two study sites, and all study subjects provided written informed consent. The Institutional Review Boards at both the Johns Hopkins Medical Institutions and Howard University Hospital approved all study procedures.

Data Collection Procedures

Participating patients completed a comprehensive baseline questionnaire administered by an audio computer-assisted self-interview (ACASI) system. Questions were read to the patient through a headset and they answered using touch-screen technology at a private computer station. We collected data on the patient's perceptions of the previous quality of their health care experiences, basic demographic information, health status, clinical complications, and psychosocial characteristics. The specific measures collected and used for the current analysis are as follows:

Dependent Variables: Perceived Discrimination from Health care Providers

Our primary outcome was SCD patients' perceptions of discrimination from health care providers. We examined two different types of discrimination as potentially perceived by patients from their providers. First, we assessed patient perceptions of discrimination on the basis of their race or ethnicity using the "Discrimination due to Race/Ethnicity" subscale from the previously validated "Interpersonal Process of Care Survey".^{20, 21} The race/ethnicity discrimination subscale is a two-item measure which asked the following: "The following questions are about the personal interactions between you and your doctor(s) over the past 12 months: 1) How often did doctors pay less attention to you because of your race or ethnicity?; and 2) How often did you feel discriminated against by doctors because of your race or ethnicity?" Responses for both are rated on a 5-point scale ranging from (1

“never”) to (5 “always”). Subscale scores for an individual were created by taking the mean of their responses to both items, with higher scores indicating a greater amount of perceived discrimination due to race/ethnicity. This subscale was found to have acceptable internal consistency in prior studies (Cronbach’s alpha = 0.79), and in our current study sample (Cronbach’s alpha = 0.72), and prior studies reported a mean (SD) score of 1.35 (0.77) out of 5 among African American respondents.²¹

We adapted the race/ethnicity discrimination measure to assess perceived discrimination due to the patient having SCD (i.e., disease-based discrimination). We substituted the phrase “because of your sickle cell disease” for the phrase “because of your race or ethnicity”. This new disease-based discrimination measure had a Cronbach’s alpha of 0.87 in the current study sample.

Independent Variables: Potential Correlates of Perceived Discrimination

We examined a number of patient characteristics as potential correlates of SCD patients’ perceptions of discrimination from health care providers. Demographic characteristics consisted of patient age, sex, and education (high school or less, some college, college grad and beyond). We asked each respondent to provide an assessment of their general health status (poor/fair, good, very good/excellent), and their self-reported annual emergency department visits for pain (none, 1–2, 3–5, 6–10, 10+). We examined one aspect of the quality of the patient’s previous experiences with health care using a single-item that asked the patient if they had ever experienced difficulty in persuading health care providers about their pain (yes/no).²² Respondents were asked to assess the burden of their chronic SCD pain using three different, single-item measures: whether or not they experience daily chronic pain (yes/no), the number of “good days” the patient experiences each week (0 to 7, with a higher score equaling a lower burden of pain during a typical week), and their self-reported level of pain on their “good days” (0 to 10, with higher scores equaling more severe pain on their “good days”).

Statistical Analyses

We used basic descriptive statistics to describe our sample’s levels of perceived discrimination and their personal characteristics. Paired t-tests were used to compare the reported burden of race-based discrimination to the reported burden of disease-based discrimination among the respondents, and one-sample t-tests were used to compare the report of race-based discrimination in the sample to scores on this measure reported in prior studies.²¹ We used Pearson correlations to assess the bivariate associations among both measures of discrimination and the continuous patient characteristics. Because our two measures of discrimination were hypothesized, and later shown empirically, to be correlated, we accounted for the correlation between them by using one-way multivariate analysis of variance (MANOVA) to examine the association between both constructs taken together and our categorical patient characteristics. Wilks’ Lambda statistic was the multivariate test used to assess statistical significance. Characteristics found to be significantly associated with discrimination at the bivariate level were included in multivariate multiple regression models. These models were constructed in order to determine which (if not both) specific measure of discrimination was associated with patient characteristics, to assess the

independence of the association after adjustment for other, potentially confounding, patient characteristics, and to compare the magnitude of any observed associations between both measures of discrimination. Because the association of pain with discrimination was of particular interest, and because of collinearity observed among the pain burden measures (having daily chronic pain, the number of “good days”, and the level of pain on the “good days”) only one of the pain burden measures was chosen for inclusion in the regression models. However, we conducted sensitivity analyses with each measure to assess how, if at all, the results would change with the use of a different measure of pain burden. A p-value of 0.05 was the threshold used to determine statistical significance in both the bivariate and multivariable analyses. All analyses were conducted using the Stata 13.0 statistical software package.²³

Results

Characteristics of the Sample

Two hundred ninety-one (291) individuals participated in the IMPORT study, and 97% of them reported their race as Black or African American. The characteristics of the study sample and distribution of the variables assessed for the current study are described fully in Table 1. The average age of the respondents was 34.5 years, and slightly more than half of the respondents were female. Fifty-four percent of the respondents reported having daily chronic pain, the median number of “good days” in a typical week reported by the patients was 4, and the median reported pain level on those “good days” was 2 out of 10.

