RESEARCH LETTER

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TO THE EDITOR:

Self-reported pain levels for emergency department visits associated with sickle cell disease in the United States

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Sickle cell disease (SCD) is a group of inherited rare blood disorders that affects an estimated 100 000 individuals in the United States. The hallmark symptom of SCD is acute and chronic pain caused by vaso-occlusion owing to deoxygenated and sickled red blood cells.[1] Acute pain episodes in SCD are frequently managed at home but also result in high levels of emergency department (ED) utilization.[2,3] On average, ~200 000 ED visits occur annually by individuals with SCD, with pain being the most common reason for ED utilization.[4] Given the importance of the ED in providing acute care to persons living with SCD, we aim to describe self-reported pain levels in the ED. Specifically, we provide nationally representative estimates of the number and percentage of ED visits made across pain levels and compare self-reported pain between visits associated with SCD compared with the general patient population in the United States.

Data come from the National Hospital Ambulatory Medical Care Survey (NHAMCS), which is an annual nationally representative survey of ED visits made to nonfederal, short-stay hospitals in the United States.[5] Survey reports from the years 1999 to 2000 and 2003 to 2019 were used to align with those from the years in which self-reported pain measures were collected and to exclude visits during the COVID-19 pandemic. ED visits associated with SCD were identified using the presence of International Classification of Diseases, Clinical Modification version 9 (ICD-9-CM) codes 282.41, 282.42, and 282.6X and any ICD-10-CM D57X code, excluding sickle-cell trait (D57.3).[6,7] Therefore, SCD-related ED visits included all SCD codes and were not relegated to only vaso-occlusive crises. Any ED visit not flagged with a diagnosis code for SCD was considered to belong to the general patient population. Self-reported pain was assessed by hospital staff at the time of triage using a numerical pain intensity scale.

Before 2009, self-reported pain was collected using a 4-level system representing no pain, mild pain, moderate pain, and severe pain. In later survey years, pain was collected on a 0 to 10 numeric rating scale. For compatibility, we followed NHAMCS guidance[8] and prior studies[9,10] by converting the numeric scores, such that 0 represented no pain, 1 to 3 represented mild pain, 4 to 6 represented moderate pain, and 7 to 10 represented severe pain. Missing data (30% of total observations for general patients and 21% for SCD) were addressed following standard procedures for complex survey analysis.[11] First, survey weights were adjusted to account for hospitals that did not collect the pain measures and second, a multiple imputation procedure was conducted to address missing responses at the level of the discharge record. Twenty multiple imputed data sets[12] were created as a function of status of patients with SCD, patient age, sex, race, survey year, and hospital census region. The SURVEYFREQ and MIANALYZE procedures were used in SAS version 9.4 to produce nationally representative estimates. Similar to prior research,[13,14] all survey years were pooled to increase precision and accuracy of estimates. A Rao-Scott χ^2 test was used to compare the overall distribution of pain between SCD-related ED visits and the general patient population. Within each pain level, we also calculated odds ratios to quantify the likelihood of reporting each level based on SCD status vs general

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patient population status, both unadjusted and controlling for sex, race, age, survey year, and hospital region. This study was considered nonhuman subjects research and approved by the Georgia State University Institutional Review Board.

A total of 925 unweighted discharge records were identified using the SCD ICD codes, representing 4 278 321 ED visits in the SCD population. For the general patient population, 519 068 records were identified, representing 2 412 691 058 ED visits nationally. National estimates for each self-reported pain level are provided in Table 1 and displayed visually in Figure 1. Relatively few SCD visits were associated with no pain (6%) or mild pain (9%). Instead, severe pain levels were reported for 64% of visits and moderate pain levels were reported for 21%. For the SCD population, this equates to an estimated 2 727 000 ED visits associated with severe pain, 902 657 visits with moderate pain, 371 976 visits with mild pain, and 276 689 visits with no pain. For the general patient population, no pain was reported at 26% of visits, mild pain at 16% of visits, moderate pain at 24% of visits, and severe pain was reported at 33% of visits.

The overall distribution of self-reported pain was significantly different between the SCD population and general patient population, χ^2_{RS} (3, N = 519 993) = 75.84, $P < .001$. The distribution appeared more left-skewed for persons with SCD and more uniformly shaped for the general patient population. Accordingly, persons with SCD were more likely to report severe pain, but less likely to report moderate, mild, or no pain. Even after controlling for demographic characteristics SCD-related visits had 3.67 times the odds of a severe pain report (P <.001) compared with general patient population visits. On the other hand, compared with the general patient population, visits by people with SCD had 50% lower odds of mild pain ($P < .001$) and 82% lower odds of no pain ($P < .001$). Differences in reporting moderate pain were not statistically significant.

