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# Perceived Discrimination, Patient Trust, and Adherence to Medical Recommendations Among Persons with Sickle Cell Disease

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**BACKGROUND:** Adults with sickle cell disease (SCD) report experiencing discriminatory behavior from some healthcare providers. The impact of discrimination on health outcomes in SCD, including adherence to physician recommendations, is not known.

**OBJECTIVE:** Our aim was to evaluate the association between perceived discrimination from healthcare providers and nonadherence to physician recommendations among persons with SCD, and to test the potentially mediating role of patient trust.

**PARTICIPANTS:** Patients with SCD (age 15 years and older) participating in the Improving Patient Outcomes with Respect and Trust (IMPORT) Study.

**MAIN MEASURES:** Perceived discrimination from healthcare providers and reported adherence to physician recommendations were assessed by patient self-report using items from the 2001 Commonwealth Fund Health Survey. Interpersonal trust in medical professionals was assessed using the short form of the Wake Forest Trust in Medical Professionals instrument.

**DESIGN:** We used a cross-sectional analysis of IMPORT participant data. Multivariable Poisson regression models were used to test the independent association of discrimination with adherence and to test patient trust as a potential mediator.

**KEY RESULTS:** Among 273 SCD patients with complete data on all variables of interest, patients reporting experiences of discrimination in the healthcare system were 53 % more likely to also report being nonadherent to physician recommendations. Trust in medical professionals appeared to mediate the discrimination/nonadherence relationship, accounting for 50 % of the excess prevalence of nonadherence among those experiencing discrimination.

**CONCLUSION:** SCD patient perceptions of discriminatory experiences from healthcare providers are associated with greater nonadherence to physician recommendations, and may be a potential factor contributing to disparities in health and health quality among this patient population. Perceived discrimination appears to affect adherence behaviors through the pathway of patient trust.

Improving relationships between healthcare providers and SCD patients may improve the trust that SCD patients have in medical professionals, which in turn may improve other outcomes among this underserved patient population.

**KEY WORDS:** sickle cell disease; discrimination; trust; adherence.

J Gen Intern Med 29(12):1657-62

DOI: 10.1007/s11606-014-2986-7

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## INTRODUCTION

Sickle cell disease (SCD) is a serious disorder of the blood that has a wide array of deleterious effects on the human body and psyche. As the most common genetic condition detected by newborn screening efforts in the United States, SCD is estimated to affect approximately 100,000 individuals.<sup>1-3</sup> Persons with the disease are subject to a high burden of acute and chronic pain, greater susceptibility to infections, strokes, neurocognitive deficits, progressive organ and tissue deterioration, and a generally low health-related quality of life.<sup>4</sup>

There are relatively few effective treatment options for SCD. Because of this, the ability and willingness of SCD patients to adhere to recommended medications and physician recommendations for treatment becomes all the more important to improving the health and quality of life of affected individuals. In a prior study, we found that only 27 % of a Medicaid-managed care population with SCD who ever utilized hydroxyurea, which is one of the few effective treatment options available for SCD, showed signs that they were adherent to the medication.<sup>5</sup> Similarly, Candrilli et al. found that 35 % of a Medicaid population with SCD were adherent to hydroxyurea, despite the clear benefit of the therapy, as observed in the study cohort.<sup>6</sup> Little is known about the reasons why persons with SCD have low levels of adherence to medications and other treatments known to be beneficial.

Of the factors that are thought to affect patient adherence to physician recommendations across many health conditions,

Received January 22, 2014

Revised June 6, 2014

Accepted July 18, 2014

Published online September 10, 2014

our focus in this study is on the quality of the relationship between the patient and the healthcare provider.<sup>7</sup> A good relationship between the patient and provider can facilitate adherence, while a problematic relationship can negatively impact patient adherence. Patients with SCD may experience problematic interpersonal experiences in the healthcare setting.<sup>8,9</sup> In previous work, we have shown that hospitalized SCD patients are more likely than other hospitalized patients to report poor interpersonal experiences of care.<sup>10</sup> Negative healthcare provider attitudes serve as a barrier to the delivery of appropriate pain management among these patients, and poor communication with healthcare providers is associated with lower trust and problematic clinical outcomes, such as discharge against medical advice.<sup>11–13</sup> While the impact of problematic experiences on the trust that SCD patients have in the medical profession is clear, the extent to which problematic experiences and lower trust have further downstream effects on important outcomes, such as patient adherence to medical recommendations, has not been adequately studied.