The Burden and Correlates of Perceived Discrimination

The mean (SD) score on the race/ethnicity discrimination subscale reported by this SCD sample of 1.6 (0.89) was significantly higher than the average scores of 1.35 and 1.23 observed on this measure in a comparison sample of African Americans and an all-race comparison sample, respectively ($p < 0.0001$), suggesting a greater level of perceived race-based discrimination among the SCD sample. The SCD sample reported an even higher level of disease-based discrimination, with a mean (SD) score of 2.1 (1.17) on the disease-based discrimination measure, which is statistically significantly higher than the observed race-based discrimination score reported by the sample ($p < 0.0001$).

Table 2 illustrates the bivariate correlations between the discrimination measures, as well as their correlations with the continuous patient characteristics of age and the measures of pain burden. As hypothesized, a significant and moderate-sized correlation between the two measures of discrimination was observed ($r = 0.51$, $p < 0.001$). Race-based discrimination was further observed to have a small, but significant, correlation with age ($r = 0.124$, $p < 0.05$), as well as a small but significant inverse correlation with the number of reported “good days” ($r = -0.162$, $p < 0.01$), suggesting that greater perceived discrimination was associated with fewer “good days” in a typical week. Compared to race-based discrimination, disease-based discrimination had a stronger inverse correlation with the reported number of “good days” ($r = -0.266$, $p < 0.001$), and disease-based discrimination also had a significant correlation with the reported level of pain observed on “good days” (r

= 0.247, $p < 0.001$), suggesting that greater disease-based discrimination was associated with a more severe level of pain on the “good days”.

Table 3 presents the association of the discrimination measures with the categorical patient characteristics. The results of the MANOVA analyses suggested that, taken together, the measures of discrimination were associated with greater emergency room utilization, having difficulty persuading providers about pain, and experiencing daily chronic pain. However, the multivariate multiple regression models (Table 4) showed an interesting pattern of associations after considering the measures of discrimination separately. In the regression models, only age and having difficulty persuading health care providers about pain remained independently associated with race-based discrimination after adjustment for emergency room utilization and experiencing daily chronic pain. In total, those patient characteristics explained about 9% of the variability in race-based discrimination scores. In contrast, age, emergency room utilization, difficulty persuading providers about pain, and having daily chronic pain were all independently associated with disease-based discrimination, and these variables explained 23% of the variability in disease-based discrimination scores overall. Furthermore, the difference in average discrimination score between patients having difficulty versus no difficulty in persuading providers about pain was larger for perceptions of disease-based discrimination (0.71, 95% CI (0.45 to 0.98) than race-based discrimination (0.45, 95% CI (0.22 to 0.67). Sensitivity analyses were conducted to determine whether the choice of measure of pain burden affected the results. Models using the number of “good days” or the pain level on the “good days” instead of the report of having daily chronic pain led to the same results and conclusions, with each model explaining about 23% of the variability in disease-based discrimination.

Discussion

Research examining the prevalence of discrimination in health care is in great need,²⁴ as is work to replicate prior studies that have found associations between discrimination and pain. Using data collected from a large cohort of mostly adult patients with SCD in the U.S., we describe the burden of discrimination as perceived by these patients, and we find compelling differences between the association of various patient characteristics, the burden of pain, and perceptions of disease-based, as opposed to race-based, discrimination.

The SCD patients reported a relatively low burden of perceived race-based discrimination from health care providers. The mean score of 1.6 on the race-based discrimination measure used in this study suggests an average burden of race/ethnicity based discrimination from providers that falls between “never” and “rarely” using the instrument’s interpretive scale. Nevertheless, this report of discrimination, while low in absolute magnitude, suggests a significantly greater burden of perceived race-based discrimination from health care providers compared to that perceived by other groups of patients of all-races, as well as other groups of African American patients specifically, when using this same measure.²¹ Both findings seem reasonable and consistent with prior knowledge. Systematic reviews of the problem of discrimination and its impact on health have found that patients tend to report relatively low levels of perceived discrimination when reporting on or thinking about their own individual experiences, but they report greater levels of perceived discrimination when

asked to report on the experiences of other members from their group or community.²⁴ This might explain the low burden of perceived race-based discrimination found in the current study as we asked our respondents to report on their own individual experiences with doctors. At the same time, SCD is a condition with a history (in the U.S.) that is inextricably bound with notions of “African American race” that continues to this day.^{25, 26} Furthermore, studies of SCD patients and health care providers have found that race is often thought by members of both groups to impact the quality of the care delivered to SCD patients.^{27, 28} Therefore, it is not surprising that patients with SCD might perceive a higher level of race-based discrimination from health care providers than other groups of African American patients, as was found here.

