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RESEARCH ARTICLE

Characteristics of Emergency Department Visits Made by Individuals With Sickle Cell Disease in the U.S., 1999–2020

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Introduction: Individuals living with sickle cell disease experience high levels of morbidity that result in frequent utilization of the emergency department. The objective of this study was to provide updated national estimates of emergency department utilization associated with sickle cell disease in the U.S.

Methods: Data from the National Hospital Ambulatory Medical Care Survey for the years 1999–2020 were analyzed. Complex survey analysis was utilized to produce national estimates overall and by patient age groups.

Results: On average, approximately 222,612 emergency department visits occurred annually among individuals with sickle cell disease, a nearly 13% increase from prior estimates. The annual volume of emergency department visits steadily increased over time, and pain remains the most common patient-cited reason for visiting the emergency department. Patient-reported pain levels for individuals with sickle cell disease were high, with 64% of visits associated with severe pain and 21% associated with moderate pain. Public insurance sources continue to cover most visits, with Medicaid paying for 60% of visits and Medicare paying for 12% of visits. The average time spent in the emergency department increased from previous estimates by about an hour, rising to approximately 6 hours. The average wait time to see a provider was 53 minutes.

Conclusions: Utilization of the emergency department by individuals living with sickle cell disease remains high, especially for pain. With more than half of patients with sickle cell disease reporting severe pain levels, emergency department staff should be prepared to assess and treat sickle cell disease–related pain following evidence-based guidelines and recommendations. The findings of this study can help improve care in this population.

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2773-0654/$36.00
https://doi.org/10.1016/j.focus.2023.100158

INTRODUCTION

Sickle cell disease (SCD) is a rare blood disorder estimated to affect approximately 100,000 people in the U.S.[1] SCD is characterized by abnormally shaped red blood cells that are more likely to adhere to blood vessels than normal red blood cells, resulting in major medical complications such as hemolytic anemia, infection, stroke, and progressive organ damage.[2,3] The hallmark symptom of SCD is recurring and debilitating pain associated with vaso-occlusive crisis (VOC), which occurs when the sickled cells heavily restrict blood flow and deprive tissues and organs of oxygen. VOC is often treated and managed in the emergency department (ED),[4,5] and therefore individuals with SCD frequently utilize the ED,[6] with population-based surveillance indicating on average 2 visits to the ED annually per person with SCD.[7] Understanding the characteristics of ED visits associated with SCD provides important contextual information that can be used to inform healthcare policy and clinical practice for this population with high acute care needs.

In a previous study, Yusuf et al. utilized data from the National Hospital Ambulatory Medical Care Survey (NHAMCS) to describe characteristics of ED visits made by individuals with SCD in the U.S.[8] They found that from 1999 to 2007, an estimated 197,333 SCD-related ED visits were made annually, most of which (72% of visits) were covered by Medicaid or Medicare. Approximately 66% of the encounters represented an initial visit to the ED, and approximately 30% resulted in admission to the hospital. The average length of time for these visits was 307 minutes, approximately 5 hours. The most common patient-cited reason for visiting the ED was pain, including chest pain (11% of visits) and other pain or unspecified pain (67% of visits). When analyzing differences in ED visits by age (0−19 years compared with ≥20 years), they found a greater percentage of initial visits made by younger patients than by older patients (74% vs 64%) and that younger individuals were more likely to visit the ED for fever or infection (16% vs 1%). However, older individuals were more likely to visit the ED for anemia (54% vs 38%).

Since the publication of their study, an additional 13 years of NHAMCS data have become available. Therefore, the objective of this study is twofold. First, we provide updated national estimates by replicating the previous study design using the newly available data to describe the characteristics of ED visits associated with SCD in the U.S. from 1999 through 2020. Second, we expand the original study by including several additional variables of interest. Given that pain was the most frequently reported reason for visit in the study by Yusuf et al., we include national estimates of the patients' self-reported pain levels, which were previously not provided. We also produce national estimates of wait times to see a healthcare provider in the ED, an important quality of care indicator for individuals with SCD. Finally, we provide a descriptive trend analysis of ED visits over time as well as yearly national estimates of the number of visits, which were previously unpublished.

