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## Problematic Hospital Experiences among Adult Patients with Sickle Cell Disease

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### Abstract

**Background**—Adults with sickle cell disease (SCD) have often reported difficulties obtaining care during vaso-occlusive crisis (VOC) in qualitative studies.

**Methods**—We measured the experiences of 45 SCD patients who received in-hospital care for VOC using the Picker Patient Experience Questionnaire (PPE-15), and used the one sample binomial test to compare with national norms.

**Results**—Most SCD patients reported that they were insufficiently involved in decisions (86%), staff gave conflicting information (64%), it wasn't easy to find someone to discuss concerns (61%), doctors' answers to questions were not clear (58%), nurses' answers to questions were not clear (56%), doctors did not always discuss fears and anxieties (53%), and nurses did not always discuss fears and anxieties (52%). A greater percentage of SCD patients than the U.S. sample in 9 of 12 areas reported problems.

**Conclusions**—Further research is needed to determine the consequences of and potential interventions to improve these poor experiences.

### Keywords

Sickle cell disease; patient experience of care; acute care; patient-provider relationships

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Sickle cell disease (SCD) is a group of inherited hematological disorders characterized by red blood cell dysfunction. In the United States, it is estimated that 100,000 individuals have sickle cell disease. It mainly affects African Americans, with the condition occurring in about 1 in every 400 African American births.<sup>1</sup> Acute, unpredictable, painful episodes or vaso-occlusive crises (VOC) are a primary reason health care is sought and is a major symptom that leads to hospitalization.<sup>2</sup> Despite a clear understanding that pain is a primary

symptom of SCD, no objective findings are indicative of VOC and, therefore, medical staff must rely on patients' reports of pain to guide treatment decisions.

Unfortunately, patients with SCD have reported difficulties in obtaining adequate pain relief and strained relationships with health care providers. In qualitative studies, patients seeking care for VOC have reported long delays in receiving pain medications, undertreatment of pain, accusations of drug-seeking behaviors or exaggeration of pain, and concerns that medical staff often has a lack of understanding and/or negative attitudes concerning SCD.<sup>3-8</sup> Similarly, studies show that significant numbers of health care providers, including physicians and nurses, believed drug addiction frequently develops in SCD patients and that prescribed opioids play a major role in the development of addiction,<sup>9-12</sup> despite evidence that addiction is rare in patients with SCD treated with opioids.<sup>13,14</sup>

Despite the consistency of these qualitative findings, few studies to our knowledge have quantified negative hospital experiences among SCD patients or compared such experiences with national averages. The primary objective of our study, therefore, was to measure the in-hospital experience of patients with SCD who received care during VOC and compare these experiences with those of a national sample of hospitalized patients. We hypothesized that patients with SCD would report a greater number of problems with their care compared with other hospitalized patients. As a secondary objective, we examined characteristics of patients that may be associated with having experienced a greater number of problems.

## Methods

### Study design, setting, and sample

From September 2006 to June 2007, we conducted a cohort study of adults with SCD at an urban academic medical center in the Mid-Atlantic region. Methods and characteristics of the cohort are described elsewhere.<sup>15</sup> An institutional review board of the Johns Hopkins Medical Institutions approved the study procedures. All participating patients gave informed consent.

When one of the patients from the cohort was admitted to the hospital with VOC, we conducted a brief interview to assess their hospital experiences near the time of discharge (in person within 24 hours prior to discharge or by phone within five days after discharge). Patients were paid \$10 for completing an acute care interview.

### Primary study measures

We measured patients' hospital experiences using a validated instrument, the Picker Patient Experience Questionnaire (PPE-15).<sup>16</sup> By convention, each PPE item is coded dichotomously, indicating the presence or absence of a problem (i.e., some part of the patient's health care that could be improved upon). For example, the response to the question *Do you think the hospital staff did everything they could to help control your pain?* is coded as a problem if a patient selected *Yes, to some extent* or *No*, and is coded as no problem if a patient selected *Yes, definitely*. Similarly, the response to the question *Did doctors talk in front of you as if you weren't there?* is coded as a problem if a patient selected *Yes, always* or *Yes, sometimes*, and is coded as no problem if a patient selected *No*. Because of our interest in the in-hospital experiences of patients, we did not administer three of the items in the PPE-15, which concern discharge planning.

