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Emergency Department Visits Made by Patients with Sickle Cell Disease:

A Descriptive Study, 1999–2007

Hussain R. Yusuf, MD, MPH, Hani K. Atrash, MD, MPH, Scott D. Grosse, PhD, Christopher S. Parker, PhD, and Althea M. Grant, PhD

Division of Blood Disorders, National Center on Birth Defects and Developmental Disabilities, CDC, Atlanta, Georgia

Abstract

Background—Patients with sickle cell disease (SCD) often use emergency department services to obtain medical care. Limited information is available about emergency department use among patients with SCD.

Purpose—This study assessed characteristics of emergency department visits made nationally by patients with SCD.

Methods—Data from the National Hospital Ambulatory Medical Care Survey (NHAMCS) for the years 1999–2007 were analyzed. The NHAMCS is a survey of hospital emergency department and outpatient visits. Emergency department visits by patients with SCD were identified using ICD-9-CM codes, and nationally weighted estimates were calculated.

Results—On average, approximately 197,333 emergency department visits were estimated to have occurred each year between 1999 and 2007 with SCD as one of the diagnoses listed. The expected source of payment was private insurance for 14%, Medicaid/State Children's Health Insurance Program for 58%, Medicare for 14%, and other/unknown for 15%. Approximately 29% of visits resulted in hospital admission; this was 37% among patients aged 0–19 years, and 26% among patients aged ≥20 years. The episode of care was indicated as a follow-up visit for 23% of the visits. Patient-cited reasons for the emergency department visit included chest pain (11%); other pain or unspecified pain (67%); fever/infection (6%); and shortness of breath/breathing problem/cough (5%), among other reasons.

Conclusions—Substantial numbers of emergency department visits occur among people with SCD. The most common reason for the emergency department visits is pain symptoms. The findings of this study can help to improve health services delivery and utilization among patients with SCD.

Address correspondence and reprint requests to: Hussain R. Yusuf, MD, MPH, Division of Blood Disorders, National Center on Birth Defects and Developmental Disabilities, CDC, 1600 Clifton Road, MS-E64, Atlanta GA 30333. hyusuf@cdc.gov.

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Introduction

Sickle cell disease (SCD) is an inherited blood disorder characterized by the production of an altered type of hemoglobin by those affected by the disease. When sickle cell hemoglobin deoxygenates while passing through blood vessels, it polymerizes and becomes fibrous, causing the red blood cell to become rigid and change shape so that it appears sickle-shaped. The altered red blood cells can occlude blood vessels, resulting in lack of oxygen to tissues, and pain. Repeated, unpredictable episodes of acute pain are a complication of SCD that affects a substantial number of patients with the disease.^{1,2} Other complications of SCD are increased susceptibility to life-threatening infections, especially among children; stroke; pulmonary complications; skin ulceration; and other deleterious health events. Vaso-occlusive episodes result in tissue and end-organ injury, which could have damaging effects on the health of people with SCD. Because of SCD-related complications, many people with SCD may make more-frequent medical care visits than others among the general population. Comparatively higher levels of hospitalization and emergency department visits among SCD patients than other selected groups have been previously reported.^{3–5} A study conducted using data from Tennessee's state-funded managed care program found that black people with SCD made two to six times more emergency department visits than blacks without SCD.³

Limited information is available related to characteristics of emergency department visits among SCD patients. Information related to emergency department use by patients with SCD can help to develop services and strategies for best meeting the healthcare needs of patients with SCD. Various factors may affect healthcare access and utilization patterns among patients, such as patients' perception, insurance, availability of transportation, and disease-related factors. For example, Logan et al.⁶ found that factors related to healthcare utilization among adolescents included parental knowledge about SCD and disease severity. The objective of the current study was to describe emergency department utilization by patients with SCD nationally. The number of such visits and associated patient and other characteristics were assessed.

