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Experiences of Pediatric Patients with Sickle Cell Disease in Rural Emergency Departments

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Abstract

Background—The aims of this study were to describe guardian perceptions of the experiences of a sample of youth with SCD in rural EDs with a focus on overall patient satisfaction and characteristics of care.

Procedure—Guardians of 139 children with SCD (0–17 years) seen at a rural pediatric SCD clinic completed a survey concerning their children's ED experiences in the past 6 months, including information about ED wait times, quality of communications and interactions with the ED health care providers (HCPs), pain management, perceptions of speed of care, and overall satisfaction.

Results—About 41% of guardians reported that their child visited the ED in the past 6 months. Guardians reported moderate satisfaction with ED care. About 25% of those who visited the ED indicated that HCPs did not spend enough time with them and their children did not receive speedy care. Shorter ED wait times and higher ratings of speed of care predicted higher satisfaction.

Conclusions—Families of youth with SCD are experiencing longer wait times in rural EDs which contribute to dissatisfaction with care. Efforts are needed to develop strategies to reduce ED wait times and improve speed of care which may improve outcomes following ED care.

Keywords

Sickle Cell Disease; Satisfaction; Emergency Department

INTRODUCTION

Severe, acute complications of sickle cell disease (SCD), such as fever and pain episodes, are often treated in emergency departments (EDs), resulting in individuals with SCD

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Conflicts of Interest

The authors have no conflicts of interest.

spending a large amount of time in EDs.^[1,2] However, there are few studies examining patient satisfaction with ED care in the pediatric SCD population. Patient satisfaction has been identified as an important patient centered outcome by the Centers for Medicare and Medicaid Services, the National Committee on Quality Assurance^[3] and the Affordable Care Act.^[4] Higher levels of patient satisfaction are related to increased treatment compliance, while lower levels of satisfaction are associated with termination of services and decreased willingness to return to the service provider.^[5] Thus, dissatisfaction with care may lead individuals with SCD to partake in poor health behaviors, which can be detrimental to their overall health and clinical outcomes. A factor consistently linked to lower patient satisfaction in adult and pediatric populations is longer waiting times,^[6,7] with researchers proposing that lengthy waiting times may increase patient frustration and thus, decrease a patients' sense of control and satisfaction.^[8] Among pediatric populations, studies have also linked reports of higher quality patient-doctor interactions and communication, and greater resolution of the child's pain to higher patient satisfaction.^[7] Findings from adult studies have indicated that providers spending more time communicating about topics other than the health of the patient,^[9] and the patient's positive perception of the physician's affect, friendliness, and social conversation are linked to higher patient satisfaction.^[10]

The few studies that have examined patient satisfaction with ED care using pediatric SCD populations have found that these patients and their families generally report high patient satisfaction. A study of 137 ED visits by 98 pediatric patients with SCD over a three month period found that 82% of families of pediatric patients with SCD were very satisfied or satisfied with the care received, 9% were dissatisfied, none reported being very dissatisfied, and 9% failed to report.^[1] Reasons reported for dissatisfaction included long wait times in the ED, a lack of communication concerning a new problem the child was experiencing, and reports of too many procedures being performed on the child. Also, the average wait time to be seen was 38 minutes, with 75% of patients being seen within 47 minutes. A study of 50 pediatric patients with SCD and 44 adults with SCD found that 63% of the pediatric patients rated their ED experience as excellent or very good in contrast to only 33% of the adult SCD sample.^[2] In addition, 28% of the pediatric sample rated the experience as good, 7% rated it as fair, and 2% rated it as poor. Fifty-nine percent of the pediatric sample rated their physician's knowledge of SCD as excellent or very good, and when asked what would improve treatment at the ED, the majority of responses focused on the need for more swift care.^[2]

Of note, these two studies focus on pediatric patients with SCD being served by EDs in urban settings; thus, their findings may not be generalizable to pediatric SCD patients being served by EDs in rural settings. This is important because 42% of EDs are located in rural environments,^[11] and EDs located in rural versus urban environments are generally more likely to be staffed by health care providers (HCPs) who lack board certification and residency training or who have limited access to advanced healthcare technology and specialists.^[12,13] In addition, there is limited of research on SCD patients in rural versus urban environments and their care experiences. Results of a study of individuals with SCD living in North Carolina indicated that individuals with SCD living in rural environments generally have lower socioeconomic statuses, live further from comprehensive SCD clinics,

and seek less care than individuals with SCD living in urban environments.^[14] Also, results indicated that children with SCD living in rural environments generally report that their SCD interfered with their daily activities more than children with SCD living in urban environments, but researchers were not able to investigate if this finding was due to issues with the care received by the children.

