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Emergency Department Utilization for Patients Living With Sickle Cell Disease: Psychosocial Predictors of Health Care Behaviors

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Study objective: Individuals living with sickle cell disease (SCD) often require urgent care; however, some patients hesitate to present to the emergency department (ED), which may increase the risk of serious clinical complications. Our study aims to examine psychosocial, clinical, and demographic factors associated with delaying ED care.

Methods: This was a cross-sectional study of 267 adults with SCD from the national INSIGHTS Study. The binary outcome variable asked whether, in the past 12 months, participants had delayed going to an ED when they thought they needed care. Logistic regression was performed with clinical, demographic, and psychosocial measures.

Results: Approximately 67% of the participants reported delaying ED care. Individuals who delayed care were more likely to have reported higher stigma experiences (odds ratio [OR]=1.09; 95% confidence interval [CI] 1.03 to 1.16), more frequent pain episodes (OR=1.15; 95% CI 1.01 to 1.32), lower health care satisfaction (OR= 0.74; 95% CI 0.59 to 0.94), and more frequent ED visits (OR=6.07; 95% CI 1.18 to 31.19). Disease severity and demographics, including sex, age, and health insurance status, were not significantly associated with delay in care.

Conclusion: Psychosocial factors, including disease stigma and previous negative health care experiences, are associated with delay of ED care in this SCD cohort. There is a need to further investigate the influence of psychosocial factors on the health care–seeking behaviors of SCD patients, as well as the downstream consequences of these behaviors on morbidity and mortality. The resulting knowledge can contribute to efforts to improve health care experiences and patient-provider relationships in the SCD community. [Ann Emerg Med. 2020;76:S56-S63.]

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INTRODUCTION

Background

The emergency department (ED) plays a vital role in the lives of individuals with sickle cell disease (SCD). The hallmark symptom of SCD, acute attacks of intense pain caused by vaso-occlusive episodes, often requires urgent treatment in the ED.[1] Individuals with SCD may also present in the ED with priapism, exacerbation of chronic anemia, acute deterioration of leg ulcers, acute chest syndrome, strokes, and other end-organ damage,[1] which hold risk for serious complications if care is delayed. The number of US ED visits attributed to SCD is estimated to be 200,000 per year,[2,3] with a substantial proportion of individuals requiring multiple visits a year.[4,5] One study found that individuals with SCD visit the ED an average of 3 times per year from the teenage years through middle age.[6] Moreover, the ED may be the primary source of care for SCD patients with no access to regular primary care services.[7]

In studies examining the experiences of SCD individuals, patients have reported that they delay seeking ED care for a variety of reasons, even when they think it is necessary, including wanting to manage pain at home, avoiding the ED and subsequent hospitalization,[8] and previous negative experiences in the ED.[8,9] These studies, however, are limited in scope and provide minimal information on the comprehensive reasons challenging SCD adult patients' access to quality care. Despite the importance of the ED in health care provision, to date, there have been no studies examining specific reasons for ED delay among this population. More broadly, the SCD community has persistently faced barriers to adequate emergency care, including excessive wait times,[10] being stereotyped as drug seeking,[11] and lack of ED provider knowledge about SCD management,[12] highlighting the importance of further research that aims to improve ED care for this population.

Table 1. Summary of measures.

Measure	Description/Summary
ED care delay	This is the outcome measure, which assesses whether an individual has delayed ED care in the past 12 mo. A response of 1 or yes indicates that an individual had chosen to delay ED care in the past 12 mo.
Stigma experiences[13]	An overall summed scale that assesses personal perceived stigma experiences of active resistance, alienation, discrimination, and social withdrawal because of SCD. Higher scores indicate more stigma experiences. See Table E1, available online at http://www.annemergmed.com, for individual scale items.
ASCQ-Me Pain Episode Frequency measure[14]	Measure asks about number and frequency of pain episodes or crises in the past 12 mo. Higher scores indicate greater frequency of pain episodes.
ASCQ-Me quality of care health care satisfaction ranking[14]	A stand-alone question with a 1–11 range asking patients to rate their health care in the past 12 mo. A score of 1 means worst care possible.
BDI scale[18]	The BDI is a self-reported measure of depressive symptomatology. It consists of 21 items with a range of 0–63. A score $\geq$17 was defined as the threshold for depression.
No. of physician visits	A stand-alone question with a range of 1–5 asking about health care use: "In the past 12 mo, how many visits have you had with this physician or nurse?" A score of 1 indicates zero visits and a 5 corresponds to 4 or more visits.
Sickle Cell Disease Severity Measure[16,17]	The SCD severity measure calculates 5-y mortality risk for children and adults with SCD. Scores range from 0–1; higher scores indicate a higher mortality risk and more disease burden.
Rosenberg Self-Esteem Scale	Measures an individual's self-evaluation and self-esteem. Scores range from 10–40, and higher scores indicate higher self-esteem.