Methods

Data were from the National Hospital Ambulatory Care Surveys (NHAMCS) from 1999 to 2007. This survey is conducted by the CDC, National Center for Health Statistics. The survey collects patient visit-related information from a national probability sample of emergency department and outpatient visits to short-stay hospitals. A multistage cluster sample design is used to select hospitals from the states and the District of Columbia. Federal, military, and Veterans Administration hospitals, hospitals with <6 beds, hospitals that are part of institutions, and hospitals with an average length of patient stay of 30 days are not included in the survey. At each hospital, trained staff collected information on patient visits occurring during a randomly assigned 4-week reporting period. Information collected includes patient demographics, triage information, diagnostics, procedures, and medications. A primary diagnosis and up to two other diagnoses are recorded on the data-collection form. In addition, information is collected on the patient-stated reason for the visit

and includes the patient's complaints and symptoms. The most important reason and up to two other reasons are recorded. More information on NHAMCS is available elsewhere.⁷

Emergency department visits by patients with SCD were identified using ICD-9-CM diagnosis codes of 282.6, 282.60, 282.61, 282.62, 282.63, 282.64, 282.68, 282.69, 282.41, and 282.42. From visits having one or more of these diagnoses, cases that had indicated that the visit was related to an injury, poisoning, or adverse effect of medical treatment were excluded to form the study group of emergency department visits by patients with SCD. Data from the NHAMCS from 1999 to 2007 were combined to develop a larger sample size. Information on some variables was available for only certain years including: mode of arrival to the emergency department (1999–2000, 2003–2007); whether the episode of care was an initial visit or a follow-up visit (2001–2004, 2007); and length of visit (2001–2007). When estimating the distribution of various types of patient-stated reasons for the emergency department visit, all reasons (up to three) stated by patients were counted in developing frequency estimates.

Analysis was conducted using SAS, version 9.2. The derived estimates were weighted to represent all emergency department visits occurring nationally in the types of hospitals included in the survey. The estimated average annual number of emergency department visits by patients with SCD was derived by dividing the weighted total estimate of these visits by 9, the number of years of survey data used. The SURVEYFREQ procedure was used to derive the percentage distributions of selected visit-related characteristics and patient-reported reasons for the emergency department visit as well as the associated SEs. The SURVEYFREQ procedure adjusts for the NHAMCS survey design in developing variance estimates. Differences by age group in the distribution visit characteristics and in the percentage reporting a particular reason for the emergency department visit were assessed using the Rao–Scott chi-square test. The Rao–Scott chi-square test is a modified version of the Pearson chi-square test and accounts for complex sampling design. The mean and SEs of the length of the visit times were estimated using the SURVEYMEANS procedure. This procedure also adjusts for the survey design.

Results

From 1999 to 2007, the NHAMCS had a combined sample of 300,394 emergency department visits. This number represents a weighted estimate of approximately 1 billion (95% CI=933,758,000, 1,073,966,000) emergency department visits occurring nationally during those years. The total numbers of emergency department visits in the sample with a primary diagnosis of SCD and any diagnosis of SCD were 415 and 502, respectively. These numbers represent weighted estimates of approximately 1,475,000 (95% CI=1,214,000, 1,736,000) and 1,776,000 (95% CI= 1,484,000, 2,068,000) emergency department visits by patients with a primary or any diagnosis of SCD, respectively. The estimated yearly average number of emergency department visits by patients with any diagnosis of SCD was 197,333. The remaining results presented in this paper, including percentage distributions of selected characteristics and reasons for the emergency department visit, refer to patients with any diagnosis of SCD. Approximately 51% (SE=3%) of the emergency department visits by patients with SCD were made by male patients, and 49% (SE=3%) by female patients (Table

1). For 94% (SE=2%) of the visits, the race of the person was listed as black/African-American.

The mode of arrival for most emergency department visits by patients with SCD was walk-in (79%), followed by ambulance (14%; Table 1). The mode of arrival was walk-in for 87% of visits by patients aged 0–19 years, and 76% of visits by patients aged ≥20 years. The age groups composing the largest percentage of emergency department visits were 20–29 years (31%) and 30–45 years (35%). The expected source of payment for emergency department visits by patients with SCD was private insurance, Medicaid/State Children's Health Insurance Program (CHIP), Medicare, and other or unknown for 14%, 58%, 14%, and 15% of visits, respectively. Among visits by patients aged 0–19 years, the expected source of payment was private insurance for 20% and Medicaid or CHIP for 70%. Among visits by patients aged ≥20 years, the expected source of payment was private insurance for 11%, Medicare for 19%, and Medicaid for 53%.