### Analysis

Data for this analysis are limited to the subset of patients who were admitted to an inpatient unit for VOC during the study period. In the case of more than one admission per patient, we

used only the first admission, so that no patient was represented more than once in the final sample of 45 patients. We first used descriptive statistics to describe our study sample. Next, we used the one-sample binomial test to compare the percentages of study patients reporting a problem for each PPE item to estimates from a published sample of 44,493 U.S. adults.<sup>16</sup> We then performed a secondary analysis using Kruskal-Wallis tests to determine which patient characteristics were associated with having a greater number of problems. Finally, we used a negative binomial regression model to examine correlates of the number of reported problems after adjustment for the age and sex of the patient. Because of the small sample size, we only included predictors in the regression model that were related to number of reported problems with a p-value of 0.20 or less at the bivariate level. All analyses were conducted using Stata 8.0 (College Station, TX).

## Results

### Patient characteristics

Characteristics of the study sample are presented in Table 1. The mean patient age was 31.2 years (range 20–59). Most patients were female (56%) and had a high school degree or less (53%), while only 31% were employed and 35% had an annual household income of \$35,000 or more. Most study patients had HbSS disease (68%) and had a history of acute chest syndrome (78%), while a minority had a history of pulmonary hypertension (44%), were on hydroxyurea (33%), and had a urine toxicology screen positive for illicit drugs (30%). During the past 12 months, 22% had only one hospitalization, 49% had two to three hospitalizations and 29% had four or more hospitalizations. Figure 1 presents the number of problems reported by the patients in our study.

### Problematic patient hospital experiences

Table 2 presents the percentage of SCD patients and patients from the national sample who reported each problematic experience. Most SCD patients perceived that they were insufficiently involved in decisions about their medical care (86%), that staff gave conflicting information (64%), that it wasn't easy to find someone to discuss concerns (61%), that doctors' answers to questions were not clear (58%), that nurses' answers to questions were not clear (56%), that doctors did not always discuss patients' fears and anxieties (53%), and that nurses did not always discuss patients' fears and anxieties (52%). Half of SCD patients reported that they were not always treated with respect and dignity and that staff did not do enough to control pain. About one-third of patients reported that their family was not given enough information to help with recovery (37%), that their family didn't get the opportunity to talk to a doctor (36%), and that the doctors sometimes talked as if the patient wasn't there (36%).

For all of the characteristics of care measured, SCD patients reported more problems than the national sample (Table 2). These differences were statistically significant for nine of the 12 domains.

### Patient characteristics associated with problematic hospital experiences

Table 3 presents the associations of problematic hospital experiences with patient demographic characteristics. Only two of the characteristics examined (having a history of acute chest syndrome and currently being on hydroxyurea) were significantly associated with a greater number of reported problematic hospital experiences with a p-value less than or equal to .10. After adjustment for age and sex, both hydroxyurea use and history of acute chest syndrome were significantly associated with the number of reported problems with p-values less than .05. Controlling for patient age and sex, patients currently using hydroxyurea reported 49% more problems on average than persons not currently on

hydroxyurea ( $p=.02$ ), and people who have ever had acute chest syndrome reported 59% more problems on average than people without a history of acute chest syndrome ( $p=.03$ ) (data not shown).

## Discussion

Our study provides evidence that patients with SCD experience significant problems during hospitalization for VOC, especially in comparison with other hospitalized patients. Because the comparative national sample used in our study includes patients of all races and ethnicities, as well as those with and without chronic pain conditions, we do not know for sure whether these problematic hospital experiences are unique to SCD. Pain, especially chronic pain, may be particularly frustrating for doctors and nurses,<sup>17</sup> and patients in pain may be more apt to recognize negative characteristics of their care. No matter what their cause, though, the extent of problematic experiences reported by SCD patients calls for concern and action.

One possible explanation for the negative experiences of SCD patients are the racial differences in the receipt of health care disfavoring African American patients in general.<sup>18</sup> Several studies<sup>19–22</sup> have used direct observation of physician communication behaviors to determine that, in interactions with African American patients, physicians have been shown to exhibit less non-verbal attention, empathy, courtesy, and information giving,<sup>19</sup> and exhibit more negative emotional tone<sup>21</sup> than with White patients. In addition, one study found that physicians rated African American patients more negatively with regard to intelligence, educational level, likelihood to comply with medical advice, and likelihood to abuse drugs, even after controlling for many of the same variables.<sup>23</sup> Large studies of primary care patients have also found that African Americans are more likely than Whites to feel they had been treated with disrespect.<sup>24</sup> Furthermore, and particularly relevant to the SCD population, studies have shown racial disparities in the quality of pain management delivered to African American compared with White patients.<sup>25</sup>

