

# Parental Perception of Quality of Hospital Care for Children with Sickle Cell Disease

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## ABSTRACT

*Problem Considered:* Children with sickle cell disease account for 75,000 hospital days annually in the United States, yet little is known about how parents perceive the quality of hospital care these children receive.

*Methods:* Parents of hospitalized children that had sickle cell disease, cancer, or were admitted to the general pediatric service completed a validated survey assessing the parent-perceived quality of hospital care their children received. The primary outcome was parent-reported quality of care. A chi-square analysis was used to compare the percent of children with low quality care who had sickle cell disease with each control group.

*Results:* Parents of 112 children completed the survey; 17 children had sickle cell disease, 36 had cancer, and 59 were admitted to the general pediatric service. Parents of children with sickle cell disease were more likely to report low quality care compared to parents of children with cancer (29.4% versus 5.6%,  $P=0.017$ ) and parents of general pediatric patients (29.4% versus 6.8%,  $P=0.011$ ).

*Conclusion:* Parents of hospitalized children with sickle cell disease perceive their children's care as being of lower quality than parents of children with cancer or children admitted to the general pediatric service.

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## INTRODUCTION

There are over 18,000 hospitalizations and 75,000 days of hospitalization annually in the United States for children suffering vaso-occlusive crises secondary to sickle cell disease (SCD).<sup>1</sup> Despite this large disease burden, only 2 previous studies have evaluated quality of care for hospitalized children with sickle cell disease,<sup>2,3</sup> both focusing on process of care measures, with no assessment of parental perception of care quality. Adults with SCD are met with a high level of mistrust by the hospital staff, with health professionals believing that they exaggerate their pain and exhibit significant drug seeking or addictive behaviors.<sup>4,5</sup> While important information can be extracted from these studies, the concerns about addiction and drug seeking may not be as applicable to children with SCD, leaving the SCD community with little understanding of the parent perception of the quality of hospital care that children with SCD receive.

Previous studies evaluating the parent-reported quality of hospital care for children of all diagnoses found that communication between the medical staff and parents and parental involvement/partnership in the child's care were the strongest determinants of high quality hospital care.<sup>6-8</sup> It's been reported that minority children and those with chronic illness receive lower parental-perceived quality of hospital care,<sup>7</sup> making children with SCD a high-risk group for low parent-reported quality of care. We therefore hypothesized that the parents of children with SCD would perceive that their children receive a lower quality of hospital care than the general pediatric population and other children with chronic disease.

## METHODS

### *Design*

The study was a cross-sectional survey of parent-reported quality of hospital care for their children. Children <19 years old who were admitted to the

Children's Hospital of Wisconsin between June 2006 and August 2006 and had SCD, cancer, or were admitted to the general pediatric service were eligible for the study. Children with cancer were chosen as a comparison group to evaluate another population of patients with a chronic disease requiring repeat hospitalizations; children admitted to the general pediatric service were chosen as a comparison group in order to represent general pediatric care, and to increase the number of children of similar race as children with SCD.

At the time of discharge, consent was obtained from parents for study participation. Parents were approached by a member of the research team who was scheduled to ensure that discharges for all days would be captured. After giving consent, the parents completed a Picker Inpatient Survey (PIS) evaluating the quality of care their child received during the hospital stay. Parents who did not speak English were excluded. The study was approved by the Institutional Review Board at the Children's Hospital of Wisconsin.

#### *Picker Inpatient Survey (PIS)*

The PIS is a validated survey used to assess quality of pediatric hospital care from the parent's perspective at over 80 hospitals.<sup>9,10</sup> The survey consists of 52 questions and requires 10 minutes to complete. It is composed of demographic questions, a single question rating the quality of hospital care, and individual item questions designed to evaluate 8 specific quality domains: (1) partnership, (2) physical comfort, (3) coordination of care, (4) information to parents, (5) information to child, (6) confidence and trust, (7) continuity and transition, and (8) overall care. PIS questions regarding emergency department care and intensive care were not included in our study. Due to the young age of many children, the "information to child" domain could not be analyzed. Sample item questions for the 7 domains that were evaluated are shown in Table 1.