The current study addresses gaps in the literature by (1) describing guardian perceptions of the experiences of youth with SCD in rural EDs with a focus on overall satisfaction and unique characteristics of care (e.g., wait times, the quality of communications/interactions with HCPs, pain management, and speed of care), and (2) examining the influences of characteristics of care on guardian ratings of patient satisfaction with rural EDs.

MATERIALS AND METHODS

Participants

Guardians of 139 children with SCD (mean age =7.3 years, SD =5.35 range =0–17 years) participated in the study. The children were primarily male (53%) and had HbSS (58%), while 36% had HbSC, 4% had HbS/ β^+ , and 2% had HbS/ β^0 . Of the guardians, 84% were mothers, 7% were fathers, and 9% were grandparents or others.

Procedure

All participants were recruited from one regional pediatric SCD clinic that is part of a hospital in a rural environment. The hospital serves as a tertiary referral center for eight smaller regional hospitals serving 29 rural counties in the southeast United States. The majority of patients served by the clinic are African American, live within the 29 county catchment area of the hospital system, and travel within 45 minutes to 1 hour of the clinic, with the furthest patients living about 2 hours away. Institutional review board approval was obtained for the study. Potential participants were approached during their routine comprehensive SCD visits, informed of the nature and details of the study, and those individuals who agreed to participate in the study were given consent forms and their children were given assent forms. Upon completion of the forms, the guardian completed a survey assessing basic demographic information, past experiences and perceptions of their child's ED care, and their satisfaction with their child's ED care.

Measures

Demographic Information and Disease Severity—Demographic information collected consisted of the child's age, sex, and the guardian's relationship to the child. To assess disease severity, the child's SCD genotype was extracted from their medical record. SCD genotype was coded as severe (HbSS and HbS/ β^0) or mild (HbSC and HbS/ β^+).

ED Use—To assess ED utilization, participants were asked: "In the past 6 months, how many times did your child go to the emergency room?" The three response choices were: none in the past six months, once or twice (1 or 2 times) in the past six months, or three or more times in the past six months. Other studies have used similar single item questions to assess patients' ED utilization.^[15,16]

Characteristics of care—Patient characteristics of care consisted of four subareas: 1) Waiting time; 2) Communication with the healthcare provider; 3) Pain management; and 4) Speed of care. To assess ED wait time, participants were asked: “In the past 6 months, when you took your child to the emergency room, how long did you have to wait to receive service on average?” The response choices were: less than one hour, 1–2 hours, 3–5 hours, 6–8 hours, or greater than 8 hours. Previous studies have used a similar item to assess patients’ perceptions of wait time in the ED prior to receiving services.^[17]

The other scales were based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program surveys, which are funded and administered by the United States Agency for Healthcare Research and Quality.^[18] Research has indicated acceptable reliability and validity for the CAHPS program surveys.^[19] Four point Likert scale items were used with “1” indicating “never”, “2” indicating “sometimes”, “3” indicating “usually”, and “4” indicating “always”. To assess quality of the communications/interactions with HCPs, participants were asked: 1) “How often did the doctors treat you with courtesy and respect?” 2) “How often did the doctors listen carefully to you?” 3) How often did the doctors explain things to you in a way that you could understand?” 4) “How often did the doctors spend enough time with you?” To assess pain management, participants were asked: 1) “How often was your child’s pain well-controlled?” and 2) “How often did the hospital staff do everything they could to help with your child’s pain?” Scores for the two sub areas were calculated by averaging the responses of all questions in that sub area. Thus the scores ranged from 1 to 4. The quality of communications/interactions with HCPs and pain management subscales demonstrated good internal consistency in the current sample with Cronbach’s alphas of .85 and .89, respectively. Speed of care was assessed by asking participants “When your child needed care right away, how often did your child get care as soon as you thought he or she needed it?”