The problematic hospital experiences described by SCD patients in our sample were fairly consistent across most sub-groups within our study population, though patients currently on hydroxyurea reported more problems than those not on hydroxyurea, and those with a history of acute chest syndrome reported more problems than those without this history. This suggests that people with more severe complications from their disease may perceive more negative in-hospital experiences. Previous studies among other patient populations have found that sicker patients tend to be less satisfied with their health care.<sup>26,27</sup> Sicker patients may report less satisfaction because of a more negative outlook generally, or worse patient health status may exacerbate communication difficulties that already exist between providers and patients.

Given the extent of the problematic experiences of our study population, it is difficult to know where to begin addressing them. Consider the most commonly-reported problem—adults with SCD not being given enough input into decisions. Adults with SCD likely know their illness better than anyone else, yet many have reported in qualitative studies that their acute health care providers do not listen or prescribe what works best for them.<sup>5,28,29</sup> Providers have reported having difficulty knowing when the patient is actually in real pain, as opposed to seeking opioids as a result of drug abuse. Perhaps the first step in improving the quality of care for patients with SCD would be to share decisions regarding pain management, which would capitalize on the expertise that the patient and the health care professionals bring to the situation.

Improving patient experiences during hospitalization for vaso-occlusive crises should be a high priority. In general medical settings, patients who report greater involvement in medical care also reported significantly more understanding, reassurance, and perceived control over their illness,<sup>30,31</sup> improvements in general medical condition,<sup>30</sup> as well as significantly more satisfaction with their physicians.<sup>30–32</sup> In addition, patients who report more patient-centered physician behaviors are more satisfied with their care and have fewer symptoms.<sup>33</sup> Furthermore, interventions designed to increase patient involvement in care have demonstrated positive effects on patient satisfaction and functional status,<sup>34</sup> quality of life,<sup>35</sup> and have reduced hospitalizations.<sup>36,37</sup> Lastly, studies that have directly observed patient-physician communication have established a positive effect of physician communication behaviors on health outcomes<sup>38,39</sup> such as pain relief,<sup>39</sup> as well as compliance and recall of information.<sup>40</sup>

The present study has a number of limitations that should be considered. First, our sample size was small and from a single institution, which may limit the generalizability of our estimates. On the other hand, our findings are consistent with patient experiences reported in qualitative studies done in other locations and summarized in a recent systematic review,<sup>41</sup> therefore, we believe this phenomenon is not unique to our location. Additionally, although our study had sufficient power to answer our primary research question, our small sample size may have limited our ability to address our secondary research question fully. Further, while we saw significant differences between our sample and the national estimates, there may be a number of potentially confounding factors that ought to be considered. The national sample of hospitalized patients was significantly older than our study participants, with approximately half of the national sample being over the age of 65. In addition, racial/ethnic information for patients in the national sample was not obtained at the time of survey administration; we can imagine that there would be significant racial differences between the two groups. Finally, the national estimates were obtained at an earlier time period than were our data, and there may be temporal trends in patient satisfaction.

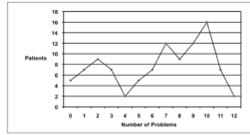
Despite these limitations, however, our study suggests that patients with sickle cell disease admitted for vaso-occlusive crises experience significant problems with care during their hospitalization. Among SCD patients, those with more severe complications may perceive more problems than those with less severe complications. As this population of patients requires significant medical care due to the acute and chronic complications of this disease, the need to improve the quality of interactions between patients and staff should not be overlooked. Further research is needed to determine the extent of these disparities and the causes and consequences of these experiences, as well as to design interventions to improve these poor experiences.

## Notes

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**Figure 1.** Distribution of number of problematic hospital experiences among 45 adult patients with sickle cell disease.