#### *Outcome: Parental-Perceived Quality of Care*

The primary outcome was the parent-reported quality of care the child received during the hospital stay. As has been done in previous work,<sup>6</sup> parent-reported quality of care was determined from the answer to a single question, answered using a 5-point Likert scale (1=poor, 5=excellent). We reported the parent-perceived quality of care in 2 ways: (1) as a mean score (utilizing the mean and standard deviation from the 5 possible Likert scale answers); (2) the Likert scale was dichotomized into low-quality and high-quality care, with responses of "poor," "fair," or "good" indicating

low-quality care and "very good" and "excellent" indicating high-quality care.

#### *Predictor Variables*

To explore potential reasons for disparities in parent-perceived quality of care, we analyzed child/hospitalization characteristics and the parent responses to the item questions in the 8 specific quality domains. These questions were in a variety of formats, with responses requiring anything from a yes/no response to choices from a 4- or 5-point Likert scale. The parent responses to each domain item question were dichotomized as "a problem" or "not a problem." For yes/no questions, an unfavorable response was considered a problem. Similar to previous studies,<sup>6,7</sup> responses to questions with more than 2 possible responses were considered a problem if any answer other than 1 of the best 2 was chosen. For example, if either of the lowest 2 responses on a 4-point Likert scale was chosen, this was considered a problem. The percentage of responses that were a problem for each child in each specific domain was that child's percent problem score for that domain. The percent problem scores for each domain were correlated with the quality of care question to determine which specific quality domains were most closely associated with high-quality care.

#### *Data Analysis*

All surveys were coded with unique identifiers. Survey responses were entered into an SPSS database. Analysis of the parent-perceived quality of hospital care for children with SCD was compared to each of the comparison groups individually, using an independent samples t-test when all 5 possible answers from the Likert scale were analyzed. A chi-square analysis was used to compare the dichotomized quality of care assessments and the percentage of problem scores for the quality domains between the groups. A Pearson's correlation ( $r$ ) was used to correlate the domain percent problem scores, age, and length of stay with the quality of care assessment.

## **RESULTS**

A total of 174 children (22 with SCD, 47 with cancer, and 115 on the general pediatric service) was eligible for study participation. Consent for participation was not possible for 49 children (4 with SCD, 7 with cancer, and 38 on the general pediatric service) due to lack of contact with a legal guardian prior to the child leaving the hospital. In addition, there were 13 refusals (1 SCD, 4 cancer, and 8 parents of children on the general pediatric service), leaving 112 (64%) children with

quality-of-care evaluations. The characteristics of the study populations are shown in Table 2. Children on the general pediatric service were younger, while children with cancer had longer lengths of stay than children with SCD. Children with SCD were more likely to be African American.

### *Outcome: Parent-Reported Quality of Care*

Children with SCD had significantly lower parent-reported quality of hospital care compared to children with cancer and children admitted to the general pediatric service (Table 3). This lower parent-reported quality of care was present when analyzed using the entire 5-point Likert scale and when dichotomized as high versus low quality as described previously.

### *Evaluation of Predictor Variables*

There was no significant correlation between parent-perceived quality of care and either length of stay or age. The percentage of problem scores for each of the 7 specific domains of care that were evaluated showed a statistically significant negative correlation with quality of care, with an increased percentage of problem scores being associated with lower parent-perceived quality of care, as measured on the Likert scale, in each domain: discharge planning ( $r=-0.343$ ), coordination of care ( $r=-0.374$ ), physical comfort ( $r=-0.516$ ), confidence and trust ( $r=-0.518$ ), information to parents ( $r=-0.582$ ), partnership ( $r=-0.665$ ), and overall care ( $r=-0.736$ ).