Our SCD sample reported a greater level of discrimination from health care providers on the basis of their having SCD than due to their race or ethnicity, and many patient-characteristics were found to be independently associated with disease-based discrimination. Perceptions of disease-based, but not race-based, discrimination from health care providers were found to be independently associated with three different measures of the burden of SCD pain. Patients reporting having daily chronic pain, reporting fewer “good days” during a typical week, and reporting more severe pain on their “good days” also reported greater levels of perceived disease-based discrimination from their health care providers. This contributes to the literature on discrimination in health care by suggesting that discrimination from health care providers can have a similar impact on the experience of pain among minority populations as has been found by studies examining general experiences of discrimination in day-to-day life and their associations with pain.^{4, 5} The exact mechanisms by which experiences of discrimination may affect the experience of pain are unclear. Discrimination outside of the health care system is hypothesized to lead to chronic stress, and that chronic stress may lower one’s pain sensitivity or ability to cope with pain.^{29–32} Our results raise the question as to whether a similar mechanism may be in place for discrimination experienced specifically within the health care setting. Repeated interactions with the health care system might lead to repeated experiences of disease-based discrimination, which in turn leads to chronic stress as experienced by the patient, and thus affects their sensitivity to, and ability to cope with, the tissue damage caused by SCD that can lead to chronic pain. The fact that disease-based, but not race-based, discrimination was found to be associated with chronic pain, independent of health care utilization, suggests that SCD patients make important distinctions between, or differentially attribute, discriminatory behaviors from health care providers and whether these behaviors are due to the patient’s race/ethnicity or their disease.

Both disease-based and race-based discrimination were found to be independently associated with having difficulty persuading health care providers about pain, though the relationship was observed to be greater in magnitude for perceptions of disease-based discrimination. Additionally, disease-based, but not race-based, discrimination was also found to be independently associated with greater emergency room utilization for pain. The negative attitudes that many health care providers have towards patients with SCD are known to be major problems and barriers to the delivery of appropriate pain management for these patients.^{11, 13–15} The attitudes of health care providers towards SCD patients have been shown to be associated with various characteristics of the SCD patients, with providers

exhibiting more negative attitudes towards SCD patients with greater hospital utilization, and for patients that have had documented disputes with staff regarding pain or analgesia.⁹ The findings of our study exactly mirror these prior findings, but from the patient's perspective. Our findings suggest that patients who have disputes with health care providers regarding their pain attribute the difficulty to both their race/ethnic status and their status as having SCD, with their status as having SCD perhaps receiving greater attribution. Our findings also suggest that SCD patients are accurately able to pick up on the attitudes exhibited by health care providers, thus validating patient reports of the problematic experiences and poor interpersonal interactions they tend to have with providers when seeking treatment for their pain.

Some limitations must be taken into account when interpreting our findings. The cross-sectional nature of our study makes it impossible to make definitive statements regarding the causal directionality of the relationships we observed between perceived disease-based discrimination and the burden of chronic SCD pain. It is possible that SCD patients with a higher burden of chronic pain are less satisfied with the care they receive from health care providers overall, and thus more likely to perceive certain communication styles or behaviors exhibited by providers as discriminatory in nature. It is also possible that medical providers discriminate against patients with frequent or chronic pain. Future research using prospective designs is required to help disentangle the directionality of these relationships. The measures of pain burden used in the current study were designed to assess chronic SCD pain. Future studies of the relationship between discrimination and pain in SCD should include measures of acute SCD pain in order to determine if similar findings will result. If so, this would further clarify and provide greater evidence for a causal relationship between discrimination and pain. Our results suggest that SCD patients make important distinctions between race-based and disease-based discrimination. However, the nature of the measurement of both types of discrimination does not allow us to understand how the patients make distinctions between the two constructs. Furthermore, the disease-based discrimination measure used in the current study is a new measure and has not been previously validated. Nevertheless, the relationships between this new measure and other variables observed in this study provide preliminary evidence in support of its construct validity. Finally, our data were collected from a regional cohort of SCD patients in the U.S., so the extent to which these findings generalize to other SCD patients is unknown. Nevertheless, our findings of the association between perceived discrimination and pain do replicate, in part, the few prior studies examining this relationship, thus adding more evidence in support of an important role of perceived discrimination in the experience of pain.

