

Acute Care Use Among People With Sickle Cell Disease, Sickle Cell Data Collection Program, 8 US States, 2018

Public Health Reports

1–8

© 2025, Association of Schools and Programs of Public Health

All rights reserved.

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/00333549251387081

journals.sagepub.com/home/phr



Parker Parks, MPH¹; Joshua I. Miller, MPH² 
Shamaree Cromartie Jones, MPH³; Brandon K. Attell, PhD⁴ 
David C. Brousseau, MD, MS^{5,6}; Catie L. Clyde, MPH⁷;
William O. Cooper, MD, MPH⁸; Mahua Dasgupta, MS⁹;
Jay Desai, PhD, MPH¹⁰; Brandon M. Hardesty, MD¹¹ 
Mariam Kayle, PhD, RN¹²; Krista Latta, MPH^{13,14};
Ayesha Mukhopadhyay, MBBS, MBA, MPH¹⁵; Allison P. Plaxco, MPH¹⁵;
Sarah L. Reeves, PhD^{13,14}; Ashima Singh, PhD, MS⁹;
Angela B. Snyder, PhD, MPH⁴ 
Jhaqueline Valle, MPH⁷; Mei Zhou, MS, MA⁴;
and Marci K. Sontag, PhD²

Abstract

Objectives: Understanding patterns of hospital admissions and emergency department (ED) visits among people with sickle cell disease is critical for improving care and access to care for this population. The objective of this study was to characterize acute care use among people with sickle cell disease and identify patterns of use across age groups and sex using 2018 data.

Methods: We conducted a cross-sectional study using population-based data from 8 states participating in the Centers for Disease Control and Prevention's Sickle Cell Data Collection program. The sample population consisted of children, adolescents, and adults with a confirmed or probable diagnosis of sickle cell disease, regardless of acute care use, in 2018. We analyzed data on hospital admissions, ED treat-and-release (T/R) visits, and readmissions after ED T/R or inpatient discharge, aggregated from each participating state.

Results: The 2018 cohort of the Sickle Cell Data Collection program consisted of 27 034 people; 40.2% had ≥ 1 hospital admission, and 57.0% had ≥ 1 ED T/R visit. Of the 98 617 people using acute care, 93.6% ($n=92\ 305$) involved the ED in some capacity.

Conclusions: Hospital admissions were frequent and occurred in less than half of the study population. More than half used the ED, with most hospital admissions initiated in the ED. Our findings call for further research to better understand differences in acute care use, high rates of ED T/R visits, and treatment of sickle cell disease in an outpatient setting.

Keywords

sickle cell disease, acute care use, emergency department visits, health care disparities, public health insurance

Sickle cell disease (SCD) is a genetically inherited blood disorder in which a single gene mutation leads to substantial comorbidities, including vaso-occlusive pain episodes and multisystem chronic organ damage. SCD is classified as an orphan disease (a rare medical condition that affects a small portion of the population), affecting approximately 100 000 people in the United States.¹ High-quality specialist outpatient care is needed to appropriately manage this condition; however, there is a shortage of hematologists and primary care providers trained to treat SCD. The lack of access to

outpatient care, in conjunction with acute pain crises, causes people to rely on acute care settings, including hospitals and emergency departments (EDs), and frequent readmissions after discharge.^{2,3}

The substantial morbidity associated with SCD leads to high levels of health care use.² However, only a few studies have combined data across states and analyzed the number of hospital admissions, ED visits, and readmissions across payers. Use studies conducted more than 10 years ago used hospital discharge data, which do not capture data on people

who had no acute care visits.⁴ Beginning in 2015, the Centers for Disease Control and Prevention (CDC) developed the Sick Cell Data Collection (SCDC) program, providing funding to states to establish a surveillance program by linking data from multiple sources to create a comprehensive picture of people living with SCD in the United States.⁵ The SCDC program aims to capture data on all people with SCD in participating states, regardless of setting and payer type. The SCDC program's case definition of SCD also reduces misclassification of people and minimizes the underreporting or underidentification of the population with SCD. SCDC program data are provided through robust linkages from numerous data sources, resulting in a population-based aggregation of people with SCD. Program data provide a population-based overview of people with SCD in the United States, allowing for an accurate representation of their patterns of health care use. These changes and improved data systems warrant an examination of acute care use among people with SCD by age, sex, and health insurance type.

The objectives of this descriptive study were to (1) characterize acute care use among all people residing in participating states with SCD and identify patterns of use across age groups and sex, using data from 2018, and (2) describe acute care use at the encounter level among people with SCD, including hospital admissions and ED treat-and-release (T/R) visits by age, sex, and payer and readmissions after ED T/R or inpatient discharge.

