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The experience, satisfaction, and Emergency Department utilization of pediatric patients with sickle cell disease during the Covid-19 pandemic

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Abstract

The COVID-19 pandemic has influenced how patients utilize healthcare. This study examines the utilization, experience, and satisfaction of patients with Sickle Cell Disease (SCD) in the pediatric Emergency Department (ED) during the COVID-19 pandemic compared to the care they had received before the pandemic. The authors surveyed fifty-eight participants ages 14 months to 20 years who presented to the ED for a complaint related to their SCD during the COVID-19 pandemic. The study analyzed five variables: race, SCD severity, hemoglobin (Hgb) genotype, who completed the questionnaire (patient versus parent/guardian), and whether the ED visit resulted in an admission to the hospital. Our results suggest that the COVID-19 pandemic significantly affected the decision of some patients as to whether and when to go to the ED. African Americans and those with severe disease did not wait longer than usual to go to the ED, possibly because these groups are more likely to have more serious and more frequent pain crises. Thus, their decision to present to the ED was driven more by their relatively worse symptoms, rather than such external factors as the pandemic. However, the pandemic did not significantly affect patients' satisfaction with their ED visit or their baseline SCD symptoms. To our knowledge, this is the first study of how the COVID-19 pandemic has affected patients' utilization of, experience in, and satisfaction with a pediatric hospital ED.

Keywords

Patient experience, patient satisfaction, patient utilization, COVID-19, pediatric, emergency department, sickle cell disease

Introduction

There are approximately 100,000 people in the United States afflicted with the group of inherited hemoglobinopathies known collectively as sickle cell disease (SCD).¹ The vast majority of patients with SCD are of African or Hispanic descent. Nationally, patients with SCD account for approximately 200,000 Emergency Department (ED) visits annually.² Patients with SCD may suffer from numerous complications including chronic pain, progressive multi-system organ damage, retinopathy, embolism and stroke, acute chest syndrome, and increased susceptibility to life-threatening infections, especially in the pediatric population.²⁻³ Acute pain exacerbation due to a vaso-occlusive crisis is the most common reason for patients with SCD to visit the ED and often requires treatment with parenteral opioid medication.²⁻⁴

Patients with SCD who contract SARS-CoV-2 have a higher risk of complications, severe disease course, and death compared to the general population.⁵ In a study of 178 patients with SCD and COVID-19 infection reported to the SECURE-SCD registry between March and May 2020, Panepinto and colleagues found that 90% of patients accessed care through an ED, 69% required

hospitalization, 11% were admitted to an intensive care unit, and 7% died.⁵ Thus, patients with SCD who delay or avoid seeking emergency medical care due to the COVID-19 pandemic may be at an increased risk of adverse outcomes.

The National Syndromic Surveillance Program found that ED visits decreased 42% overall during the early stages of the COVID-19 pandemic.⁶ Patients with SCD have consistently expressed a significant level of dissatisfaction regarding the ED care they have received, especially when compared to the care that these patients have received from their usual physician.⁷⁻⁸ The multifactorial reasons that patients with SCD are dissatisfied with ED care include, but are not limited to, long wait times that may result in treatment delays, lack of communication and co-management between the ED and patients' primary medical provider, perceived lack of empathy, absence of standardized treatment protocols, ED provider attitudes and discomfort with acute pain management in this patient population, and inadequate analgesic dosing.⁷⁻⁸ The well-established negative perception of ED care raised the question of the COVID-19 pandemic's impact on the decision-making process of patients with SCD. This study examines whether and when patients with SCD sought ED care and their satisfaction with and experience in the

ED during the COVID-19 pandemic compared to the ED care that they received before the pandemic.

Very few studies have focused on pediatric patients with sickle cell disease and healthcare utilization during the COVID-19 pandemic. Tsitsikas and colleagues evaluated the strategy of preventing hospitalizations and extended hospitalizations in the United Kingdom.⁹ One study surveyed providers at 28 practices to determine how the COVID-19 pandemic affected outpatient care of patients with SCD.¹⁰ Another study assessed the level of anxiety of adolescents and young adults with SCD to evaluate the correlation between COVID-19 experiences, anxiety levels, and painful episodes.¹¹ Finally, one study evaluated how the pandemic and stay-at-home orders affected ED visits to a tertiary care hospital; although this study reviewed all patients presenting to the ED, there was a small subset who had sickle cell disease.¹² To our knowledge, this is the first study to investigate the effect of the COVID-19 pandemic on the utilization of, experience in, and satisfaction with Emergency Department services by pediatric patients with sickle cell disease.