We designed the current study to address this shortcoming in our knowledge. Our objectives were to test an explanatory model of the impact of poor interpersonal communication with healthcare providers, specified in the form of perceived experiences of discrimination from healthcare providers, on SCD patient self-reported adherence to physician recommendations. We hypothesized that trust in the medical profession would be found to mediate the relationship between experiences of discrimination and adherence to physician recommendations, independent of potential confounding variables.

## METHODS

### Study Design, Subjects and Setting

This study was conducted 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 healthcare taking place at two academic medical centers in the Baltimore/Washington D.C. metropolitan area. This study was approved by the Institutional Review Boards at both the Johns Hopkins Medical Institutions, as well as Howard University.

Persons eligible to participate in the IMPORT study: 1) were age 15 years or older; 2) diagnosed with one of the following sickle hemoglobinopathies (ICD-9-CM code): HbSS (282.60–282.62), HbSC (282.63–282.64), Hb SS/B-thalassemia or Hb SS/a-thalassemia (282.41–282.42); 3) reported no plans to relocate 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. Data from all IMPORT study participants were eligible for the current analysis.

### Data Collection Procedures

At baseline, participating patients completed a comprehensive questionnaire administered by an audio computer-assisted self-interview (ACASI) system. The ACASI system read questions to the patient through a headset and allowed the patients to answer using touch-screen technology at a private computer station. We collected data on their perceptions of the quality of prior healthcare experiences, basic demographic information, health status, clinical complications, and psychosocial attitudes. The specific measures collected and used in the current study are as follows:

### Dependent Variable: Adherence to Physician Recommendations

Our dependent variable was the patient's self-reported adherence to physician recommendations over the prior 2-year period, and it was assessed using an item from the Commonwealth Fund 2001 Health Care Quality Survey.<sup>14</sup> The single, binary (yes/no) item read "Has there been a time in the last two years when you didn't follow the doctor's advice or treatment plan, including getting a recommended test or seeing a referred doctor?" A response of "yes" was coded as a 1 (i.e., patient categorized as "Nonadherent"), while a "no" was coded as a 0 (i.e., patient categorized as "Adherent").

### Independent Variable: Experiences of Discrimination from Healthcare Providers

For our independent variable, we assessed perceived discrimination from healthcare providers using a five-item instrument designed to measure Health System Bias and Cultural Competence and adapted from the Commonwealth Fund 2001 Health Care Quality Survey.<sup>14,15</sup> Of the five items, one read: "Do you think there was ever a time when you would have gotten better medical care if you had belonged to a different race or ethnic group?" (yes/no). The four remaining binary (yes/no) items had the following stem: "Thinking about all of the experiences you have had with health care visits in the last 2 years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect because [of:]" 1) your race or ethnic background? 2) how well you speak English? 3) the type of insurance you have? 4) you have sickle cell disease?

Patients with a response of "yes" to any of the five items were categorized as having "An Experience of Discrimination" from healthcare providers over the prior 2-year period,

while patients responding “no” to all five items were categorized as having “No Prior Experience of Discrimination”.

### Potential Mediator: Patient Trust in the Medical Profession

We assessed patient-reported trust in the medical profession using the five-item Wake Forest Trust in Medical Professionals instrument described by Dugan et al.<sup>16</sup> This instrument measures respondent trust in medical professionals generally (in contrast to trust in a specific physician or healthcare provider). Scores on this instrument are placed on a 0 to 100 scale, with higher scores signifying greater levels of trust in the medical profession.

### Covariates

We examined seven patient characteristics as potential covariates: age, sex, education (high school or less, some college, college and beyond), annual household income ( $\leq$  \$29,999; \$30,000+), perceived health status (poor/fair, good, very good/excellent), the experience of daily chronic pain (yes/no), and self-reported annual emergency department utilization (none, 1–2, 3–5, 6–10, more than 10).

### Analytic Methods

We used t-tests and chi-square tests as appropriate to examine the bivariate associations among study variables, using differences in means and proportions as our reported bivariate unstandardized measures of effect size. Due to the relatively high frequency of our outcome variable (nonadherence), and because odds ratios from logistic regression are known to overestimate relative risks when the outcome of interest has a high frequency,<sup>17–19</sup> we used multivariable Poisson regression models with a robust variance estimator to test the independent association of experiences of discrimination with nonadherence to physician recommendations, and to test the role of patient trust as a mediator of the discrimination/nonadherence relationship. With this modeling approach, we generated prevalence ratios (PRs) that were used as our reported multivariable measures of effect size, and that avoided the built-in bias in the magnitude of effects that can come from logistic regression models on common outcomes.<sup>19,20</sup> Model building proceeded, using our three primary variables of interest (discrimination, trust, and nonadherence), and any covariates found to be significantly associated with adherence status at a level of  $p \leq 0.05$  in bivariate analyses. Because none of the patient characteristics were found to be associated with adherence status at the stipulated level of significance, we subsequently included age, sex, and education in all multivariable models due to their importance in studies of this type, and for the purpose of face validity of our models. We adapted Baron and Kenny’s approach to the study of mediation by using three multivariable models to explore our study