METHODS

Study Sample

Data on ED visits were obtained from the NHAMCS. NHAMCS is a multistage, nationally representative survey of ED visits made to nonfederal, short-stay hospitals in the U.S. Complete methodology and data collection procedures for the NHAMCS data set are available online.[9] ED visits associated with SCD were identified using the presence of ICD-9-CM and ICD-10-CM (Appendix Table 1, available online) codes present in any of the 3 diagnosis fields consistently available in NHAMCS. ICD-9-CM codes were derived from the previous study by Yusuf and colleagues, and ICD-10-CM codes were identified from methodologic guidance on surveillance for SCD.[10,11] To maintain consistency with the previous study[8] and because they were unavailable in the NHAMCS data, additional indicators of SCD-related procedures and treatments previously found to improve the accuracy of identifying individuals with SCD in secondary data[12,13] were not utilized to identify the sample in this study. Visits that were flagged by NHAMCS as an ED visit for an injury, poisoning, or adverse effect of medical treatment were excluded from the analysis, consistent with the previous study.

Measures

On an annual basis, staff at participating hospitals were trained to collect information on patient visits during a randomly assigned 4-week period using standardized patient record forms, which were uniformly processed and cleaned for public use by the National Center for Health Statistics.[14] From the patient record forms, we reported on the following categorical measures (Table 1): patient sex, race, mode of arrival, age group, expected source of payment, episode of care, admission to the hospital, and self-reported pain level. Continuous measures of interest included length of ED visit and wait time to see a healthcare provider (either a physician, advanced practice registered nurse, or physician assistant), both reported in minutes. Length of ED visit comprised the entire episode of care: from arrival to the ED through triage, treatment, and patient discharge. Up to 3 patient-reported reasons for visit were collected on the patient

Table 1. Characteristics of Emergency Department Visits by Patients With Sickle Cell Disease, 1999–2020

Characteristic	All visits	Visits by patients aged 0–19 years	Visits by patients aged ≥20 years	*p*-value
Sex				
Male	50.86 (46.47, 55.26)	62.22 (53.79, 70.64)	47.22 (42.38, 52.06)	<0.01
Female	49.14 (44.74, 53.53)	37.78 (29.36, 46.21)	52.78 (47.94, 57.62)	—
Race				
Black/African American	93.52 (91.32, 95.72)	90.44 (84.32, 96.56)	94.51 (92.41, 96.61)	0.14
Other or >1 race	6.48 (4.28, 8.68)	**9.66 (3.44, 15.68)**	5.49 (3.39, 7.59)	—
Mode of arrival[a]				
Ambulance	13.49 (10.33, 16.65)	**10.01 (4.35, 15.67)**	14.59 (10.77, 18.40)	0.19
Walk-in	82.30 (79.08, 85.51)	83.57 (76.64, 90.51)	81.90 (78.03, 85.78)	—
Other/unknown	4.22 (2.62, 5.80)	**6.42 (2.05, 10.78)**	3.52 (2.04, 5.00)	—
Age (years)				
0–9	9.04 (6.71, 11.37)	—	—	—
10–19	15.24 (11.13, 19.34)	—	—	—
20–29	33.82 (29.36, 38.27)	—	—	—
30–45	33.05 (28.69, 37.41)	—	—	—
>45	8.86 (6.54, 11.17)	—	—	—
Expected source of payment				
Private insurance	12.54 (10.00, 15.09)	16.12 (10.08, 22.16)	11.40 (8.57, 14.23)	<0.001
Medicaid/SCHIP	59.83 (55.01, 64.65)	71.60 (63.40, 79.81)	56.06 (50.41, 61.71)	—
Medicare	12.37 (9.48, 15.27)	**1.87 (0.00, 3.82)**	15.74 (12.09, 19.39)	—
Other/unknown	15.25 (11.72, 18.77)	10.41 (4.58, 16.24)	16.80 (12.57, 21.03)	—
Episode of care[b]				
Initial visit	67.60 (62.53, 72.67)	72.98 (64.13, 81.83)	65.95 (60.00, 71.90)	0.08
Follow-up visit	22.14 (17.85, 26.43)	14.41 (8.06, 20.77)	24.52 (19.34, 29.69)	—
Unknown	10.26 (7.29, 13.23)	**12.61 (6.20, 19.02)**	9.54 (6.33, 12.74)	—
Admitted to the hospital				
Yes	27.96 (24.23, 31.70)	35.36 (28.08, 42.65)	25.59 (21.58, 29.60)	0.01
No	72.04 (68.30, 75.77)	64.64 (57.35, 71.92)	74.41 (70.40, 78.42)	
Mean length of visit (in minutes)[c]	364.20 (305.14, 423.25)	319.98 (261.33, 378.62)	376.70 (303.63, 449.76)	0.22
Mean wait time to see provider (in minutes)[d]	53.23 (44.86, 61.61)	55.78 (31.07, 80.48)	52.46 (44.66, 60.26)	0.80
Pain level[a]				
No pain	6.86 (4.25, 9.45)	14.98 (7.91, 22.06)	**4.29 (1.69, 6.89)**	<0.01
Mild pain	8.01 (5.43, 10.60)	**7.95 (1.86, 14.04)**	8.03 (5.33, 10.74)	—
Moderate pain	20.81 (16.69, 24.95)	27.92 (16.69, 39.14)	18.57 (14.46, 22.67)	—
Severe pain	64.31 (59.70, 68.92)	49.15 (38.62, 59.66)	69.10 (64.28, 73.93)	—