Materials and Methods

Participants

Potential study participants were identified from patients with a diagnosis of SCD who were followed long-term at

the Marian Anderson Sickle Cell Center at St. Christopher’s Hospital for Children. The center maintains a database of its patients; the authors mined the database to identify patients with SCD who visited the ED for a complaint related to their SCD during the COVID-19 pandemic (February 2020 – March 2021). Potential participants were contacted to verify the information, ensure that they met the inclusion criteria, and were willing to participate in the study.

A total of 58 participants were included in the study. Of these, 23 (40%) were female and 35 (60%) were male. The ages ranged from 14 months to 20 years (m = 13.8 years, SD = 5.98 years).

Most of the patients had sickle cell SS (n = 27; 47%), followed by SC (n = 20; 35%), Sβ⁺ thalassemia, (n = 7, 12%), Sβ⁰ thalassemia (n = 2; 3%) and S/HPFH (n = 2; 3%). The disease was classified as severe if patients had more than three hospital admissions in a year, cerebral vasculopathy, chronic packed red blood cell transfusions, or a history of acute chest syndrome in the last three years. Most patients were classified as not severe (n = 40; 69%) rather than severe (n = 18; 31%). Most of the participants were African American (n = 48; 83%) followed by Hispanic (n = 6; 10%) and those who self-identified as “other” (n = 4; 7%). Table 1 summarizes the demographics of the participants.

Table 1. Patient Demographics

	Variable	n (%) or mean (SD)
Gender ^a	Female	23 (40%)
	Male	35 (60%)
Age in years		13.8 (5.98)
Hgb Genotype	SS	27 (47%)
	SC	20 (35%)
	Sβ ⁺ thalassemia	7 (12%)
	Sβ ⁰ thalassemia	2 (3%)
	S/HPFH	2 (3%)
Disease Severity	Severe	18 (31%)
	Not Severe	40 (69%)
Race ^b	African American	48 (83%)
	Hispanic	6 (10%)
	Other	4 (7%)
^a Gender as identified from the electronic medical record.		
^b Race was self-identified by the patient and/or parent/guardian		

Table 2. Likert Questionnaire Responses Scored from Strongly Disagree (1) to Strongly Agree (5)

1) My decision to go to the Emergency Room was affected by the COVID pandemic.
2) I waited longer before going to the Emergency Room (vs. before the pandemic).
3) I tried more medications at home for fever and/or pain (vs. before the pandemic).
4) My experience in the Emergency Room was better during the pandemic (vs. before the pandemic).
5) I got to a room and/or got care faster during the pandemic (vs. before the pandemic).
6) I felt the hospital took the proper COVID-related precautions (e.g., staff wore masks, ER was cleaned regularly, etc.).
7) I feel like my Sickle Cell Disease symptoms (pain, fever, etc.) are milder now (vs. before the pandemic).

Intervention

Patient responses to their experience in and satisfaction with a recent Emergency Department visit were recorded using a specifically-designed Likert questionnaire (Table 2). Telephone interviews were conducted in lieu of in-person interviews due to social distancing and safety measures implemented during the COVID-19 pandemic. The responses to these seven questions were graded on a 1 to 5 Likert scale, with 1 signifying strong disagreement and 5 signifying strong agreement (Table 2). Analysis of covariance was performed to compare means. The remaining four questions, numbered 8 through 12, were open-ended or yes/no questions (Table 3). For these purposes, patient experience is defined as something that happened to a patient, or how something happened while patient satisfaction refers to patients’ expectations and whether they were met. As depicted in Table 2, questions 4 and 5 relate to patient experience, while the other questions relate to patient satisfaction. The data were analyzed as a whole and also grouped by five variables: race, SCD severity, Hgb genotype, who completed the questionnaire (parent/guardian versus patient), and whether the ED visit resulted in hospital admission. An ED visit that resulted in hospital admission was thought to be severe enough to require inpatient management and thus was used as a surrogate for the severity of an episode. Two-tailed p-values less than 0.05 were considered statistically significant.