ASCQ-Me, Adult Sickle Cell Quality of Life Measurement Information System; *BDI*, Beck's Depression Inventory.

Goals of This Investigation

This study aims to identify and quantify factors that lead some adults living with SCD to delay seeking needed care in an ED. We examine psychosocial along with clinical and demographic factors, including self-reported stigma, pain frequency, and health care satisfaction experiences, in addition to use of primary care, to assess reasons individuals may delay ED care.

MATERIALS AND METHODS

Study Design and Setting

We completed a cross-sectional study of 267 adults with SCD recruited between June 2014 and January 2020 for the ongoing Insights into Microbiome and Environmental Contributions to Sickle Cell Disease and Leg Ulcers Study (ClinicalTrials.govNCT02156102) which examines the psychosocial, environmental, genetic, and clinical contributors to disease variation in patients with SCD. The data collection for this study was completed before the outbreak of the coronavirus disease 2019 pandemic. All participants provided consent before enrollment and received study compensation. Participants were treated either at the NIH Clinical Center in Bethesda, MD, or the Montefiore Medical Center in Bronx, NY. Institutional review board approval for the study was obtained from the NIH Clinical Center and Montefiore Medical Center.

Selection of Participants

Eligibility criteria was age of 18 years or older and a clinical diagnosis of SCD, including all genotypes. Participants enrolled at the NIH Clinical Center were recruited at national SCD conferences and advocacy events, through letters to SCD providers informing them of the study, through social media, and snowball sampling. Participants enrolled at Montefiore Medical Center were mostly patients treated by hematologists at that center but also included those recruited by letters to providers and snowball sampling to targeted individuals in the New York City area.

Methods of Measurement

In this study, each participant completed a study visit that included a medical history, clinical examination (vital signs check and physical assessment), and laboratory evaluation, along with an interviewer-administered survey. Table 1 presents a summary of the measures pertinent to this study, which are further detailed later.

Outcome and Predictor Measures

The outcome measure, ED care delay, asks the question "In the past 12 months, did you ever delay or avoid going to an ED when you thought you needed care?" Binary

responses were assessed, with the likelihood of yes being the outcome of interest.

One of our main predictor variables of interest is the stigma measure. When this study was initiated, there were no stigma measures specific for SCD. As a result, the stigma measure used here was adapted from the Internalized Stigma of Mental Illness scale originally developed for individuals with mental health conditions.[13] It consisted of 4 subscales covering various areas of stigma experiences, including social withdrawal, alienation, resistance to stigma, and discrimination. For the purposes of this study, the 4 subscales consisting of 22 items were combined into 1 summed stigma score with a range of 22 to 88. Because the stigma scale was adapted from the Internalized Stigma of Mental Illness Scale, we ran a validity test to determine reliability. Cronbach's α was .83 for this combined measure. Higher scores indicate more stigma experiences. The individual items for the stigma measure are presented in Table E1, available online at http://www.annemergmed.com.

The Adult Sickle Cell Quality of Life Measurement Information System Pain Frequency Episode measure includes 2 questions regarding the frequency of sickle cell pain events. The first question asks about the number of pain attacks in the past 12 months, whereas the second question asks when the last event occurred. The measure has a composite score with a range of 0 to 12, with higher scores indicating higher pain frequency during the past 12 months.[14,15]

The Sickle Cell Disease Severity Measure was based on a scale developed by Sebastiani et al[16] in 2007, which uses an algorithm predicting 5-year mortality risks for children and adults with SCD. Scores range from 0 to 1; higher scores indicate a higher mortality risk and more disease burden. An online tool called the Sickle Cell Disease Severity Calculator[17] uses several clinical and laboratory measures to estimate a final score: age, sex (male/female individual) and hemoglobin genotype; history of acute chest syndrome, stroke, priapism, avascular necrosis, and sepsis; pain occurrence and long-term blood transfusion status; systolic blood pressure measurement; bilirubin levels; lactate dehydrogenase levels; mean corpuscular volume; reticulocyte percentages; and white blood cell count. In our study, the following data were not collected: clinically reported history of acute chest syndrome and sepsis. However, the severity calculator allowed for missing variables and calculated scores based on available data.