Note: Unless otherwise noted, cell values represent percentages. Values in parentheses represent 95% CIs. Estimates in boldface have an RSE (SE/point estimate) >30% and/or are based on <30 observations; estimates with an RSE >30% do not meet standards of reliability or precision.
[a]Analysis was based on data from only 1999–2000 and 2003–2020.
[b]Analysis was based on data from only 2001–2020.
[c]Analysis was based on data from only 2001–2015 and 2018–2020.
[d]Analysis was based on data from only 1999 and 2002–2020.
RSE, relative SE; SCHIP, State Children's Health Insurance Program.

record form. NHAMCS administrators utilized a standardized reason-for-visit classification system to recode and categorize these visits for uniform reporting purposes across participating hospitals.[15] Similar to the previous study, these visits were further reviewed and collapsed for the current analysis by 1 pediatric hematologist and 1 adult hematologist who specialize in care for patients with SCD. Their independent reviews resulted in an initial agreement rate of 81% for 140 unique visit codes, and 100% agreement was met in a separate consensus-reaching session. Consistent with the previous study, all survey years were pooled to produce the most stable population-level estimates possible, considering the relatively small sample size of SCD-related visits.

Statistical Analysis

All analyses were conducted using SAS, Version 9.4. Survey weights were utilized to account for the NHAMCS complex sampling design and to produce national estimates for the measures of interest. In addition, domain estimation procedures were used to account for SCD-related visits as a subpopulation of the NHAMCS sampling frame.[16] Point estimates and 95% CIs were produced using the SURVEYFREQ procedure for categorical measures and the SURVEYMEANS procedure for continuous measures. National estimates were produced using the fully pooled data set that included all survey years for the sex, race, age group, expected source of payment, and admission to the hospital variables (unweighted n=1,075). The following variables were not available in all years, and for these estimates, subsets of the main data set were utilized in the analysis: mode of arrival (unweighted n=956; only available from 1999−2000 to 2003−2020), episode of care (unweighted n=986; only available from 2001−2020), length of ED visit (unweighted n=836; only available from 2001−2015 to 2018−2020), and wait time to see a provider (unweighted n=821; only available in 1999 and 2002−2020).

Trends in yearly estimates for the number of ED visits were assessed visually. Consistent with the prior study, the estimated average annual number of ED visits made by individuals with SCD was derived by dividing the total estimate by 22 (the number of years in the analysis). Differences in characteristics of ED visits by age group were examined by comparing individuals aged 0−19 years with individuals aged ≥20 years, consistent with the prior study. Specifically, differences by age group were tested using the Rao−Scott chi-square test for categorical measures and a survey-weighted t-test for continuous measures, both of which account for the complex sampling design of NHAMCS.[17] Consistent with the prior study, when reporting the distribution of patient-cited reasons for visiting the ED, all reasons (up to 3 for each encounter) were counted when producing the national estimates. This study was considered non-human subjects research and exempt by the IRB at Georgia State University.