objectives: Model 1 examined the relationship of discrimination to patient trust, while adjusting for age, sex, and education. Model 2 examined the relationship of discrimination to nonadherence, while adjusting for age, sex, and education. Finally, Model 3 examined the relationship of discrimination and trust to nonadherence, while accounting for age, sex, and education.<sup>21</sup> The magnitude of the impact of trust on the discrimination/nonadherence relationship was estimated using a seemingly unrelated regression approach combined with a test of the proportionate change in model effect sizes constructed with a non-linear combination of estimators. Stata 13.1 was used for all statistical analyses.<sup>22</sup>

## RESULTS

### Description of the Sample

Two hundred and ninety-one individuals enrolled into the IMPORT Study. Table 1 lists the demographic breakdown of the IMPORT respondents overall and by their self-reported adherence status. None of the patient demographic characteristics assessed were associated with adherence status. In total, 35.9 % of the sample reported nonadherence to a physician’s recommendation within the prior 2-year period of the patient interview.

### Bivariate Associations Among Discrimination, Trust, and Nonadherence

Our two primary predictors of interest (discrimination and trust) were significantly associated with adherence status at the bivariate level. Fifty-eight percent of the nonadherent group, compared to 43 % of the adherent group, reported at least one experience of discrimination ( $p=0.01$ ). The nonadherent group reported significantly lower levels of trust than did the adherent group (52.4 vs. 60.8,  $p=0.001$ ).

### Multivariable Results: Testing Trust as a Mediator of the Discrimination/Nonadherence Relationship

The results of our multivariable modeling are found in Table 2. Model 1 depicts the relationship of discrimination with trust independent of age, sex, and education. Experiences of discrimination were associated with an approximately 17-point reduction in reported trust in medical professionals, adjusting for age, sex, and education ( $\beta=-16.7$ , 95 % CI [–20.9, –12.5]). Model 2 illustrates the relationship of discrimination to nonadherence. The prevalence ratio for nonadherence comparing those with prior experiences of discrimination to those without was approximately 1.5 (95 % CI [1.1, 2.1]). This suggests that those with prior experiences of discrimination were 53 % more likely to report nonadherence to physician

Table 1. Patient Demographics by Self-Reported Adherence

	Overall No. (Col%)	Nonadherence with doctor's advice—prior 2 years		<i>p</i> value
		Adherent ( <i>n</i> =184) No. (Col%)	Nonadherent ( <i>n</i> =103) No. (Col%)	
Prior experience of discrimination (any type)—2 years				
No discrimination	149 (51.4)	104 (56.8)	43 (41.7)	0.01
Experienced discrimination	141 (48.6)	79 (43.2)	60 (58.3)	
Patient age—mean (SD)	34.5 (12.5)	34.5 (13.2)	34.7 (11.1)	0.93
Female	157 (54.0)	98 (53.3)	57 (55.3)	0.74
Education				0.20
HS or less	185 (64.9)	122 (67.8)	60 (59.4)	
Some college	45 (15.8)	29 (16.1)	16 (15.8)	
College grad & more	55 (19.3)	29 (16.1)	25 (24.8)	
Annual household income				0.66
≤ \$29,999	127 (50.4)	79 (51.3)	46 (48.42)	
\$30,000+	125 (49.6)	75 (48.7)	49 (51.58)	
Perceived health				0.55
Poor/fair	111 (38.4)	68 (37.4)	43 (41.7)	
Good	123 (42.6)	81 (44.5)	39 (37.9)	
V. good/excellent	55 (19.0)	33 (18.1)	21 (20.4)	
Have daily chronic pain	157 (54.3)	96 (52.7)	60 (58.3)	0.37
ED utilization				0.69
None	47 (16.3)	33 (18.1)	14 (13.6)	
1 to 2	93 (32.2)	59 (32.4)	30 (29.1)	
3 to 5	78 (27.0)	48 (26.4)	30 (29.1)	
6 to 10	42 (14.5)	26 (14.3)	16 (15.5)	
More than 10	29 (10.0)	16 (8.8)	13 (12.6)	
Trust in medical professionals—mean (SD)	57.8 (19.6)	60.8 (18.5)	52.4 (20.5)	0.001