Despite these limitations, we believe that our results provide important contributions to the literatures on discrimination in health care and discrimination as a significant cause of the greater burden of pain experienced by minorities. If the relationship between experiences of disease-based discrimination from health care providers and a greater burden of pain among SCD patients is ultimately found to be causal, this then becomes an important new area through which the burden of SCD pain may be mitigated, which is needed for a condition that has historically seen relatively few advances in the treatment of pain.

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Table 1

IMPORT Sample Characteristics

Age (years), mean(sd)	34.5	(12.5)
Sex,	n	(%)
Male	134	46.0
Female	157	54.0
Education,		
HS or less	185	64.9
Some College	45	15.8
College Grad & more	55	19.3
General Health Status,		
Poor/Fair	111	38.4
Good	123	42.6
Very Good/Excellent	55	19.0
Annual Visits to Emergency Room/Infusion Center		
None	47	16.3
1 to 2	93	32.2
3 to 5	78	27.0
6 to 10	42	14.5
More than 10	29	10.0
Difficulty persuading providers about pain		
No	177	61.0
Yes	113	39.0
Daily chronic pain		
No	132	45.7
Yes	157	54.3
# of "Good" Pain Days (range 1–7), median(IQR)	4	(3, 6)
Pain level on "Good" Days (range 0–10), median(IQR)	2	(0, 4)

Table 2

Pearson Correlations Among Perceived Discrimination, Patient Age, and Pain Burden

	1 [†]	2	3	4	5
1. Race Discrimination Score	---				
2. Disease Discrimination Score	0.507***	---			
3. Age	0.124*	0.0845	---		
4. # of "Good" Pain Days	-0.162**	-0.266***	-0.0673	---	
5. Pain on "Good" Days	0.0980	0.247***	0.123*	-0.472***	---

* $p < 0.05$,** $p < 0.01$,*** $p < 0.001$ [†] Column numbering corresponds to the matching row number. For example, Column #1 is "Race Discrimination Score"; Column #2 is "Disease Discrimination Score"; and etc.- The individual Pearson correlations represent the magnitude of the linear association between the variables depicted at the intersection of each column/row pair. For example, the Pearson correlation between Race discrimination scores and disease discrimination scores is 0.507, which is significant at $p < 0.001$.

Table 3

Perceived Discrimination by Patient Characteristics

	Perceived Discrimination Score		p-value ¹
	Race-based	Disease-based	
	Mean (SD)	Mean(SD)	
Overall	1.6(0.89)	2.1(1.17)	
Sex			0.219
Male	1.6(0.90)	2.0(1.16)	
Female	1.6(0.89)	2.1(1.17)	
Education			0.264
HS or less	1.6(0.89)	2.0(1.18)	
Some College	1.6(0.98)	2.3(1.19)	
College Grad +	1.6(0.85)	1.9(1.00)	
General Health Status			0.201
Poor/Fair	1.6(0.93)	2.2(1.18)	
Good	1.6(0.85)	2.0(1.09)	
VeryGood/Excellent	1.6(0.93)	1.8(1.20)	
Emergency Room/Infusion Center Annual Visits			<0.0001
None	1.5(0.89)	1.5(0.95)	
1 to 2	1.6(0.84)	1.9(1.04)	
3 to 5	1.6(0.97)	2.1(1.12)	
6 to 10	1.7(0.96)	2.5(1.15)	
More than 10	1.5(0.78)	2.8(1.34)	
Difficulty Persuading Providers about Pain			<0.0001
No	1.4(0.78)	1.7(1.04)	
Yes	1.9(1.00)	2.6(1.17)	
Daily Chronic Pain			<0.0001
No	1.4(0.76)	1.7(0.92)	
Yes	1.7(0.98)	2.4(1.27)	

¹ Joint test of group differences in discrimination means by MANOVA (Wilks' Lambda)

Table 4

Multivariate Multiple Regression Results

	Estimated Average Change in Race-Discrimination Score [95% CI]	Estimated Average Change in Disease-Discrimination Score [95% CI]
Age (years)	0.01 * [0.00,0.02]	0.01 * [0.00,0.02]
ED Utilization		
None	Reference	Reference
1 to 2	-0.05 [-0.37,0.27]	0.29 [-0.10,0.67]
3 to 5	-0.04 [-0.37,0.30]	0.41 * [0.01,0.81]
6 to 10	0.01 [-0.38,0.41]	0.66 ** [0.20,1.13]
More than 10	-0.24 [-0.69,0.21]	0.94 *** [0.41,1.48]
Difficulty Persuading – Yes vs. No	0.45 *** [0.22,0.67]	0.71 *** [0.45,0.98]
Chronic Pain – Yes vs. No	0.15 [-0.07,0.37]	0.27 * [0.00,0.53]
N	276	276
R ²	0.09	0.23

*
 $p < 0.05,$ **
 $p < 0.01,$ ***
 $p < 0.001$