Other Variables

Demographic variables were also adjusted for in the final model and included age, sex, health insurance type, educational status, marital status, and annual income. Clinical factors included high ED utilizers (ie, $\geq$3 visits in the past 12 months according to Aisiku et al[11]), Adult Sickle Cell Quality of Life Measurement Information System quality of care health care satisfaction ranking during the past 12 months (range 0 to 10, with 10 being best care possible),[14,15] how many physician visits they had in the past 12 months, and Beck's Depression Inventory scale score (range 0 to 63; a cutoff score of $\geq$17 defined depression in SCD; Wallen et al[18]). The Rosenberg Self-Esteem Scale score (range 1 to 20, with higher scores indicating higher self-esteem) was also included in this analysis.

Primary Data Analysis

The analytic frame for the study was developed out of a desire to understand contributors to the delay of needed ED care by individuals with SCD. Given Bediako and Harris's[19] assessment that the cultural and social factors for health care use are understudied for SCD individuals, and that stigma and prejudice in health care are unfortunate realities of living with SCD,[20,21] we chose to focus our analyses around survey measures related to stigma experiences, satisfaction with previous health care, and mental health and well-being (Beck Depression Index and Rosenberg Self-Esteem Scale). Additionally, previous literature has shown connections between delay of ED care in non-SCD contexts and clinical factors, demographic characteristics, and access to non-ED care (ie, whether patients have a primary physician).[22] For that reason, our model adjusted for demographic variables (eg, age, income, sex), clinical indicators of SCD severity (disease severity and pain frequency), and access to or use of non-ED preventive services (primary care physician access, number of physician visits, and insurance status).

We used descriptive statistics to characterize the variables mentioned earlier. We reported frequency percentages for the categoric variables and means with SDs for the continuous variables.

A multiple binary logistic regression model was used to examine the association between our 14 independent variables and the outcome variable, delay of ED care, given that it is a dichotomous measure. The overall fit of the model was determined by the Hosmer-Lemeshow test and the –2 log-likelihood statistic; both analyses indicated that the model was a good fit for the data. The odds ratios (ORs) for effect sizes and confidence intervals (CIs), along with the parameter constants (β estimates) are provided below for ease of final model reconstruction. Regression diagnostics were performed on our model, residuals were examined, and no concerning values were detected. A type I error of 0.05 was used for statistical significance in all

Table 2. Characteristics of the study population.

Characteristic	N	Percentage or Mean/Median (SD [Range])
Age, y	267	38.7/37.0 (12.0 [19–71])
Sex		
Male subjects	121	43.7
Female subjects	156	56.3
Race/ethnicity		
Black/non-Hispanic	206	92.0
Hispanic	14	6.3
Other	4	1.7
Household No.	211	2.7/2.0 (1.9 [0–9])
Insurance type		
Medicaid	53	23.6
Other government program	13	5.8
Private/Medicare	135	60.5
No health coverage	22	9.9
Education		
Some college and below	130	58.0
Bachelor's/master's degree	80	35.7
Professional/doctoral degree	14	6.3
Marital status		
Married/living with partner	68	24.4
Divorced/separated/widowed	43	15.4
Never married	168	60.2
Income, $		
<10,000–29,000	90	43.5
30,000–59,000	57	27.5
60,000–90,000	24	11.6
>90,000	36	17.4
Work status		
Working currently	96	42.7
Retired/student/keeping house/temporarily not working	42	18.7
Unemployed, looking for work	30	13.3
Disabled	55	24.4
Other	2	0.9
Stigma experiences score	242	50.2/50.0 (8.6 [24.0–78.0])
Sickle Cell Disease Severity Measure	267	0.5/0.5 (0.2 [0.05–1.0])
ASCQ-Me pain frequency	266	6.8/8.0 (3.0 [0–11])
Rosenberg Self-Esteem Scale	264	32.1/32.0 (5.4 [17–40])
ASCQ-Me quality of care health care satisfaction ranking	267	8.1/8.0 (2.3 [1–11])
Depression prevalence		
Yes	53	21.0
Do you have a physician/nurse you usually consult if you need a checkup, want advice about a health problem, or get sick or hurt?		
Yes	258	96.6
No	9	3.4
ED utilizers		
Low	210	78.9

Table 2. Continued.

Characteristic	N	Percentage or Mean/Median (SD [Range])
High (>3 visits/y)	56	21.1
Delay of ED care		
Yes	179	67.0
No	88	33.0
Delay of ED care because of bad experiences		
Nothing/a little bit	44	24.6
Some	28	15.6
Quite a bit/very much	107	59.8
Delay of ED care because of insurance issues		
Nothing	110	61.8
A little bit	17	9.5
Some	16	9.0
Quite a bit/very much	18	19.7

analyses ($P \leq .05$), which were conducted with SAS (version 9.4; SAS Institute, Inc., Cary, NC).