The average percentage of problem scores across all 7 domains that were evaluated was 23% for children with SCD, 14% for children with cancer, and 15% for children on the general pediatric service, a difference that was not statistically significant (Table 3). However, when the analysis was restricted to percent problem scores from the 2 domains most strongly correlated with parent-perceived quality of care—partnership and overall care—children with SCD had a higher percentage of problem scores (24.5%) compared to children with cancer (11.1%) and those on the general pediatric service (11.5%); however, due to a smaller sample size of children with cancer, only the difference from children on the general pediatric service reached statistical significance ( $P=0.074$  and  $P=0.025$  respectively).

To further evaluate the 2 domains most highly correlated with parent-perceived quality of care, we analyzed the individual questions comprising those domains. For overall care, the responses were similar between the groups, with questions concerning nurse and doctor availability and courtesy being most highly correlated with parent-perceived quality of care (data not shown).

**Table 1.** Sample Item Questions from the Picker Inpatient Survey

#### **Partnership (6 questions total)**

- Attention paid to your experiences and suggestions in caring for your child
- Extent of involvement in making decisions about child's care
- Child treated differently because of type of insurance
- Child treated differently because of race/ethnicity

#### **Physical comfort (3 questions total)**

- Everything done to control child's pain
- Adequacy of pain medication received

#### **Coordination of care (4 questions total)**

- Knowledge of which doctor was in charge of child's care
- Told who to ask for help if needed
- Quick response to call button

#### **Information to parents (5 questions total)**

- Doctor/nurse availability to answer your questions or concerns
- Understandability of responses from doctors/nurses to questions asked

#### **Confidence and trust (2 questions total)**

- Confidence and trust in doctors/nurses caring for your child

#### **Continuity and transition (9 questions total)**

- Adequate time spent discussing home care with physician
- Told when to see physician for follow-up
- Taught what needed to know to care for child at home

#### **Overall care (6 questions total)**

- Courtesy and availability of doctors/nurses
- Hospital policy for visiting or stay with child

For partnership, 2 individual questions showed significant differences among the groups. With regard to parent involvement in the care of their children while hospitalized, 59% of parents of children with SCD would have liked to have been more involved in decisions about their child's care, compared to 31% of parents of children on the general pediatric service and 22% of parents of children with cancer. Secondly, 29% of the parents of children with SCD believed their child was treated differently because of his/her race/ethnicity, compared to 3% of parents of a child with cancer and 3% of parents from the general pediatric service.

As partnership concerns about race were present, and there were obvious racial/ethnic differences between the groups, a subset analysis was performed on African American children. While the number of children is too small for meaningful statistical comparisons, 5 of 16 (31.3%) parents of children with SCD reported low quality care, compared to 0 of 6 (0%) in the cancer

**Table 2.** Characteristics of the Sample Children

	Sickle Cell Disease n=17	Cancer n=36	General Pediatric Service n=59
Age in years; median (IQ range)	10.0 (2.25–14.0)	9.0 (3.0–15.0)	1.0 (0–7.25) <sup>a</sup>
Female (%)	4 (23.5)	9 (25.0)	20 (33.9)
Length of stay in days; median (IQ range)	2.0 (1.5–2.0)	4.5 (2.0–7.0) <sup>a</sup>	2.0 (1.0–4.0)
<b>Race/Ethnicity</b>			
White	0	24 <sup>a</sup>	33 <sup>a</sup>
African American	16	6	16
American Indian/Alaska native	0	2	0
Hispanic	0	3	4
Asian or Pacific Islander	0	0	2
Mixed race	1	0	4
Missing	0	1	0

<sup>a</sup> Significantly different from children with sickle cell disease ( $P < 0.05$ )

**Table 3.** Comparison of the Assessment of Hospital Care Quality and Percent Domain Specific Problem Scores Between Children with Sickle Cell Disease, Children with Cancer, and Children Admitted to the General Pediatric Service