Methods

Data Source and Analytic Sample

We derived health care use data for 2018 from SCDC reports submitted annually to CDC from all 8 states participating in the SCDC program: Alabama, California, Colorado, Georgia, Indiana, Michigan, Tennessee, and Wisconsin. The SCDC program collects individual- and encounter-level information

on people with SCD to study disease outcomes and trends in diagnosis, treatment, and access to care.⁴ We used data from 2018 because that is the most recent year of comprehensive data from all participating SCDC states. Data sources vary by state (eTable 1 in the Supplement) and include newborn screening results, Medicaid claims, all-payer claims databases, birth certificates, death certificates, SCD specialty clinical records, electronic health records, and hospital discharge and ED records. We linked and deduplicated records at the state level, and people with SCD were identified according to the SCDC case definition.⁶ The SCDC case definition follows an algorithm that classifies cases as confirmed if records indicate a laboratory confirmation or reported clinical diagnosis or as probable if records indicate ≥ 3 SCD-related diagnostic codes accompanied with an acute care visit or Medicaid enrollment within a 5-year period. The 8 states participating in the SCDC program underwent independent ethical review in each state and received either institutional review board approval or exempt status as not human subjects research.

Study Population and Period

We included in our analysis people with SCD living in each participating state in 2018, identified through the application of the case definition through each of the 8 SCDC programs. We summarized data as patient-level data (demographic characteristics, number of hospital admissions, number of ED T/R visits, total number of inpatient days in the year) and acute care encounter-level data (number of hospital admissions, number of ED T/R visits, payer data for each encounter, and number of hospital admissions or ED T/R visits that resulted in a repeat ED T/R visit or readmission within 30 d of discharge). Hospital admissions, ED T/R visits, repeat ED T/R visits, and readmissions include all-cause encounters by people with SCD, regardless of the inclusion of an SCD-related code for the encounter.

¹ Division of Population Health Data, Office of Family Health Services, Virginia Department of Health, Richmond, VA, USA

² Center for Public Health Innovation, Evergreen, CO, USA

³ Division of Child and Family Health, Office of Family Health Services, Virginia Department of Health, Richmond, VA, USA

⁴ Georgia Health Policy Center, Georgia State University, Atlanta, GA, USA

⁵ Department of Pediatrics, Nemours Children's Health, Wilmington, DE, USA

⁶ Sidney Kimmel Medical College at Thomas Jefferson University, Philadelphia, PA, USA

⁷ Tracking California, Public Health Institute, Oakland, CA, USA

⁸ Vanderbilt University Medical Center, Nashville, TN, USA

⁹ Section of Hematology/Oncology/Blood and Marrow Transplantation, Department of Pediatrics, Medical College of Wisconsin, Milwaukee, WI, USA

¹⁰ Minnesota Department of Health, St. Paul, MN, USA

¹¹ Indiana Hemophilia and Thrombosis Center, Indianapolis, IN, USA

¹² Duke University School of Nursing, Durham, NC, USA

¹³ Susan B. Meister Child Health Evaluation and Research Center, Department of Pediatrics, University of Michigan, Ann Arbor, MI, USA

¹⁴ Department of Epidemiology, School of Public Health, University of Michigan, Ann Arbor, MI, USA

¹⁵ Division of Epidemiology, Biostatistics and Environmental Health, School of Public Health, The University of Memphis, Memphis, TN, USA

Corresponding Author:

Joshua I. Miller, MPH, Center for Public Health Innovation, 891 Evergreen Pkwy, Evergreen, CO 80439, USA.

Email: joshua.miller@CPHInnovation.org

Table 1. Demographic characteristics and use of acute care among people with sickle cell disease, by age and sex, in 8 states participating in the Centers for Disease Control and Prevention's Sickle Cell Data Collection program, 2018^a

Characteristic	Total, no. (%)	≥1 Hospital admission, no./total (%)	≥1 ED T/R visit, no./total (%)
Overall	27 034 (100.0)	10 858/27 034 (40.2)	15 408/27 034 (57.0)
Sex			
Male	11 739 (43.4)	4678/11 739 (39.9)	6404/11 739 (54.6)
Female	15 295 (56.6)	6180/15 295 (40.4)	9004/15 295 (58.9)
Age group, y			
<20	10 512 (38.9)	3330/10 512 (31.7)	4848/10 512 (46.1)
20-29	5516 (20.4)	2565/5516 (46.5)	3655/5516 (66.3)
30-39	4693 (17.4)	2185/4693 (46.6)	3120/4693 (66.5)
≥40	6313 (23.4)	2778/6313 (44.0)	3785/6313 (60.0)

Abbreviation: ED T/R, emergency department treat and release.