The percentage of visits indicated to be initial visit, follow-up visit, and unknown as to the episode of care were 66%, 23%, and 11%, respectively (Table 1). Among visits by patients aged ≥20 years, the episode of care was indicated as a follow-up visit for 27% of the visits. Approximately 29% of emergency department visits by patients with SCD resulted in hospital admission. This was 37% among visits by patients aged 0–19 years, and 26% among visits by patients aged ≥20 years. The difference by age group in the percentage admitted to the hospital came close to but did not reach significance ($p=0.059$).

The most commonly cited reason for the emergency department visit was pain, including chest pain (11%) and other pain or unspecified pain (67%; Table 2). Fever or infection was cited as a reason for 6% of visits. Among visits by patients with SCD, shortness of breath, breathing problem, or cough was a cited reason for approximately 5% of visits.

The mean length of visit for emergency department visits by patients with SCD was approximately 307 minutes (SE=16). Among visits by patients aged 0–19 years, this was 294 minutes (SE=36); and among visits by patients aged ≥20 years, this was 311 minutes (SE=19), not appreciably different.

Discussion

Information on emergency department utilization among patients with SCD can be helpful in developing strategies for improving health services and health outcomes, such as through their use in the planning of services and improving effectiveness. The findings in this study indicated that a substantial number of emergency department visits are made annually by patients with SCD. These findings are consistent with previous studies that have reported heavy use of emergency departments among SCD patients.^{3,5} Emergency departments are a major mode of healthcare utilization among SCD patients.

Emergency departments play an important role in providing acute and urgent care. Such services are indispensable in selected situations and circumstances. Emergency departments also act as a safety net for those who do not have a regular source of health care. However, emergency departments are not structured for optimal provision of routine care. Medical

homes, which by definition provide a regular source of care, are able to provide comprehensive care to patients that include preventive services and counseling. Of note, comprehensive care should be distinguished from multidisciplinary care. Patients with SCD experience a wide range of complications affecting multiple organ systems. Thus, it is important for primary care providers to refer patients with SCD to subspecialists and to other types of providers as appropriate.⁸ In particular, it is recommended that individuals with SCD be seen by a hematologist at least once per year.⁹

Emergency department visits by patients with SCD can possibly be reduced by greater availability and/or utilization of other outpatient services. One study reported that patients with SCD seen at a comprehensive health clinic had a lower frequency of emergency department visits,⁴ although the reasons for this were not clear. In addition, pain management care through SCD day hospitals in outpatient settings can possibly divert individuals with SCD from emergency departments.^{10–12}

Routine care among children with SCD may be less than optimal. A study conducted among children in a Medicaid and SCHIP managed care health plan in Texas reported that approximately 60% of children with SCD averaged one well child–care visit per year, not significantly different from the number for other children in the plan.⁵ However, a national study reported that both publicly and privately insured children with SCD average approximately 12 non–emergency department outpatient encounters per year.¹³ Only 10% of children with SCD in the Texas study were reported to have had at least one visit to a hematologist per year.⁵ A previous study that used Medicaid data from California, Georgia, Michigan, and Tennessee reported that 36% of children with SCD who were enrolled in Supplemental Security Income (SSI) saw any subspecialist in the previous year, and this was 19% among those with SCD who were not enrolled in SSI.¹⁴

The disposition of a substantial proportion of emergency department visits among patients with SCD was hospital admission; this may possibly be higher among patients aged 0–19 years than among patients aged ≥20 years. The substantial levels of hospital admissions may be at least partially because of the acuteness of or the management needed for the presenting complaint. The extent to which this could reflect problems in healthcare access and utilization is not known. For instance, we do not know the extent to which more routine care could have resulted in fewer hospitalizations. Better knowledge of how access- and utilization-related factors relate to hospital admission characteristics is needed. The finding that among visits by patients aged ≥20 years, the episodes of care for 27% were recorded as follow-up visits also indicates that more efforts are needed to assess health service needs and utilization among patients with SCD.