RESULTS

Characteristics of Study Subjects

Our population was predominantly non-Hispanic black (92%), female subjects (56%), and never married (60%); subjects had an average age of 38.7 years (SD 12.0) and had private or Medicare insurance coverage (61%), with only 24% having Medicaid insurance. Mean values for continuous variables were 0.5 (SD 0.2) for disease severity, 8.1 (SD 2.3) for health care satisfaction ranking, 32.1 (SD 5.4) for Rosenberg Self-Esteem Scale score, and 50.2 (SD 8.6) for stigma experiences. In our cohort, 67% reported delaying necessary ED care, with the majority (60%) noting previous poor ED experiences as an important reason for doing so. The majority (62%) of individuals who delayed care also reported that health insurance was not a reason for this delay. Nearly all our participants (97%) also reported having a physician or nurse they could consult for routine health problems. Table 2 indicates the characteristics of our population.

Main Results

In the final multivariable logistic regression model (Table 3), the following variables were significantly associated with delaying ED care: stigma experiences, pain frequency, ED utilization, and health care satisfaction rankings. Individuals with higher stigma scores were more likely to have delayed care (OR=1.09; 95% CI 1.03 to 1.16), along with individuals with more frequent pain episodes (OR=1.15; 95% CI 1.01 to 1.32) and those with more frequent ED visits in the past year (OR=6.07; 95% CI 1.18 to 31.19). On the other hand, individuals with higher reported satisfaction with health care experiences were 26% less likely to have delayed care (OR=0.74; 95% CI 0.59 to 0.94). Demographic characteristics (age, sex, education, and insurance type), depression, SCD severity measure, and number of physician visits were not significantly associated with our outcome.

LIMITATIONS

There are several limitations in this study. First, this is a cross-sectional study and examines these experiences at only one specific point in the patient's life. This includes the outcome measure as well, ED delay of care, because our general time frame was the past 12 months, but we did not assess the elapsed time from when delay of ED care occurred to when the survey was assessed. Second, many of the factors collected were self-reported and at risk for response bias possibly because of recall error, as well as desirability bias, given that the study was interviewer administered. Third, there may have been selection bias resulting from study enrollment and possibly evidenced by the moderately high socioeconomic status and educational level of our study population. However, our study recruited participants nationwide to expand the generalizability of our findings.

DISCUSSION

To our knowledge, this study is the first to quantitatively examine multiple factors that are associated with delaying perceived necessary ED care for individuals with SCD. We found that a majority of individuals who reported delaying care did so because of previous negative experiences with ED care. The final multivariable analysis provided a more

Table 3. Adjusted logistic regression model predicting likelihood of delayed ED care.

Characteristic	Adjusted β*	OR	95% CI
Stigma experiences	.09	1.09	1.03 to 1.16
ASCQ-Me Pain Episode Frequency measure	.14	1.15	1.01 to 1.32
ED utilization (vs low)			
High	.93	6.07	1.18 to 31.19
ASCQ-Me quality of care health care satisfaction ranking	−.30	0.74	0.59 to 0.94
No. of physician visits	.20	1.24	0.87 to 1.76
Sickle Cell Disease Severity Score	−1.51	0.22	0.02 to 2.07
Age	−.02	0.98	0.94 to 1.02
Sex (vs male sex)			
Female sex	.26	1.69	0.72 to 3.97
Depression (vs none)			
Yes	−.15	0.86	0.24 to 3.12
Insurance type (vs private/Medicare)			
No insurance	−.16	0.93	0.19 to 4.52
Government/Medicaid	.26	1.42	0.51 to 3.93
Highest education (vs professional/doctoral)			
High school/associate/some college	.71	4.17	0.76 to 23.0
Bachelor's/master's	.01	2.07	0.40 to 10.65
Marital status (vs never married)			
Married/living with partner	−.05	0.81	0.29 to 2.47
Divorced/separated/widowed	−.09	0.84	0.23 to 2.77
Income	.07	1.07	0.93 to 1.24
Rosenberg Self-Esteem Scale	.01	1.01	0.92 to 1.12

*The β coefficient gives the likelihood of delaying ED care for every one-unit increase (eg, every additional year in age) or between the indicated group and reference group (eg, female vs male individuals).

granular description of that response and identified that patients who delayed necessary ED visits were more likely to have reported higher stigma experiences, higher number of ED visits in the past 12 months, more frequent pain episodes in the past 12 months, and worse overall health care experiences in the past 12 months. There were no differences among the demographic factors nor among the clinical factors, including disease burden, prevalence of depression, and number of physician visits in the past 12 months. Emergency medicine care is an important access point in mitigating SCD-associated comorbidities,[1] and these findings provide insight into the reasons why SCD individuals decide to delay perceived necessary ED care and future points of intervention that can facilitate quality improvement.