^a The 8 states are Alabama, California, Colorado, Georgia, Indiana, Michigan, Tennessee, and Wisconsin.

Outcomes of Interest

Acute care includes hospital admissions and ED T/R visits. We counted ED visits that resulted in admission as hospital admissions. Repeat acute care consisted of 2 categories: a repeat ED T/R visit or hospital readmission after an initial ED T/R visit or a repeat ED T/R visit or hospital readmission after an initial hospital admission.

Variables

The variables used to stratify acute care use were age, sex, and primary payer. We determined age as of December 31, 2018, and categorized age into the following groups: <20, 20 to 29 years, 30 to 39 years, and ≥40 years. We categorized sex as male or female. We used the US Department of Agriculture's 2013 Rural–Urban Continuum Codes (1-3=urban, anything else=rural)⁷ to assign metropolitan and nonmetropolitan status according to county of residence in 2018. We categorized payer type as the primary payer of the initial encounter (Medicaid, Medicare, private; and other, which includes self-pay, other, and unreported/unknown). We did not obtain data on payer type for readmission. We categorized race as Black, other, or unknown, according to state-specific data sources, and ethnicity as Hispanic, non-Hispanic, or unknown.

Analysis

We summarized descriptive data on hospital admissions and ED T/R visits by age, sex, and payer type. We calculated rates and 95% CIs for the number of hospital admissions and ED T/R visits per person and by age and sex. We calculated rates and 95% CIs for repeat acute care encounters as the number of repeat ED T/R visits or readmissions per initial admission or initial ED T/R visit by age and sex. In addition, we examined data on people who had a high frequency of hospital admission, defined as being in the 90th percentile of hospital admissions; we calculated the median length

of hospital stays for this group. Six states (Alabama, California, Georgia, Indiana, Michigan, and Wisconsin) provided data by age, sex, and payer, while 2 states (Colorado and Tennessee) provided data by age and sex. We conducted analyses at the state level and then combined data into aggregated totals. We did not conduct formal statistical testing.

Results

Population Characteristics and Acute Care

The 2018 SCDC program cohort consisted of 27 034 people in 8 states; 56.6% were female, 38.9% were aged <20 years (Table 1), 85.3% identified as Black, and 88.7% lived in a metropolitan area. Only 2.7% identified as Hispanic, and 41.4% had unknown ethnicity. A total of 360 patients died in 2018 (1.3% of the cohort). The largest percentage of deaths by age group occurred among those aged ≥40 years, with 197 deaths in this category (2.2% of cohort).

In 2018, 16 176 (59.8%) people had no inpatient hospital admissions, and 10 858 (40.2%) people had ≥1 hospital admission (Table 1). Almost one-third (31.7%) of those aged <20 years had ≥1 hospital admission. Among those aged ≥20 years, the percentage with ≥1 hospital admission was greater than 40%. In addition, 11 626 (43.0%) people had no ED T/R visits, while more than half (57.0%) had ≥1 ED T/R visit. More than 60% of those aged ≥20 years had ≥1 ED T/R visit in 2018, while 46.1% of those aged <20 years had ≥1 ED T/R visit.

In 4 of the 8 states, people with a high frequency of hospital admissions were hospitalized for a median of ≥2 weeks; the shortest median length of stay overall among the 8 states was 5 days. For the group aged 20 to 29 years with a high frequency of hospital admission, 7 states reported a median length of stay of >14 days, with 6 states reporting the same trend for those aged 30 to 39 years and 5 states for those aged ≥40 years. Among all states, people aged <20 years with a high frequency of hospital admissions had a median length of stay of <14 days.