Patient satisfaction—A global satisfaction rating was obtained by asking participants to rate their emergency room visits in the past six months on a scale from 0 to 10, with 0 indicating “worst” and 10 indicating “best”. Previous studies have assessed overall satisfaction using a similar item and it has been related to reports of communication and partnership with HCPs.^[20,21]

Data Analysis Plan

First, descriptive statistics related to the demographic variables, characteristics of care, ED use, disease severity, and satisfaction were calculated. To narrow the variable pool for further analysis, Pearson correlations and point biserial correlations were conducted to determine which variables were significantly related to patient satisfaction. Then a simultaneous multiple regression model was calculated predicting overall patient satisfaction using related characteristics of care, SCD type, and patient characteristics (age and sex).

RESULTS

Emergency Department Use

Of the 139 children, 57 (41%) had visited the ED in the past six months. Of the 57 children and adolescents who visited the ED, 54% were males and 46% were females. About 75% of the guardians of the subsample who visited the ED reported that their child went to the ED once or twice in the past six months and 25% reported that their child went to ED three or more times in the past six months. The average age of the participants who visited the ED in the past six months was 6.3 years ($SD = 5.6$ years, range 0 to 17 years). Forty (70%) of the 57 participants who visited the ED had a severe genotype. There were no significant differences in those who went to the ED versus those who did not based on age, sex, or SCD genotype.

Emergency Department Experiences

For the subsample of participants who visited the ED, the average rating of satisfaction with ED care was 6.36 on a 10 point scale, which indicates moderate satisfaction. When responses were dichotomized (0–4 = dissatisfaction; 5–10 = satisfaction), 77.78% of the guardians reported being satisfied with their child's ED care and 22.22% reported being dissatisfied. As for characteristics of care, the guardians reported that on average they usually experienced good quality communication, pain management, and speed of care (see Table 1). Individual responses to the characteristics of care questions indicate that the areas that most guardians rate as occurring less in the ED are doctors spending enough time with them (26.31%) and their child getting speedy care when needed (26.78%; Table 2). Also, 40.4% of the guardians reported ED wait times of less than one hour, 35.09% reported waiting times between 1–2 hours, and 24.56% reported waiting times between 3–5 hours.

Factors Related to Overall Patient Satisfaction

Correlations indicated that shorter wait times ($r = -.48$, $p < 0.01$) and higher ratings of speed of care ($r = .38$, $p < 0.01$) were related to higher satisfaction. Other characteristics of care, age, sex, and SCD type were not significantly correlated with satisfaction. Notably, all three characteristics of care (patient/provider communication, quality of pain management, and speed of care) were significantly inter-correlated with the strength of the correlations ranging from 0.60 to 0.73. In addition, ratings of patient/provider communication, quality of pain management, and speed of care were all negatively related to wait time, with correlations ranging from -0.31 to -0.37 .

To reduce the likelihood of over fitting the model due to the small sample size of those who visited the ED, only those variables that were found to be significantly correlated with satisfaction (wait time and speed of care) were included in the regression model predicting satisfaction. The model was significant ($F = 10.18$, $p < 0.01$, $df = 2$), and indicated that 26% of the variance in overall satisfaction was accounted for by wait time (16%) and speed of care (9%). Shorter wait times ($\beta = -0.41$, $p < 0.01$, standard error = 0.40) and higher ratings of speed of care ($\beta = 0.30$, $p = 0.02$, standard error = 0.37) both uniquely predicted higher satisfaction.

DISCUSSION

The aims of the study were to describe guardian perceptions of the experiences of a sample of youth with SCD in rural EDs with a focus on overall patient satisfaction and characteristics of care. Results of the study indicated that a large percentage (41%) of children with SCD visited the ED in a 6 month period, with at least a quarter of those visiting three or more times during that period. Consistent with research using children from urban settings,^[1,2] a majority (77.78%) of the guardians of the current sample reported being satisfied with the ED care their child received. However, in contrast to only 9% of parents and children indicating dissatisfaction with experiences at urban EDs,^[1,2] 22.22% of the current sample of parents indicated they were dissatisfied with their child's ED experience. Approximately 25% of the current sample indicated that HCPs did not spend enough time with them and that their children did not receive speedy care. Also, while 75% of families of pediatric SCD patients in urban environments reported wait times of 47 minutes or less, approximately 40% of guardians in the current study reported wait times of less than 1 hour; with approximately 35% reporting wait times of 1–2 hours and 25% reporting wait times of 3–5 hours. A secondary aim of the current study was to examine the influences of characteristics of care on guardian ratings of patient satisfaction with rural ED. Consistent with research with other pediatric populations,^[7] results indicated that shorter ED wait times and higher ratings of speed of care significantly predicted higher patient satisfaction among guardians of pediatric SCD patients in rural environments.