	Sickle Cell Disease n=17	Cancer n=36	General Pediatric Service n=59
Quality of hospital care; mean (standard deviation)	3.12 (1.22)	3.67 (0.59) <sup>a</sup>	3.68 (0.66) <sup>a</sup>
Number (%) of children receiving low quality care, when quality dichotomized <sup>b</sup>	5 (29.4%)	2 (5.6%) <sup>a</sup>	4 (6.8%) <sup>a</sup>
Percent problem scores across all domains	23.1%	14.1%	15.2%
Percent problem scores for partnership and overall care	24.5%	11.1%	11.5% <sup>a</sup>

<sup>a</sup> Significantly different from children with sickle cell disease ( $P < 0.05$ ).

<sup>b</sup> Responses of “poor,” “fair,” or “good” indicate low-quality care; “very good” and “excellent” indicate high-quality care.

group, and 2 of 16 (12.5%) for African American children on the general pediatric service.

## DISCUSSION

This first study of the parent-perceived quality of hospital care for children with SCD indicates that children with SCD receive lower parent-reported quality of hospital care than children with cancer or those admitted to the general pediatric service. While the small number of enrolled children makes it impossible to generalize these findings to all children with SCD, or to fully explain the differences between the groups, the disparity is important to document, and hypotheses can be generated about the reasons for the findings.

While the specific reasons for this difference cannot be explained by this study, some things are apparent.

Age and length of stay did not appear to explain the differences. As in previous studies, a parental feeling of “partnership” in the child’s care was very strongly correlated with parental ratings of care quality.<sup>6-8</sup> More than 25% of parents of children with SCD believed that their child was treated differently because of his/her race, and over 50% of parents of children with SCD would have liked to have been more involved in decisions about their child’s care. These findings suggest that greater recognition of the parent as a caregiver for the child, especially during the stress of a hospitalization, can improve parent ratings of care quality, which may serve to diminish the perception that the children are treated differently because of their race. The disparity in parent-reported quality of care is not all due to race, however, as the percentage of African Americans

reporting low quality care on the general pediatric service and among parents of children with cancer was less than half the proportion of those with children with SCD.

Chronic illness has also been shown to be associated with decreased care quality;<sup>7</sup> however parents of children with cancer did not report lower quality care than those on the general pediatric service, and none of the 6 African American children with cancer received low parent-reported quality of care. It may well be that there is something specific to sickle cell disease, especially as a chronic disease primarily affecting African Americans, that affects perception of care quality. One previous study showed that adults with SCD reported lower satisfaction with nursing care than patients with other medical conditions.<sup>11</sup> Previous reports by adults of a lack of trust from their health care professionals and feeling that they are treated differently from those with other conditions may have taken root due to the treatment that children with sickle cell disease receive early in their care.<sup>5</sup> Parents of these children may recognize differential treatment, especially in a hospital setting where children with other chronic illnesses may be in close proximity.

Limitations of this study include the number of missed eligible children and the number of refusals to participate. However, the overall response rate of 64% is higher than other studies assessing hospital care for children. In addition, there were too few African Americans in the comparison groups to adequately address the racial component of this disparity and to more fully understand the relationship between race and evaluations of partnership and other aspects of care. Finally, there were only a small number of children with SCD in the study; however, even with these small numbers, significantly lower parent-reported quality of care was shown, and more studies are needed to further define the reasons for these disparities. Such studies could include interviews with parents who report low quality care to determine when the disparities begin to manifest themselves and how the families would like to be more involved in the care of their children. Additionally, gathering information from the medical staff to determine their comfort in treating children (and the parents of children) with SCD may uncover potential explanations for these findings.

In conclusion, children with SCD receive lower parent-reported quality of hospital care than children with cancer or children on the general pediatric service.

Increasing parental involvement in the care these children receive may improve perceived care quality.

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