recommendations. Model 3 depicts our tests of trust as a mediator of the discrimination/nonadherence relationship. With patient trust in the model, the magnitude of the effect of discrimination found in model 3 (PR=1.26, 95%CI [0.89, 1.79]) was attenuated by approximately 50 % (95%CI [3.4 %, 97.4 %]) when compared to the magnitude of its observed effect in model 2. Furthermore, the discrimination effect in model 3 was no longer found to be statistically significant.

## DISCUSSION

Our work is among the first to quantitatively demonstrate the potential impact of experiences of discrimination in the healthcare setting on health behaviors in the SCD population. Specifically, we found that experiences of discrimination in the healthcare setting are associated with patient-reported nonadherence to physician recommendations among SCD patients. The results of our statistical analyses provide evidence in support of our hypothesized model, suggesting that discriminatory experiences in the healthcare setting are associated with less SCD patient trust in medical professionals, and lower levels of trust in medical professionals are associated with a greater likelihood of nonadherence to physician recommendations.

Discrimination in healthcare is hypothesized as a contributor to the problem of racial and ethnic health and healthcare disparities. Our findings are consistent with the findings of studies conducted among other chronically ill patient populations in suggesting that patient trust may be an important component of the mechanism through which discrimination exerts an effect on health and healthcare quality. Cuffee

et al. found that trust in medical professionals explained 39 % of the association between experiences of racial discrimination and medication adherence among a sample of African Americans with hypertension.<sup>23</sup> Elder et al. found greater trust to be independently associated with better medication adherence among another sample of African Americans with hypertension, while perceived racial discrimination was not independently associated with adherence in the tested model.<sup>24</sup> Saha et al. found that trust was independently associated with greater adherence to anti retroviral therapy among a cohort of patients with HIV, and that accounting for trust reduced the magnitude of disparities in HIV care among black and white HIV patients.<sup>25</sup>

SCD patients experience many problems with the interpersonal quality of their care from healthcare providers, and these problems have an impact on the trust that SCD patients have in the medical profession. In the current study, respondents categorized as nonadherent were more likely to report having an experience of discrimination. Nevertheless, over 40 % of the adherent group also reported having at least one experience of discrimination in the prior 2-year period, which suggests a high underlying magnitude of perceived discrimination among SCD patients overall. These experiences of discrimination were associated with significant reductions in trust reported by the patients in our sample.

The current work further extends existing knowledge, by suggesting that the experiences of discrimination perceived by SCD patients have downstream effects on outcomes, particularly on patient adherence to physician recommendations, through the mechanism of SCD patient trust. SCD patients

Table 2. Multivariable Testing of Hypothesized Model—Trust as Mediator of Discrimination and Nonadherence

	Model 1 (β)	Model 2 (PR)	Model 3 (PR)
No discrimination	Ref	Ref	Ref
Experienced discrimination	-16.68 <sup>‡</sup> [-20.89, -12.47]	1.53* [1.11, 2.11]	1.26 [0.89, 1.79]
Age	-0.17* [-0.34, -0.00]	1.00 [0.99, 1.01]	1.00 [0.99, 1.01]
Female vs. male (ref)	-3.81 [-8.01, 0.38]	1.08 [0.79, 1.49]	1.04 [0.76, 1.42]
HS or less	Ref	Ref	Ref
Some college	-4.47 [-10.33, 1.39]	1.00 [0.64, 1.57]	0.96 [0.62, 1.49]
College grad+	-3.42 [-8.83, 1.99]	1.43 [1.00, 2.06]	1.39 [0.97, 1.98]
Interpersonal trust	—	—	0.99* [0.98, 1.00]
N	273	273	273

Models 2 & 3 present exponentiated coefficients (i.e., prevalence ratios)  
95 % confidence intervals in brackets

Model 1—Trust (outcome); Discrimination, age, sex, education (predictors)

Model 2—Nonadherence (outcome); Discrimination, age, sex, & education (predictors)

Model 3—Nonadherence (outcome); Discrimination, age, sex, education, & trust (predictors)

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

with lower levels of trust in medical professionals may be less likely to adhere to physician recommendations for treatment or self-care. In turn, the SCD patients may not be receiving the full benefits of care that can result from their relationship with the healthcare provider. Improving adherence through increasing patient trust by reducing the interpersonal quality of care problems experienced by SCD patients is important, in order to improve the quality of life for a population that is known to face significant reductions in their quality of life compared to other patient groups.<sup>26</sup>