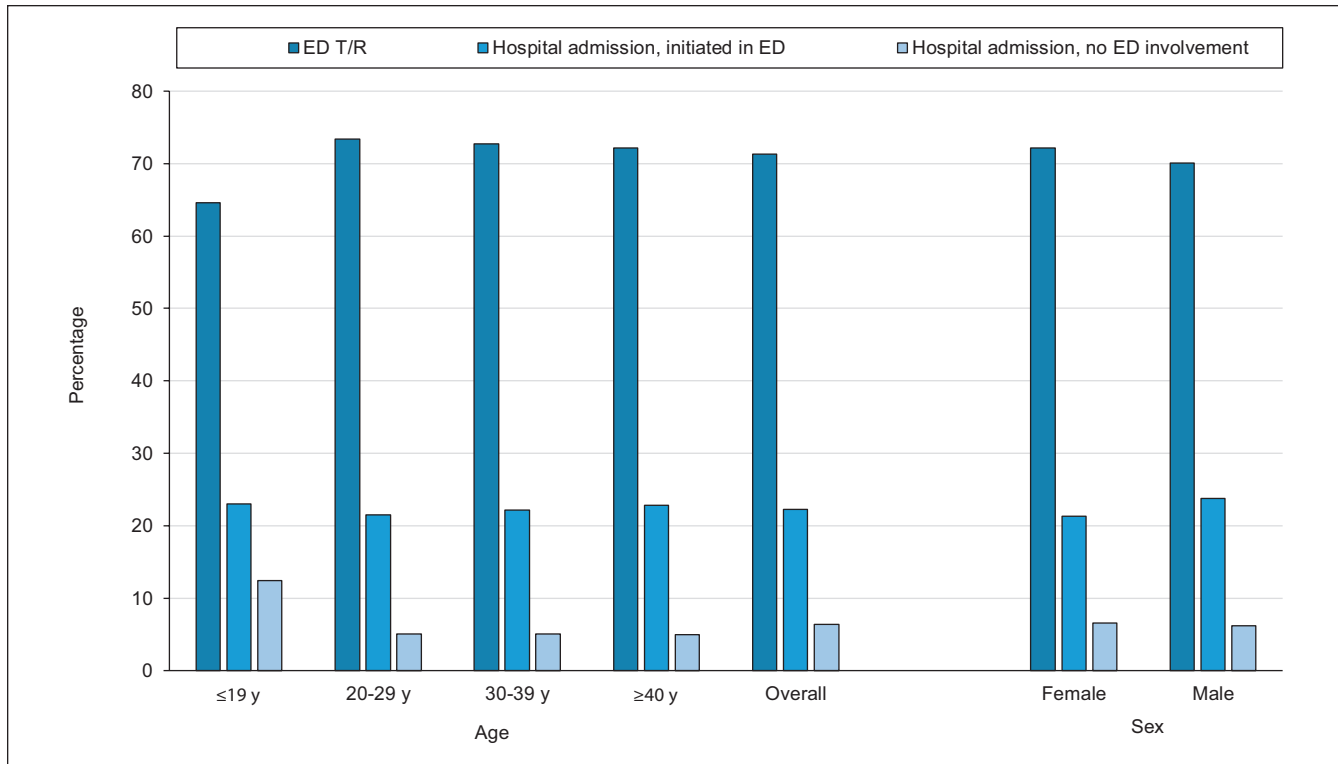


Figure 1. Types of acute care visits as a percentage of all acute care visits to hospitals by people with sickle cell disease in 8 states participating in the Centers for Disease Control and Prevention's Sickle Cell Data Collection program, 2018. The 8 states are Alabama, California, Colorado, Georgia, Indiana, Michigan, Tennessee, and Wisconsin. Abbreviation: ED T/R, emergency department treat and release.

ED T/R Visits, Hospital Admissions, and Repeat Acute Care Encounters

The 98 617 acute care encounters (ED T/R visits or hospital admissions) in 2018 yielded an acute care use rate of 3.65 encounters per person. Overall, of all acute care visits, 71.3% were ED T/R visits and 6.4% were hospital admissions with no ED involvement (Figure 1 and eTable 2 in the Supplement). Overall, 26 979 of 34 712 hospital admissions (77.7%) were initiated in the ED. Of the 98 617 people using acute care, 93.6% (n=92 305) involved the ED in some capacity.

Overall, 70 307 ED T/R visits occurred among the 27 034 people in the study population, for a rate of 2.60 (95% CI, 2.58-2.62) visits per person in 2018 (Table 2). The rate was 4.10 (95% CI, 4.04-4.15) visits per person among people aged 20 to 29 years and 3.80 (95% CI, 3.75-3.86) visits per person among people aged 30 to 39 years.

Overall, 28 310 hospital admissions occurred among all people in the study population, resulting in 1.05 (95% CI, 1.04-1.06) admissions per person in 2018. Among people aged 20 to 29 years, the rate was 1.49 (95% CI, 1.46-1.52) admissions per person.

When we calculated the rates of acute care encounters among people with ≥ 1 hospital admission or ED T/R visit,

the rate was 3.75 (95% CI, 3.73-3.78) acute care encounters per person. The rate for ED T/R visits increased to 4.56 (95% CI, 4.53-4.60) visits per person, and among people with ≥ 1 hospital admission, the rate increased to 2.61 (95% CI, 2.58-2.64) admissions per person.