Patient-Reported Pain Levels

Several methodologic issues associated with patient-reported pain warrant discussion. Patient-reported pain was assessed by hospital staff at the time of triage using a numerical pain intensity scale (scores ranging from 0 [representing no pain] to 10 [representing the worst pain possible]) provided by the Agency for Healthcare Research and Quality.[18] The pain measure was not collected in 2001 and 2002, and therefore, these years were excluded from the analysis. In 1999−2000 and 2003−2008, patient-reported pain was collected on the NHAMCS patient record form on a 0-to-3 scale, with values of 0 representing no pain, values of 1 representing mild pain, values of 2 representing moderate pain, and values of 3 representing values of severe pain. Beginning in 2009, data collection for this measure switched to a 0-to-10 numeric rating scale. For compatibility, we back cross-walked the different coding schemes following NHAMCS guidance[19] and prior studies[20,21] such that 0 represented no pain, scores of 1−3 represented mild pain, scores of 4−6 represented moderate pain, and scores of 7−10 represented severe pain.

Among the 956 unweighted records flagged with SCD diagnosis codes between 1999−2000 and 2003−2008, 203 records (21.2%) were missing data on the pain measure. We followed a standard 2-stage process to address the missing data.[17] In Stage 1, we addressed unit-level nonresponse by adjusting the complex survey weights to account for sampling units that did not collect the pain measure (n=23 records). Specifically, we utilized a logistic regression to estimate the propensity of unit-level response as a function of patient age, sex, race, survey year, and hospital census region. These variables were selected because they were readily available in the NHAMCS data and were consistently utilized in prior pain studies in the general population.[22,23] We also included an indicator for SCD patient status as a proxy measure to represent SCD-specific predictors of pain levels found in previous research that were unavailable in the NHAMCS data (such as laboratory-confirmed SCD genotype; prior hydroxyurea use; psychosocial functioning; and existing conditions, including retinopathy and stroke).[24,25] On the basis of the model, a set of 5 ranked propensity strata was utilized to rescale the existing survey weights to account for unit-level nonresponse.[26,27] During Stage 2, we utilized the same predictor variables to multiply impute the remaining missing data (180 records). A total of 20 multiply imputed data sets were created following guidelines from the simulation study conducted by Bodner.[28] The MIANALYZE procedure in SAS was utilized to account for within- and between-imputation variability in the point estimates for each pain level. To test for differences in imputed pain level by age, p-values for the pooled Rao−Scott chi-square test were analyzed using methods outlined elsewhere.[29,30]

RESULTS

Between 1999 and 2020, the NHAMCS had a pooled sample size of 625,433 ED visits, representing 2,765,910,714 visits in the general U.S. population. Within the

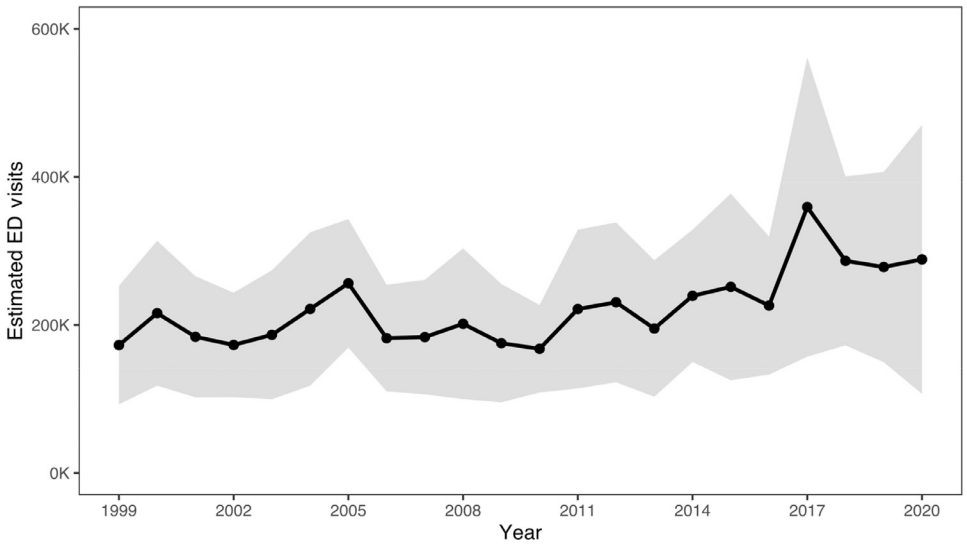

Figure 1. Estimated annual ED visits for sickle cell disease, 1999–2020.
Note: Black points represent the annual point estimate, and the gray area represents the annual 95% CI.
ED, emergency department; K, thousand.