The finding that adults aged ≥20 years accounted for an estimated 73% of emergency department visits by patients with SCD confirms that SCD is not primarily a pediatric health issue. A previous study reported a similar age distribution of SCD-related inpatient admissions, with an estimated 75% of all hospital admissions for which SCD was the principal diagnosis occurring among individuals aged ≥18 years.¹⁵ Although adults are more likely not to have health insurance,¹⁶ this may not be the major reason or the only major reason for the high level of emergency department visits by adults, given that the same

pattern is observed for inpatient admissions. A greater degree of severity and less optimal management among adults with SCD could be possible contributors.

Adults aged 45 years accounted for only a small percentage of emergency department visits by patients with SCD. This fact may reflect shorter life expectancy among people with sickle cell anemia that had been reported previously.¹⁷ A number of studies in recent years have indicated decreased mortality among children with SCD,^{18–21} but there have not been reports of lowered mortality among adults in the U.S. with SCD. However, it is unknown whether other factors could have also contributed the small percentage of emergency department visits by older patients.

The expected source of payment for a very large percentage of visits by patients aged 0–19 years as well as patients aged 20 years was public insurance (Medicaid or SCHIP and Medicare). These findings are consistent with those of other studies in which the majority of patients with SCD in the respective studies had public insurance as their source of payment.^{22–24} For example, public insurance was indicated as the primary payer for 79% of SCD hospitalizations during 2004.¹⁵ In the U.S., SCD predominantly affects African Americans. The prevalence of lack of insurance and underinsurance and Medicaid status are also higher among African Americans and Hispanics relative to other groups.¹⁶ It is unclear if other factors could have also contributed to the high frequency of public insurance use among these visits. For example, it is not clearly understood how insurance status may affect healthcare utilization patterns among patients with SCD or how disease severity may be related to insurance status.

Research is needed to identify effective ways to improve utilization of medical homes among people with SCD.⁵ Such strategies could include referral assistance to patients during emergency department visits who do not have a medical home. In a study conducted by Marr et al.,²⁵ emergency department patients without medical homes were linked to community-based healthcare providers through patient advocates by interacting with patients during emergency department visits, offering referrals for primary care, scheduling referral visits, and faxing medical information. In a study conducted at a hospital emergency department and hematology clinic assessing emergency department visits, clinic visits, and hospital admissions among patients with SCD, the authors reported that after implementation of a pain management protocol and proactive efforts to increase clinic visits, the number of emergency department visits decreased and clinic utilization increased.¹⁰ Also, more efforts are needed for identifying and implementing the best methods of providing medical care to patients with SCD. Research indicates that SCD day hospitals may be an effective mechanism for treatment of uncomplicated vaso-occlusive crisis.^{11,12}

An important complication of SCD is the occurrence of unpredictable episodes of pain that result from vaso-occlusion. In this study's findings, pain was cited by the patient as a reason for the visit in approximately 78% of the emergency department visits by patients with SCD. Other studies have reported similar findings related to emergency department visits and hospitalizations.^{4,13,22} Yang et al.⁴ found that among patients with SCD in Alabama, sickle cell pain crisis was the most common cause of emergency department and hospital treatment. Medical evaluation is recommended for people with SCD who develop fever or

infection.⁹ In this study, fever or infections were cited as the reason for a visit for 6% of emergency department visits.

This study has several limitations. The NHAMCS samples for each year contained only a small number of visits by patients with SCD. This issue was addressed by combining several years of data so that a larger sample of visits by patients with SCD was available for analysis. Nonetheless, there was a total of only 502 observations with any diagnosis of SCD in the 1999–2007 NHAMCS samples. Combining data increased the capability to assess group-specific differences among SCD-related visits, but the study's strength was still limited. For selected categories of several variables assessed (Tables 1 and 2), there were a small number of cases in the categories resulting in relatively large SEs, making interpretation of these estimates difficult; these estimates have been indicated in the Tables 1 and 2. Estimates with relative SEs of >30% do not meet standards of reliability or precision. Similarly, appropriate caution should be applied in interpreting the Rao–Scott chi-square tests. In the current study, the reasons patients used emergency department services rather than other types of services could not be assessed.

More research is needed on healthcare utilization, such as that pertaining to care facilities and settings, among patients with SCD. The findings of this study indicate the large role played by emergency department services for health care for patients with SCD, and they provide information on characteristics related to emergency department services utilization. Although emergency departments are an important mode of healthcare delivery, better outpatient care could reduce the number of emergency department visits substantially. Strategies and activities are needed to improve delivery and utilization of health care as appropriate to reduce morbidity and improve health outcomes among patients with SCD.