**Table 1****PATIENT CHARACTERISTICS (N=45)**

|  |              |
|--|--------------|
| Age in years, mean (range)                         | 31.2 (20–59) |
| Female, n (%)                                      | 25 (56%)     |
| Education ≤ high school degree, n (%)              | 24 (53%)     |
| Currently employed, n (%)                          | 14 (31%)     |
| Household income ≥\$35,000, n (%)                  | 15 (35%)     |
| SS disease, n (%)                                  | 30 (68%)     |
| Currently on hydroxyurea, n (%)                    | 15 (33%)     |
| History of acute chest syndrome, n (%)             | 35 (78%)     |
| Documented pulmonary hypertension, n (%)           | 20 (44%)     |
| Positive urine toxicology in past 12 months, n (%) | 13 (30%)     |
| Number of hospitalization in past 12 months, n (%) |              |
| 1  | 10 (22%)     |
| 2–3  | 22 (49%)     |
| >3   | 13 (29%)     |

**Table 2****PATIENT-REPORTED PROBLEMS IN EXPERIENCE OF HOSPITAL QUALITY, SCD PATIENTS VS. U.S. POPULATIONS SAMPLE**

|  | <b>% US population sample reporting problem N=44,493</b> | <b>% SCD patients reporting problem N=45</b> | <b>p-value<sup>a</sup></b> |
|--|--|--|----------------------------|
| Doctors' answers to questions were not clear                       | 23.9   | 57.8   | .001 *                     |
| Nurses' answers to questions were not clear                        | 28.7   | 55.6   | .001 *                     |
| Doctors did not always discuss patients fears/anxieties            | 15.9   | 53.3   | .001 *                     |
| Nurses did not always discuss patients ears/anxieties              | 12.5   | 52.3   | .001 *                     |
| Doctors sometimes talked as if patients weren't there              | 23.6   | 35.6   | .077                       |
| Not easy to find someone to discuss patients' concerns             | 36.9   | 61.4   | .001 *                     |
| Had insufficient involvement in decisions about care and treatment | 32.4   | 86.4   | .001 *                     |
| Were not always being treated with respect and dignity             | 33.5   | 50.0   | .025 *                     |
| Staff gave conflicting information                                 | 17.9   | 64.4   | .001 *                     |
| Staff did not do enough to control pain                            | 17.3   | 50.0   | .001 *                     |
| Family didn't get the opportunity to talk to a doctor              | 27.6   | 36.4   | .236                       |
| Family was not given enough information to help with recovery      | 25.5   | 37.2   | .082                       |

<sup>a</sup>One-sample binomial tests to compare SCD patients with US population.

\*Indicates statistically significant difference from nationally reported percentages.

**Table 3****NUMBER OF PROBLEMATIC HOSPITAL EXPERIENCES REPORTED BY ADULTS WITH SICKLE CELL DISEASE, BY PATIENT CHARACTERISTICS**

|   | Mean (SD) Problems | p-value <sup>a</sup> |
|---|--------------------|----------------------|
| Age                                       |                    |                      |
| ≤30 years                                 | 6.5 (3.2)          |                      |
| >30 years                                 | 6.4 (4.1)          | 0.95                 |
| Sex                                       |                    |                      |
| Female                                    | 6.3 (3.6)          |                      |
| Male                                      | 6.8 (3.5)          | 0.61                 |
| Education                                 |                    |                      |
| ≤High School                              | 6.4 (3.8)          |                      |
| >High School                              | 6.6 (3.3)          | 0.99                 |
| Employed                                  |                    |                      |
| No  | 6.8 (3.5)          |                      |
| Yes                                       | 5.8 (3.5)          | 0.36                 |
| Annual Income                             |                    |                      |
| <\$35,000                                 | 6.6 (3.6)          |                      |
| ≥\$35,000                                 | 6.3 (3.7)          | 0.81                 |
| Hemoglobinopathy                          |                    |                      |
| SS disease                                | 6.9 (3.2)          |                      |
| Other                                     | 5.6 (4.1)          | 0.34                 |
| On Hydroxyurea                            |                    |                      |
| No  | 5.8 (3.9)          |                      |
| Yes                                       | 7.9 (2.3)          | 0.10★                |
| History of Acute Chest Syndrome           |                    |                      |
| No  | 4.6 (3.3)          |                      |
| Yes                                       | 7.1 (3.4)          | 0.04★                |
| Documented Pulmonary Hypertension         |                    |                      |
| No  | 6.3 (3.7)          |                      |
| Yes                                       | 6.7 (3.4)          | 0.73                 |
| History of Positive Urine Toxicology      |                    |                      |
| No  | 6.7 (3.5)          |                      |
| Yes                                       | 5.8 (3.7)          | 0.58                 |
| ≥10 Hospital Admissions in Past 12 Months |                    |                      |
| No  | 6.2 (3.6)          |                      |
| Yes                                       | 7.9 (3.1)          | 0.25                 |

<sup>a</sup>Kruskal Wallis tests to compare number of problems reported by patient characteristics.

★Indicates statistically significant difference.