NHAMCS, there were 1,075 ED visits found in the sample among patients with SCD. This number represents 4,897,456 ED visits in the SCD population. Point estimates and CIs for the annual number of ED visits made by individuals with SCD are displayed in Figure 1 and provided in Appendix Table 2 (available online). There was a slow and relatively stable increase in the annual number of ED visits over time. Relative to neighboring years, 3 peaks in the annual number of ED visits occurred in 2000 (215,884 visits), 2005 (256,228 visits), and 2017 (359,272 visits). The estimated yearly average of ED visits attributable to individuals with SCD was 222,612.

Characteristics of ED visits made by individuals with SCD are displayed in Table 1. There was a nearly equal split in the percentage of ED visits made by men (51%) and women (49%). Most visits were made by Black or African American individuals (94%), whereas 6% of visits were made by individuals of other races or individuals of more than one race. Regarding mode of arrival, 82% of visits were walk-ins, whereas 13% of visits were made by ambulance and 4% were of some other or unknown source. Roughly one third (34%) of the visits were made by patients aged 20–29 years, whereas another third (33%) was made by individuals aged 30–45 years.

Table 2. Patient-Cited Reasons for the Visit by Patients With Sickle Cell Disease, 1999–2020

Reason for visit	All visits	Visits by patients aged 0–19 years	Visits by patients aged ≥20 years	*p*-value
Any pain	75.10 (71.40, 78.79)	67.62 (59.70, 75.55)	77.49 (73.68, 81.30)	0.01
Chest pain	11.72 (9.38, 14.08)	9.50 (5.05, 13.95)	12.43 (9.50, 15.38)	0.33
Other pain or unspecified pain	71.56 (67.65, 75.48)	66.90 (58.97, 74.83)	73.06 (68.86, 77.25)	0.14
Fever/infection	6.00 (4.31, 7.70)	17.46 (11.36, 23.56)	**2.33 (1.10, 3.57)**	<0.001
Shortness of breath/ breathing problem/cough	6.90 (4.82, 8.97)	9.62 (5.23, 14.01)	6.02 (3.72, 8.32)	0.11
Anemia, including sickle cell anemia	57.93 (53.26, 62.60)	45.09 (37.36, 52.81)	62.05 (56.89, 67.20)	<0.001
Gastrointestinal issues	5.63 (3.98, 7.28)	**8.13 (4.14, 12.12)**	4.83 (2.90, 6.76)	0.12
Medication/treatment/ testing	2.42 (1.28, 3.56)	**2.68 (1.30, 5.23)**	**2.34 (1.06, 3.62)**	0.81
Other	9.48 (6.39, 12.57)	16.12 (8.67, 23.56)	7.35 (4.17, 10.53)	0.01

Note: Cell values represent percentages. Values in parentheses represent 95% CIs. Estimates in boldface have an RSE (SE/point estimate) >30% and/or are based on <30 observations; estimates with an RSE >30% do not meet standards of reliability or precision.
RSE, relative SE.

Comparatively fewer visits were made by persons aged 10−19 (15%), 0−9 (9%), and ≥46 (9%) years.

Public insurance sources covered the majority of ED encounters, with Medicaid/State Children's Health Insurance Program as the primary expected payer for 60% of visits and Medicare as the primary expected payer for 12% of visits. Private insurance sources were the primary payer for 13% of visits, and insurance sources for the remaining 15% of visits were other or unknown. Approximately two thirds (68%) of the encounters represented the initial visit to ED, whereas 22% of the encounters represented a follow-up visit for the original reason for visit and 10% of encounters were unknown regarding the episode of care. Twenty-eight percent of ED visits resulted in admission to the hospital. For 68% of ED visits, individuals with SCD reported experiencing severe pain, whereas moderate pain was reported for 21% of visits, mild pain for 8%, and no pain for 7%. The mean length of visit for ED encounters was 365 minutes (approximately 6 hours; 95% CI=305, 423 minutes), whereas the mean wait time to see a healthcare provider in the ED was 53 minutes (95% CI=45, 62 minutes). The median length of visit for ED encounters was 256 minutes (95% CI=238, 278 minutes; IQR=174−380 minutes). The median wait time to see a healthcare provider in the ED was 27 minutes (95% CI=22, 33 minutes; IQR=10−61 minutes).