The results of our analysis indicate a striking difference in the distribution of self-reported pain between ED visits associated with SCD compared with that associated with the general patient population. Prior research indicates that for most individuals with SCD pain is typically managed at home, with use of the ED necessary during acute crises, for which immediate health care attention is necessary.[15,16] The findings of our analysis lend support to this claim, with nearly two-thirds of the ED visits for those with SCD associated with severe pain. These findings are particularly important for the provision of care in the ED setting. Current clinical guidelines recommend rapid assessment and administration of analgesia for individuals with SCD in the ED setting.[17] However, prior research indicates that negative attitudes by health care providers are a significant barrier to providing appropriate pain management for persons living with SCD,[18] with providers frequently associating them with stigmatized drug seeking and addictive behaviors.[19-21] One survey of ED health care providers found that on average physicians believed only 16% of general ED patients but 45% of ED patients with SCD to be addicted to opioids.[22] Provider education and awareness is therefore a crucial component in reversing these attitudes and improving adherence to evidence-based guidelines for SCD pain management. Notably, persons with SCD are significantly more

Table 1. Self-reported pain levels for emergency department visits associated with sickle cell disease compared with the general patient population

	Sickle cell disease visits		General patient visits		SCD vs general patient	
Pain level	N (95% CI)	Column % (95% CI)	N (95% CI)	Column % (95% CI)	OR (*P* value)	aOR (*P* value)
No pain	276 689 (158 424-394 953)	6.47 (3.82-9.11)	632 466 388 (579 109 780-685 822 997)	26.21 (25.61-26.82)	0.19 (<.001)	0.18 (<.001)
Mild pain	371 976 (232 608-511 343)	8.69 (5.64-11.75)	387 784 400 (357 606 166-417 962 634)	16.07 (15.55-16.59)	0.50 (<.001)	0.50 (<.001)
Moderate pain	902 657 (671 696-1 133 619)	21.10 (16.65-25.54)	584 447 012 (532 358 997-636 535 027)	24.22 (23.80-24.65)	0.84 (.18)	0.89 (.39)
Severe pain	2 727 000 (2 261 884-3 192 115)	63.74 (58.77-68.71)	807 993 258 (726 303 430-889 683 086)	33.49 (32.70-34.28)	3.49 (<.001)	3.67 (<.001)

Column percentages may not total to 100% because of rounding. The referent group for odds ratios is the general patient population. Adjusted odds ratios control for sex, race, age, survey year, and hospital region.
aOR, adjusted odds ratio; OR, odds ratio.

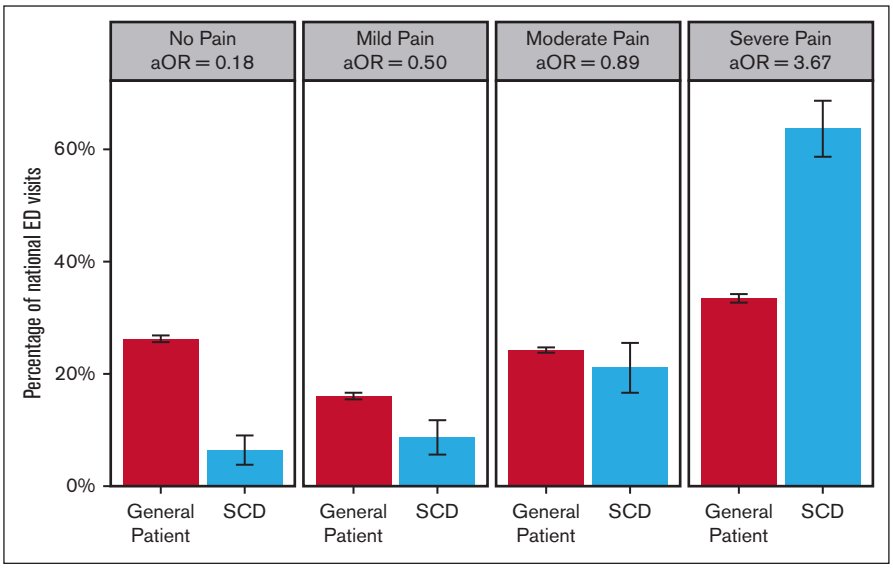

Figure 1. Patients with sickle cell disease are more likely to be in severe pain compared with the general patient population. Colored bars represent the percentage of emergency department visits associated with each pain level by patient group. Error bars represent 95% confidence intervals for percentages within each group. The referent group for odds ratios is the general patient population. aOR, adjusted odds ratio; controlling for sex, race, age, survey year, and hospital region.

likely to be in severe pain and are likely presenting to the ED in pain that they could not otherwise manage at home.

There are important limitations to this study that should be noted. Namely, we relied on ICD codes in a limited set of diagnosis fields to identify ED visits associated with SCD, which is known to underestimate the SCD population.[23] Because NHAMCS data were nonidentifiable, we were also unable to track individuals at the patient-level to confirm the validity of the SCD diagnoses. There was also a modest amount of missing data that was addressed using standard imputation procedures. Nonetheless, to our knowledge, this is the first study to provide national estimates of self-reported pain for individuals with SCD compared with the general patient population. Our findings indicate that individuals with SCD are significantly more likely to present to the ED in severe pain. Future research should aim to further understand these important differences and could examine differences in pain by geography or trends in pain levels over time, including differences in pain levels before and after the transition to ICD-10 coding.

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