To provide the context of the patient experience relevant to this study, patients with SCD who present to the St.

Table 3. Open-Ended and Yes/No Questions

8) My answers to one (or more) of the choices above are different now than it would have been at the beginning of the COVID-19 pandemic. If Yes, Question number: ___ My score would have been: ___
9) My biggest concern about going to the Emergency Room was (circle all that apply): (a) waiting area (b) registration (c) other patients (d) providers (e) admissions
10) I was screened for COVID symptoms when I arrived at the Emergency Room: Y / N
11) I used telemedicine (video or telephone appointment) during the pandemic: Y / N If Yes, how was the experience? ___

Christopher’s Hospital for Children ED are evaluated and treated according to a standardized algorithm. For patients with SCD and a fever greater than or equal to 38.5 degrees Celsius, intravenous access is obtained, an appropriate workup is initiated, and broad-spectrum intravenous antibiotics are begun within one hour of arrival. For patients with SCD and pain, patients are given intravenous analgesics within 20 to 30 minutes of registration. The treatment algorithms were not changed during the COVID pandemic. However, new patient social distancing and COVID-related safety measures were implemented beginning in April 2020 and remain in place. All patients and guardians are briefly interviewed upon arrival to the ED to assess COVID-19 risk factors including pertinent symptoms, recent travel, exposure to a suspected or confirmed COVID-positive patient, and whether there is a pending COVID-19 test. All patients and visitors to the ED are screened for body temperature. All patients with SCD who admitted from the ED to an inpatient bed undergo a COVID-19 polymerase chain reaction (PCR) test.

Results

Fifty-eight patients participated in the study. The overall results for the first seven Likert-scale questions are depicted in Table 4. Most patients reported that their decision to go to the Emergency Room was affected by the COVID-19 pandemic (n = 38; 62%). The responses to question 1 were statistically significant across all groups except for race. There were significant differences when

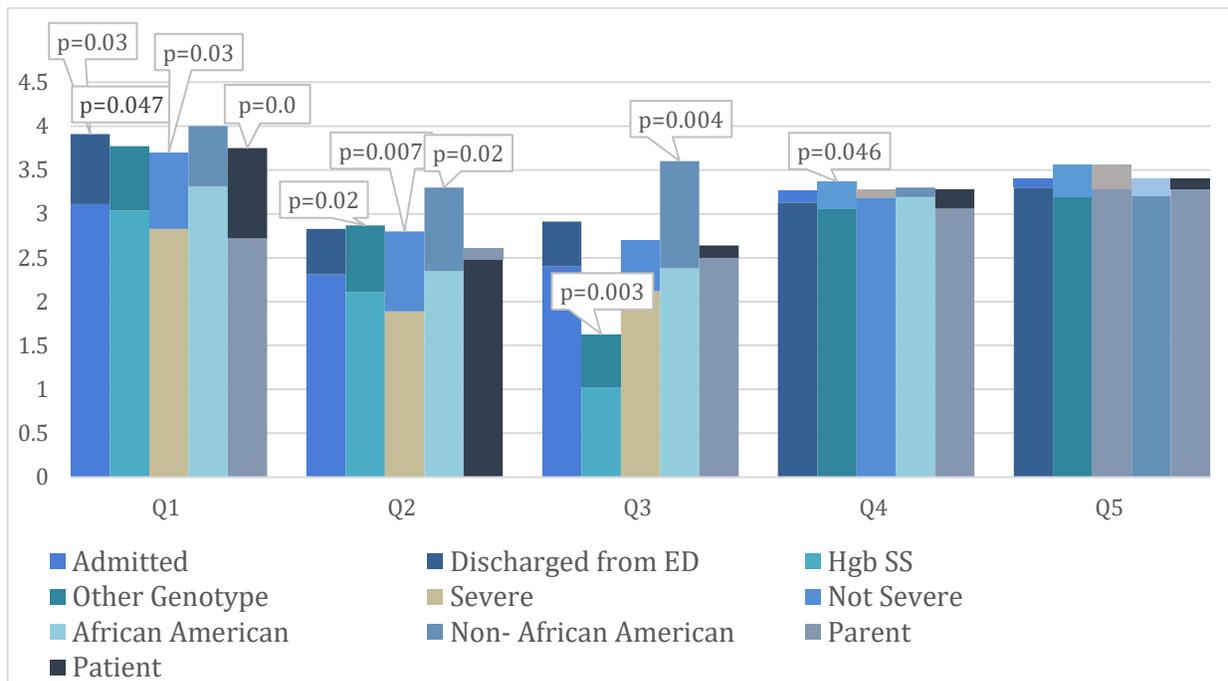
patient responses were analyzed by hemoglobin genotype (mean = 3.04 for Hgb SS versus a mean = 3.77 for other genotypes, $p = 0.047$), whether the parent/guardian or patient completed the questionnaire (mean = 2.72 for parents/guardians, mean = 3.75 for patients, $p = 0.01$), whether a patient was admitted (mean = 3.11 for admitted patients versus a mean = 3.91 for those patients discharged from the ED, $p = 0.034$), as well as disease severity (mean = 2.83 for severe disease versus mean = 3.70 for disease considered as not severe, $p = 0.03$). These results are illustrated in Figure 1.