Regarding differences by age group, there were several notable findings. There was a statistically significant difference in the percentage of ED visits made by men and women when stratified by age, such that in younger patients (those aged 0−19 years), there was a greater percentage of visits made by men (62%), and in older patients (those aged ≥20 years), there was a greater percentage of visits made by women (53%) ($p<0.01$). In addition, there was a greater percentage of younger patients with Medicaid (72%) than of older patients (56%) ($p<0.001$) and a greater percentage of younger patients admitted to the hospital (35%) than of older patients (26%) ($p=0.01$). Older patients more frequently reported severe pain (69%) than younger patients (49%), whereas younger patients more frequently reported moderate pain (28%) than older patients (19%) ($p<0.01$).

The most commonly reported reason for visit was pain (75%), including chest pain (12%) and other pain or unspecified pain (72%), followed by anemia (58%) (Table 2). Otherwise, 9% of visits were classified into other reasons; 7% of visits were associated with shortness of breath or a breathing problem; 6% were associated with fever or infection; 6% were associated with gastrointestinal issues; and 2% were associated with medication, treatment, or testing. A greater percentage of older patients (77%) than younger patients (68%) cited any pain as the reason for visit ($p=0.01$). Older patients also more frequently reported anemia as a reason for visit (62% vs 45%) ($p<0.001$).

DISCUSSION

The objective of this study was to update and expand national estimates describing characteristics of ED visits made by individuals with SCD in the U.S. Compared with prior research,[8] the estimated average annual number of ED visits increased by nearly 13%, rising from 197,222 visits to 222,612 visits. The mean length of these visits also increased, rising from an average of 307 minutes to 364 minutes, a difference of approximately 1 hour longer in the ED. Hospital admissions rates were consistent with the findings of the prior study[8] but lower than rates found in other research.[31,32] Considering the long time period included in our analysis (22 years), this may be in part because of increased utilization of observation units over time, which would divert patients from inpatient admission.[33] In addition, recent findings indicate hospital admissions for individuals with SCD to be highest in more recent years[34]; therefore, inclusion of earlier survey years may have skewed the overall national estimates. In this study, we also found new statistically significant age-based differences in ED visits by sex, expected source of payment, reason for visit, and admission to the hospital. These new differences may be the result of a larger sample size of ED visits associated with SCD, which rose from 502 unweighted records in the prior study to 1,075 records in this study, more than doubling in size.

The findings of our study have several important implications regarding clinical care for individuals with SCD. Our descriptive trend analysis indicated that the number of ED visits made by individuals with SCD has continued to steadily increase over more than 2 decades. This finding may be in part explained by the aging and increased life expectancy of the SCD population in the U.S.[35−37] Newborn screening and medical advancements in care for SCD have resulted in substantial improvements in life expectancy, but the aging of the SCD population has also brought about the onset of additional comorbidities that may further exacerbate the medical burden of an already complex population,[38] potentially resulting in increased acute care utilization. High rates of ED utilization may also be a result of dispersed and fragmented treatment given poor access to primary and specialty care.[39] In 1 prior study, only 38% of individuals with SCD over the age of 40 years had a primary care doctor.[40] Given the limited availability of SCD

specialists, prior research has found that nearly 50% of adults with SCD visit multiple hospitals for acute care needs.[41]

The upward trend in the number of ED visits may also be a result of Medicaid expansion, especially given that Medicaid/State Children's Health Insurance Program was the expected payer for 60% of visits. A previous study examining Medicaid expansion in California found a 1% annual decrease in ED visits among individuals with SCD in the first 2 years of expansion.[42] However, NHAMCS data include ED visits from all 50 states, and the rising trend may reflect better access to the ED and increased utilization in states that implemented Medicaid expansion, although this was not directly testable in this study. The identified trend in increased ED visits could also be an artifact of the transition from ICD-9-CM to ICD-10-CM coding in October 2015. Prior research for other conditions found an artificial increase in encounters during the transition period, but this impact has not been specifically evaluated in SCD.[43,44]

Consistent with previous estimates,[8] pain remained the most common patient-cited reason for visiting the ED. Moreover, 64% of the SCD-related ED visits in this study were associated with severe pain levels, and 21% were associated with moderate pain levels. Opioid analgesics are core in the treatment of SCD-related pain, with an estimated 40% of people with SCD taking an opioid during a given year.[45] Healthcare providers working in the ED setting should therefore be prepared to assess and treat SCD-related pain. This is especially important given documented systemic inequities in the treatment of pain in individuals living with SCD. Healthcare providers commonly associate patients with SCD with opioid abuse and addiction,[46,47] and prior studies found that the onset of the opioid epidemic in the U.S. resulted in increased stigmatization and barriers to accessing opioids for individuals living with SCD.[48,49] However, opioid-related death among individuals with SCD remains markedly low. One analysis of population-level death certificates from 1999 through 2018 found only 348 opioid-related deaths among 15,765 individuals with SCD, contrasted to 840,629 opioid-related deaths in the general patient population during the same period.[50]