Approximately 36 % of our sample reported nonadherence to physician recommendations. As our study is among the first to examine the level of SCD patient nonadherence to physician recommendations, this establishes a baseline figure for further study and validation in future work. The current study found significant associations between reported nonadherence and perceived discrimination and trust among these patients. Further work is needed to assess the specific reasons why SCD patients report being nonadherent to physician recommendations. Also, we examined SCD patient nonadherence to physician recommendations construed broadly, but work is needed to examine rates of adherence among SCD patients to specific treatment modalities, including hydroxyurea, recommended self-care behaviors, iron chelation, and chronic blood transfusions. Additionally, the adherence literature has noted a tendency for patients to generally overestimate adherence in using medications.<sup>27,28</sup> A more systematic analysis of specific adherence behaviors, particularly related to the use of medications, may yield an even higher rate of nonadherence in sickle cell.

Some limitations of our study must be considered. Adherence was measured using a single self-report item summarizing adherence to physician recommendations over 2 years, rather than more objective and specific measures of the many dimensions of adherence that may occur in the management of sickle cell disease. While patient self-report is widely used in studies of adherence due to its simplicity, inexpensive nature, and known clinical utility,<sup>7,29,30</sup> it has also been known to lead to overestimates of adherence. One study found that patients overestimated their level of adherence to antihypertensive

medications by an average of 17 %.<sup>31</sup> Nevertheless, research has shown that patients reporting poor adherence tend to be more accurate than those who deny poor adherence.<sup>31,32</sup> Given the nature of our current study, then, the level of nonadherence found among our cohort is more likely to be an underestimate rather than an overestimate. Furthermore, our study is observational and cross-sectional in design, so we are limited in our ability to make strong statements about the true causal directionality of the observed relationships. Despite these limitation, we believe that our study advances an important, and heretofore understudied, area of inquiry involving SCD patients, as it is among the first to estimate the negative impact on clinical outcomes and health behavior that results from the interpersonal problems in healthcare quality that SCD patients have commonly noted in study after study examining their experiences in seeking health care.

The interpersonal problems in healthcare interactions experienced by persons with SCD are of significant, intrinsic concern, given the implications of what it means to treat patients with respect and trust, as well as what it means to adhere to principles of justice in the healthcare system.<sup>33,34</sup> Our results suggest that these problems are also of great instrumental importance to the SCD community. For example, we have shown that poor interpersonal experiences of care, operationalized in the form of experiences of discrimination in the healthcare system, are associated with a reduced likelihood among SCD patients of adhering to physician recommendations. This likely has a negative impact on additional clinical outcomes and the quality of life experienced by this patient population. Outside of the need to develop new treatments and treatment modalities to improve conditions for this patient population, efforts to improve the trust that SCD patients have in the medical profession by improving the quality of their interpersonal experiences with care may ensure that the few treatment modalities that currently exist for these patients are being utilized and adhered to, so that the maximum benefit is actually attained. In order to improve SCD patient trust, it is important for the healthcare system and healthcare providers to demonstrate that they are worthy of the SCD patient's trust. Improving the interpersonal experiences of care delivered to patients with

SCD will go a long way towards demonstrating the trustworthiness of the healthcare system.

**Contributors:** The authors thank all members and participants of the *IMPORT* study for their contributions. The full list of *IMPORT* investigators includes the authors, as well as the following individuals—Johns Hopkins Investigators: Tanita Woodson, Jordan Wilks, Benjamin Ajiboye, Nina Shah. Howard University Investigators: Abiodun Akintilo; Margaret Fadojutimi-Akinsiku; Patricia O'Neal, MD; Adriana Medina; Seyed- Mehdi Nouraie; John Kwagyan; Kemi Owoyemi; and Ronke Ajala.

Study data were collected and managed using REDCap electronic data capture tools hosted at Johns Hopkins University. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

**Funders:** This study was funded by a grant from the National, Heart, Lung and Blood Institute (NHLBI) (#1R01HL088511-01). Dr. Haywood's effort was funded by a Career Development Award from the NHLBI (#1K01HL108832-01). Dr. Lanzkron's effort was funded by a Career Development Award from the NHLBI (#K23HL083089). The funders played no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

**Prior Presentations:** None.

**Conflict of Interest:** The authors declare that they do not have a conflict of interest.

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