Most participants responded that their experience in the ED was the same during the pandemic as it was before the pandemic ($n = 45$, 78%) (Table 4). The results were statistically significant when analyzed by Hgb genotype (mean = 3.37 for Hgb SS versus a mean = 3.06 for other genotypes, $p=0.046$) (Figure 1). Most participants stated that there was no change in the time it took to get an ED bed or to receive medical care ($n= 35$; 60%) (Table 4). All patients reported that they felt the ED personnel took proper infectious precautions ($n=58$; 100%) (Table 4). Overall, most participants felt their baseline sickle cell

disease symptoms were unchanged compared to before the pandemic ($n= 41$; 70%) (Table 4).

All participants were asked if they would answer the survey differently at the time that it was administered compared to at the beginning of the pandemic (Table 3). Five participants responded, and all felt differently about their decision to go to the ED. Two participants were more worried about returning to ED during the pandemic, and three participants were more comfortable going to the ED. Twenty-four participants responded to question 9 about their biggest concern for their ED visit. Most were worried about other patients ($n=18$), followed by the waiting area ($n = 13$), then ED providers ($n = 2$). All but 2 of the participants remembered being screened for COVID-19 exposure and symptoms ($n = 56$; 97%). Most participants did not choose to utilize telemedicine during the pandemic ($n = 39$; 67%). Many participants commented that the wait to see a provider in the ED was not longer than usual, but the wait to get a hospital room after admission was longer than usual, most likely due to the time it took to obtain the results of COVID-19 PCR testing.

Figure 1. Responses to Likert Questions 1 through 5, Analyzed by Subgroups



Subgroup analysis of response organized by question. 1) My decision to go to the Emergency Room was affected by the COVID-19 pandemic. 2) I waited longer before going to the Emergency Room (vs. before pandemic). 3) I tried more medications at home for fever and/or pain (vs. before the pandemic). 4) My experience in the Emergency Room was better during the pandemic (vs. before the pandemic). 5) I got to a room in the ED and/or got care faster during the pandemic (vs. before the pandemic).

Table 4. Responses to Likert Questions

Question	Mean (SD)	n (%)				
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	3.43 (1.41)	11 (19%)	3 (5%)	8 (14%)	22 (38%)	14 (24%)
2	2.52 (1.22)	18(31%)	8 (14%)	17 (29%)	14 (24%)	1(2%)
3	2.60 (1.25)	16 (28%)	9 (16%)	17 (30%)	12 (21%)	3 (5%)
4	3.21 (0.59)	0 (0%)	2 (3%)	45 (78%)	8 (14%)	3 (5%)
5	3.36 (0.77)	0 (0%)	4 (7%)	35 (60%)	13 (23%)	6 (10%)
6	5.00 (0)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	58 (100%)
7	3.03 (0.59)	0 (0%)	8 (14%)	41 (70%)	8 (14%)	1 (2%)

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 6) I felt the hospital took the proper infectious precautions (staff wore masks, ER was cleaned regularly, etc.).
 7) I feel like my sickle cell disease symptoms (pain, fever, etc.) are milder now (vs. before the pandemic).