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Table 1

Selected characteristics of emergency departments visits by patients with SCD, 1999–2007 (% [SE] unless otherwise indicated)

Characteristic	All visits	Visits by patients aged 0–19 years	Visits by patients aged 20 years	<i>p</i> -value *
Gender				
Male	50.6 (3.0)	57.1 (5.7)	48.1 (3.5)	0.172
Female	49.4 (3.0)	42.9 (5.7)	51.9 (3.5)	—
Race				
Black/African-American	93.9 (1.5)	91.0 (3.3)	95.0 (1.7)	0.223
Other or >1 race	6.1 (1.5)	9.0 (3.2)	5.0 (1.7)	—
Mode of arrival^a				
Ambulance	14.0 (2.2)	6.7 (3.2)	16.6 (2.8)	0.151
Walk-in	79.2 (2.6)	87.2 (4.3)	76.3 (3.2)	—
Other/unknown	6.8 (1.6)	6.1 (3.2)	7.1 (1.9)	—
Age (years)				
0–9	12.2 (2.3)	—	—	—
10–19	15.0 (2.1)	—	—	—
20–29	31.1 (2.9)	—	—	—
30–45	34.6 (3.3)	—	—	—
45	7.0 (1.4)	—	—	—
Expected source of payment				
Private insurance	13.6 (2.0)	19.7 (4.4)	11.4 (2.1)	NA
Medicaid/SCHIP	57.8 (3.0)	70.2 (5.3)	53.2 (3.6)	NA
Medicare	13.8 (2.4)	—	19.0 (3.0)	NA
Other/unknown	14.7 (2.2)	10.1 (3.6)	16.4 (2.8)	NA
Episode of care^b				
Initial visit	66.2 (4.2)	74.3 (6.3)	63.7 (5.4)	0.047
Follow-up visit	22.7 (4.6)	9.5 (3.8)	26.9 (5.7)	—
Unknown	11.1 (2.3)	16.2 (5.9)	9.4 (2.6)	—
Admitted to the hospital from emergency department				
Yes	29.4 (2.8)	37.4 (5.6)	26.4 (3.0)	0.059
No	70.6 (2.8)	62.6 (5.6)	73.6 (3.0)	—

Note: Estimates in boldface have relative SE (RSE; SE/point estimate) of >30% and/or are based on <30 observations; estimates with RSE of >30% do not meet standards of reliability or precision.

^a Analysis was based on data from only 1999–2000 and 2003–2007 NHAMCS (383 cases).

^b Analysis was based on data from only 2001–2004 and 2007 NHAMCS (292 cases).

* *p*-value for Rao–Scott chi-square test for % with characteristic among patients aged 0–19 years and those aged 20 years.

NA, not available/could not be computed; NHAMCS, National Hospital Ambulatory Medical Care Survey; SCD, sickle cell disease; SCHIP, Medicaid/State Children's Health Insurance Program

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Table 2

Patient-cited reasons for the visit by patients with SCD, 1999–2007 (% [SE] unless otherwise indicated)

Reason for visit	All visits	Visits by patients aged 0–19 years	Visits by patients aged ≥ 20 years	<i>p</i> -value*
Chest pain	11.1 (1.7)	8.7 (2.7)	12.0 (2.2)	0.357
Other pain or unspecified pain	67.2 (3.1)	62.1 (6.1)	69.1 (3.3)	0.276
Fever/infection	5.5 (1.4)	16.4 (4.6)	1.4 (0.6)	<0.001
Shortness of breath/breathing problem/cough	4.8 (1.0)	8.1 (2.7)	3.5 (0.9)	0.052
Anemia ^a	49.8 (2.8)	37.7 (5.1)	54.3 (3.1)	0.004
Other	14.0 (2.0)	27.9 (6.2)	8.8 (1.7)	0.001

Note: Estimates in boldface have a relative SE (RSE; SE/point estimate) of >30% and/or are based on <30 observations; estimates with an RSE of >30% do not meet standards of reliability or precision.

^aCategory includes sickle cell anemia.

**p*-value for Rao–Scott chi-square test for % with characteristic among patients aged 0–19 years and those aged ≥ 20 years.