Considering the high pain levels associated with SCD-related ED visits in this study, the finding of an approximately 53-minute wait time on average to see a healthcare provider is particularly concerning. One possible explanation for this finding is the continued increase in overcrowding of EDs nationally, which is known to increase patient wait times and the overall length of the ED visit.[51] Nonetheless, evidence-based guidelines recommend that patients with SCD experiencing acute pain episodes receive rapid analgesic therapy within 30 minutes of ED triage or within 1 hour of ED registration, followed by frequent reassessments of pain every 30–60 minutes.[52,53] For individuals experiencing a VOC associated with severe pain, guidelines include rapidly initiating treatment with parenteral opioids during the same time period but with pain reassessments every 15–30 minutes until pain is under control.[52]

Although we were unable to directly assess time to administration of analgesics using NHAMCS data, it is likely that for those experiencing pain, the wait was longer than guideline recommendations, given the average 53-minute wait time to see a provider. Previous research has found that individuals with SCD experience 25% longer wait times in the ED setting than the general population and 50% longer wait times than patients with long-bone fractures (a comparison group utilized with pain levels similar to those of individuals with SCD).[54] Addressing suboptimal wait times in the ED setting for individuals with SCD, especially those in pain crises, should be a high priority for healthcare providers. Individualized pain plans for persons with SCD have been shown in multiple settings to decrease wait times and overall length of ED visits as well as reduce ED readmission rates.[55,56]

The results of this study also point toward important differences by age group in the expected source of payment for ED visits. Medicaid was the expected primary payer for 72% of visits for younger patients but only 56% of visits for older patients. The age groups utilized in this study closely align with the transition age in which many patients lose Medicaid eligibility while also moving out of pediatric care. For the SCD population, the transition from pediatric to adult care is considered a high-risk time period, with a marked increase in the utilization of ED services and potential shifts in disease severity, including increased risk for mortality.[57–59] Continuity of healthcare insurance during this transition period is essential to help minimize disruption of routine and preventive care, which may help minimize utilization of the ED.

Limitations

The main limitation of this study is the reliance on single-source and single-encounter methods for identifying ED visits associated with SCD, which have been shown to underestimate the true population size.[60] However, with only 11 states currently implementing population-level surveillance systems for SCD[11] and the absence of a national longitudinal registry,[61] data sources such as NHAMCS still provide useful national-level estimates, especially over long periods of time as in this study. Nonetheless, when stratifying certain characteristics by

age, sample sizes became too small to produce reliable and precise estimates, and these results should be interpreted with caution. Limitations such as these further the case for investment in a national SCD surveillance system,[62] especially in light of NHAMCS administrators announcing the sunsetting of the data source after the 2022 survey year.[63] In addition, although we included encounter data from 2020 in our analysis (particularly for the purposes of the trend analysis), examining the impact of the COVID-19 pandemic on ED utilization in the SCD population was beyond the scope of this study. Therefore, one area for future research using these data is to explore potential causal mechanisms for the long-term trends in ED utilization over time and during the pandemic in particular.

CONCLUSIONS

Individuals living with SCD experience complex disease-related morbidity, resulting in frequent acute care utilization in the ED setting. In this study, we updated previous national estimates to describe the characteristics of ED visits associated with SCD in the U.S. from 1999 to 2020.

Although many utilization patterns remained the same, we found the average annual number of visits to be higher than previously estimated, and the overall time spent in the ED increased by approximately 1 hour. We also found a steady increase in the annual number of ED visits over time. Pain remains the most common patient-cited reason for visiting the ED, with 85% of SCD-related visits being associated with moderate or severe patient-reported pain levels. The results of these national estimates provide important contextual information about the high utilization of the ED by individuals with SCD in the U.S.

ACKNOWLEDGMENTS

The study sponsor had no role in the study design; collection, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication.

Support for this study was provided by Georgia State University's Research Innovation and Scholarly Excellence Challenge (Project RISE).

CREDIT AUTHOR STATEMENT

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SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.focus.2023.100158.

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