Taken together, these findings indicate that youth with SCD living in rural environments are waiting longer in EDs than youth living in urban settings and that these higher wait times are significantly reducing their guardian's satisfaction with ED care. In addition, the impact of longer wait times experienced by youth with SCD in rural EDs are probably being exacerbated by the longer distances that families living in rural environments have to travel to receive medical care.^[14] Thus, youth with SCD may be arriving to rural EDs with more severe symptoms than youth with SCD living in urban setting, and may be more likely to need more aggressive treatment or hospitalization. Lastly, wait times and perceived speed of care may impact the guardian's sense of control over the ED experience^[8] with shorter wait times contributing to a greater sense of control during a difficult situation, and lengthy wait times making caregivers feel that HCPs are not quickly attending to their child's needs and thus, leading to high frustration and feelings of being discounted.

On possible reason for the longer wait times these families have reported experiencing at rural EDs may be due to ED inefficiencies associated with lower resource hospitals that have limited access to advanced technology and training.^[22] An intervention study focused on reducing ED wait times in an academic medical center ED found that improving ED staff to patient ratios, shortening the triage and registration process, and using electronic means to make lab processes more efficient significantly decreased the median ED wait time from 31 minutes to four minutes.^[23] Research is needed to examine the feasibility of implementing similar interventions in rural EDs. Another possible reason for the longer wait times reported may be the lack of familiarity with treating SCD by rural ED HCPs. This would be consistent with a study that found that in non-specialized care centers, such as the ED, HCPs are often unfamiliar with SCD and its treatment.^[24] This is possibly exacerbated in rural

EDs given that HCPs in these settings are less likely to have received specialized training.^[22] A lack of knowledge of SCD may lead to less of a feeling of urgency when dealing with pediatric SCD patients, which could result in longer wait times. Educating rural ED HCPs concerning the severity of SCD complications and the need for timely interventions may assist in improving speed of care and reducing ED wait times. Of note, previous research has related higher levels of patient satisfaction with wait times that were shorter than expected by the patient.^[8] This suggests that patients' expectations when they arrive in the ED are an important factor. Future research is needed to investigate what are the expectations of caregivers of pediatric patients with SCD concerning rural ED wait times. If caregivers are underestimating possible ED wait time times, providing family education around this issue and the need to go to the ED when serious symptoms first arise may affect patient satisfaction, and care. Also, working to empower and teach families how to communicate with ED HCPs about requesting timely care may lead to faster service, and ultimately, improve satisfaction with ED care for these families. Well informed and communicative families can more effectively seek higher quality care for their children.

Of note, disease severity, quality of pain management and patient-provider communication were not related to rural ED satisfaction ratings. Because we are dealing with a select group of individuals who evidence the most severe symptoms of SCD, particularly complications requiring them to go to the ED, it is possible that there may have been a ceiling effect which minimized the relation between disease severity and satisfaction. Also, SCD type is just one indicator of disease severity and a gross one at that versus the daily experience of pain. Future research should include multiple indicators of disease severity, such as descriptions of pain patterns, and number of ED visits and hospital admissions over the prior 2 years. The lack of relation between the ratings of quality of pain management and ED patient satisfaction were surprising given previous research indicating that delays in analgesic administration for pain is a significant problem for individuals with SCD.^[25] Of note, the lack of relation between pain management ratings and ED patient satisfaction may be because delays in analgesic administration were accounted for in the guardians' reports of speed of care, while the effectiveness of the analgesics to reduce pain was accounted for in the pain management ratings. Thus, future research should specifically examine the relation between timing and effectiveness of pain medications given and rural ED satisfaction. In addition, future research should assess additional factors associated with rural EDs that may impact patient satisfaction, such as distance to the ED, transportation barriers experienced by the family, and whether their ED HCPs seemed knowledgeable about SCD or were able to consult with a hematologist concerning their care.