Discussion

Our results suggest that the COVID-19 pandemic has not significantly affected patients’ experience in and satisfaction with ED visits or their baseline SCD symptoms. Overall, most people felt that the COVID-19 pandemic affected their decision to go to the Emergency Room, which was also notable when analyzed by subgroup. Patients with Hgb SS genotype, severe disease, patients who were subsequently admitted to the hospital, and parents responding to the survey were less affected by the pandemic in their decision-making process. One possible explanation is that patients who have the Hgb SS genotype and severe disease are more likely to have more serious and more frequent pain crises. Thus, their decision to present to the ED was driven more by their relatively worse symptoms, rather than such external factors as the pandemic, compared to participants with other genotypes and less severe disease. Using admission to the hospital as a surrogate for episode severity, it can be argued that patients who were having more severe episodes or crises were less hesitant to go to the ED. Finally, when considering who responded to the survey, recall bias and parental concern may account for parents wishing to take their children to the Emergency Room regardless of the additional risks posed by the COVID-19 pandemic.

Interestingly, most participants did not wait longer than usual before going to the ED and took the same amount of medication for pain or fever as they usually did during

the pandemic. Those patients with Hgb SS, severe disease, and who self-identified as African American were less likely to have waited before going to the ED. In addition, those patients with Hgb SS and who self-identified as African American were less likely to have taken more medication before going to the ED as compared to before the pandemic. These subgroups are more likely to have more serious and frequent pain crises, which may account for the observation that they did not delay in seeking medical care. Given the evidence that patients with SCD have a much higher risk of significant morbidity and mortality if they were to contract SARS-CoV-2 than patients without SCD, it is imperative that patients with SCD do not defer seeking appropriate, emergent medical attention.⁵

Although there is a substantial level of dissatisfaction with ED care that has been well documented among the population of patients with SCD, our results indicate that the COVID-19 pandemic did not worsen patients’ experience or satisfaction with their care.⁷⁻⁸ Most of the participants in this study reported that their experience in the ED was similar to their ED experiences before the pandemic, especially for those with the Hgb SS genotype. All respondents reported that the hospital took appropriate sanitary and social distancing precautions implemented during the pandemic. This result is further supported by most respondents not being concerned about staying in the waiting room or by the ED providers, but expressing concern about the potential risk posed by

other patients. Our results infer that, as most patients did not have a more negative experience in the ED during the pandemic, they would not be opposed to returning to the ED if necessary.

Overall, most participants felt their baseline sickle cell disease symptoms were unchanged compared to before the pandemic. One theory for the decrease in ED visits by patients with SCD during the pandemic is that such protective measures such as mask-wearing and social distancing result in less spread of viral respiratory illnesses in general, thereby leading to fewer SCD exacerbations. Our data do not support this theory. Most participants stated that there was no change in the time it took to get an ED bed or to get medical care. Interestingly, most participants did comment on the long wait time to get an inpatient bed assigned, most likely due to the time it took to run a COVID-19 PCR test per hospital protocol.

There are limitations to the study. The survey was conducted with a relatively small sample size of patients with SCD who were seen at a single pediatric ED. Therefore, care should be taken when generalizing our results. There is a risk of recall bias as the survey questioned participants about a past ED visit. The study was retrospective, as are most survey studies.

Despite the above limitations, this study is meaningful given the consistently negative ED encounters historically reported by patients with SCD. The results imply that the COVID-19 pandemic did not deter those pediatric patients with SCD who needed emergency care from seeking it, and that their experience and satisfaction with the ED was not substantially impacted by the additional screening and safety protocols implemented during the pandemic. To our knowledge, this is the first study of how the COVID-19 pandemic has affected patients' utilization of, experience in, and satisfaction with a pediatric hospital ED.

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