Our study highlighted the substantial role of psychosocial factors such as previous negative experiences in the ED, disease stigma, and low health care satisfaction in delaying ED care. Stigma and negative ED or health care experiences within the SCD population have been empirically noted across several other studies.[8,10] In 2009, Haywood et al[23] performed a systematic review to investigate barriers to care in SCD. A common finding from multiple studies was that negative provider attitudes toward SCD contributed to poor pain management during vaso-occlusive crises. Provider stigma and insensitivity toward the sickle cell population, including lack of belief about the patient's self-reported pain and inclinations to suspect drug abuse and addiction, are all factors that serve as barriers to tailored SCD care. Previous literature has also shown that providers with negative attitudes are significantly less likely to repeat doses of opioids for sickle cell pain,[24] leading to poor quality of care and poor treatment outcomes.

Other studies on delay of ED care often find that blacks are more likely than non-Hispanic whites to delay seeking care for serious conditions such as acute chest pain.[22,25,26] These studies also found that demographic factors such as socioeconomic status, educational level, insurance type, and lack of outpatient care are predictors of delaying seeking ED care.[22] In our study, the majority of the participants were black and reported delaying necessary ED care. However, unlike acute chest pain studies, our study did not

find that other demographic factors were significant predictors of ED care delay. This finding highlights the importance of further investigating and addressing how psychosocial factors may be related to delay of ED care for all SCD patients, regardless of demographic differences. These findings may also be due to differences in defining delay of care and what constitutes urgent care, and warrant further research. One study compared the urgency of ED visits by children with SCD across other pediatric chronic conditions. The results of that study established that SCD ED visits are indeed urgent and not overused.[27] Although the findings of that study may not be conclusive for adults, it bears suggestive implications for our study and calls for a replication among adults with SCD.

Many studies specific to SCD have examined trends in health care use in this population. However, most studies on ED use tend to report on overall utilization in the SCD population with a focus on superutilizers and ED visit reduction approaches.[4,5,7,11,19,28-35] Similar to some of these studies, our study also found that the majority of participants were not high ED utilizers.[11] However, the stigma and pervasive negative ED experiences have been empirically noted across our study and several others.[8,10] Most studies also noted that SCD pain is the most dominant feature of ED presentation.[20,36] However, our study found that higher pain frequency was a significant predictor of having delayed ED care. Possible reasons for this can be considered in light of our other findings. In accordance with our study, it can be assumed that an SCD patient with previous negative ED-visit experiences, combined with perceived disease stigmatization and poor health care satisfaction, would try at all costs to avoid seeking further ED care.

In certain cases for SCD, delayed presentation for health care is understood to affect clinical outcomes.[37-39] For example, in leg ulcers, which is a rare but significant complication of SCD, studies have shown that presenting 60 to 90 days from initial occurrence has a negative influence on healing rates.[40] An additional example includes delayed diagnosis of priapism and therapy, which can result in impotence.[41] In the ED, mortality and morbidity outcomes are often a concern with delayed presentation.[42] Although our study did not examine or establish a direct link between delayed care and mortality or morbidity outcomes, it adds to the existing body of research on barriers to care. There is a need for future research to examine the association between ED delay of care and negative health outcomes.

In conclusion, access to primary and ambulatory care is essential to maintaining individual health and reducing downstream costs, including ED visits and readmission rates. Cost-effective and appropriate use of health services is also a constant goal for health care systems. However, the ED continues to be a vital source of acute care for SCD individuals, especially during periods of unmanageable disease exacerbations.[1] This study contributes to the understanding of barriers in appropriate ED care for SCD while highlighting the unique challenges posed by stigma and dissatisfaction with the ED experience on the use of appropriate care. Current guidelines, including the National Heart, Lung, and Blood Institute and American Society of Hematology guidelines,[24,41] provide some framework for improving overall quality care for SCD in the ED. Other guidelines for SCD care in the ED exist.[1,20,43] From a policy and educational perspective, however, more work is needed to reduce these "educational gaps and biases among providers, staff, and patients [that] create barriers to communication and trust, and erode the provider-patient relationship."[43] Building patient and ED provider communication will be fundamental to improving care for the SCD patient population in the United States, with the goal of improving quality of life and ultimately reducing morbidity and mortality.

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