One limitation of the current study is that it is retrospective nature; thus, participants may have exhibited some biases when asked to recall ED experiences. It would be beneficial to have participants describe their ED experiences as soon as they occur to avoid recall bias. Also, a limitation of the study is not gathering information on the presenting concern to the ED. Future research should gather information on presenting concerns and whether or not the concern was SCD-related, as this information may have an impact on wait times and patient satisfaction. Another limitation is that all of the data used in the current study is based on guardian-report. This is consistent with previous research in this area;^[1,2] however, future research would be improved by including both child and family reports of satisfaction

to gain a more complete picture of the rural ED care experience. Also, there were no objective measures of wait time in the study, only the guardians' perceptions of wait time. Of note, previous research that has compared the effects of actual versus perceived wait times upon patient satisfaction found that perceived waiting time, rather than actual waiting time, was predictive of patient satisfaction.^[8] In addition, the small sample size for the subsample that visited the ED may have reduced the ability to detect the relations between characteristics of care and satisfaction as well as the ability to generalize findings to a larger population.

An additional limitation is that guardians did not indicate which EDs they attended; thus, no specific information concerning the EDs and ED providers was available, including the number ED visits for each patient or the type of providers (e.g., pediatric versus adult) they encountered in the ED. This would have allowed investigators to confirm that all of the EDs visited were in rural environments, to take into account differences in specific EDs and ED providers, and to account for the number of distinct EDs in the analyses. Future research should gather more detailed ED information and investigate the relationship these factors and patient satisfaction. Of note, the pool of participants was drawn from a clinic serving pediatric SCD patients living primarily in the 29 rural counties, and being serviced by a nine hospital system all located in rural environments. Thus, the likelihood that participants in the study received care at non-rural EDs outside of the catchment area was determined to be small.

In conclusion, the current study addresses gaps in the literature concerning the experience of youth with SCD in EDs in rural environments. Findings indicate that the majority of guardians of youth with SCD report being satisfied with EDs in rural environments. However, a larger percentage of families of youth with SCD report being dissatisfied by EDs in rural environments versus EDs in urban environments. This is significant because patient satisfaction is considered an important patient centered outcome by the Affordable Care Act,^[4] and previous research has linked higher ratings of patient satisfaction to better treatment compliance, medication adherence, and clinical outcomes.^[5] Also, findings indicate that shorter wait times and higher ratings of speed of care are important predictors of overall satisfaction with rural EDs for guardians of youth with SCD, and that in general, youth with SCD are experiencing longer wait times in rural EDs than urban EDs. Reduction of rural ED wait times may be aided by supplying ED providers with continued education concerning the urgency of SCD emergencies and by implementing systematic interventions to decrease ED wait times. Also, educating guardians of youth with SCD regarding the importance of going to the ED when serious symptoms first arise and about the possible rural ED wait times they are likely to encounter may improve their overall satisfaction with their child's ED care. Lastly, future studies are still needed to identify additional factors that might reduce patient satisfaction and compromise ED care for youth with SCD living in both rural and urban settings.

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Table I

Demographic, ED Satisfaction, and Characteristics of Care Information for the Subset of Patients who Visited the ED in the Past 6 Months.

	<i>M</i>	<i>SD</i>	Range	Possible Range
Age (years)	6.3	5.6	0–17	0–17
Patient Satisfaction	6.4	2.6	1–10	0–10
Characteristics of Care				
Patient/Provider Communication	3.3	0.6	2–4	1–4
Pain Management	3.5	0.7	2–4	1–4
Speed of Care	3.0	0.9	1–4	1–4

Note. M=mean. SD=standard deviation.

Table II

Percentages for Individual Characteristics of ED Care Questions

	Never	Sometimes	Usually	Always
Treated w/ courtesy/respect	1.72%	6.90%	31.03%	60.34%
Listened carefully to you	0%	15.79%	28.07%	56.14%
Things explained clearly	0%	15.79%	40.35%	43.86%
Spent enough time w/ you	5.26%	21.05%	42.11%	31.58%
Pain well controlled	0%	14.04%	28.07%	57.89%
Did everything to help w/ pain	0%	8.77%	36.84%	54.39%
Speed of care when needed	7.14%	19.64%	35.71%	37.50%