Of the 28 310 hospital admissions, 13 975 (49.4%) resulted in a hospital readmission or repeat ED T/R visit within 30 days of discharge. The rate of readmission or repeat ED T/R visits per initial admission was 0.58 (95% CI, 0.56-0.60) among adults aged 20 to 29 years and 0.31 (95% CI, 0.30-0.32) among those aged < 20 years (Table 2). Of 70 307 ED T/R visits, 42 459 (60.4%) resulted in a repeat ED T/R visit or hospital readmission within 30 days of discharge (0.60 [95% CI, 0.60-0.63] per initial ED T/R visit). The repeat acute care use rate after a hospital stay was 0.68 (95% CI, 0.67-0.69) per ED T/R visit among adults aged 20 to 29 years and 0.36 (95% CI, 0.35-0.37) among those aged < 20 years. Repeat acute care use rates were 1.2 times higher after an ED T/R visit (0.60 encounters per ED T/R visit) than after a hospital stay (0.49 encounters per hospital admission).

Payer information for ED T/R and hospital admissions were available from 6 states representing 24 687 people with SCD. Public health insurance covered 81.8% of all acute care encounters: Medicaid accounted for 62.7% and Medicare accounted for 19.1% (Figure 2). Private health

Table 2. Rates of ED T/R visits and hospital admissions per person per year and rates of repeat acute care use per initial encounter, among people with sickle cell disease in 8 states participating in the Centers for Disease Control and Prevention's Sickle Cell Data Collection program, by age and sex, 2018^a

Characteristic	ED T/R rate per person per year (95% CI)	Hospital admission rate per person per year (95% CI)	Repeat acute care use	
			Inpatient encounter resulting in readmission or ED T/R visit within 30 d of discharge, rate per initial hospital admission (95% CI)	ED T/R visit resulting in readmission or ED T/R visit within 30 d of discharge, rate per initial ED T/R visit (95% CI)
Overall	2.60 (2.58-2.62)	1.05 (1.04-1.06)	0.49 (0.49-0.50)	0.60 (0.60-0.63)
Age group, y				
<20	1.13 (1.12-1.15)	0.62 (0.60-0.63)	0.31 (0.30-0.32)	0.36 (0.35-0.37)
20-29	4.10 (4.04-4.15)	1.49 (1.46-1.52)	0.58 (0.56-0.60)	0.68 (0.67-0.69)
30-39	3.80 (3.75-3.86)	1.42 (1.39-1.46)	0.56 (0.55-0.58)	0.65 (0.64-0.67)
≥40	2.86 (2.82-2.90)	1.10 (1.06-1.13)	0.50 (0.48-0.51)	0.62 (0.61-0.63)
Sex				
Male	2.43 (2.40-2.46)	1.04 (1.02-1.06)	0.49 (0.48-0.50)	0.61 (0.60-0.61)
Female	2.73 (2.71-2.76)	1.05 (1.04-1.07)	0.50 (0.49-0.51)	0.60 (0.59-0.61)

Abbreviation: ED T/R, emergency department treat and release.

^a The 8 states are Alabama, California, Colorado, Georgia, Indiana, Michigan, Tennessee, and Wisconsin.

insurance accounted for 10.7% of all acute care, and “other” health insurance comprised the remaining 7.4%. The self-pay category comprised 2.6% of people aged <20 years and 7.1% of people aged 20 to 29 years.

Discussion

To our knowledge, our study is the largest representation of data from state-based surveillance systems to describe acute care use among people with SCD. These data provide a population-based aggregation of people with SCD in 2018, including people who did not use acute care services. This population-based surveillance study sheds light on overall acute care use among people with SCD and underscores the substantial number of SCD patients who did not require hospitalization. Our analysis of hospital admissions, length of hospital stay, ED T/R visits, and repeat acute care use across various age groups and sex showed that 40.2% of the 2018 SCDC cohort had ≥1 hospital admission and 57.0% had ≥1 ED T/R visit.

Among the 6 states that provided hospital use data stratified by payer, public health insurance accounted for 81.8% of acute care (Medicaid, 62.7%), while private health insurance accounted for 10.7%. Our study also showed that the percentage of people with no health insurance (self-pay) was greater among those aged 20 to 29 years (7.1%) than among those aged <20 years (2.6%). This result is consistent with prior research, which noted the risk for high levels of acute care use among young adults with SCD as they transition from pediatric to adult care.^{2,8} The literature indicates that adults aged 18 to 30 years have higher hospitalization and readmission rates than their pediatric counterparts, which aligns with our study

group aged 20 to 29 years.^{4,9} Finally, consistent with our findings, the literature indicates that women use more acute care services than men do and that people seeking acute care for SCD predominantly use public health insurance.¹⁰

The rates of acute care use (ED T/R visits, hospital admissions, and repeat acute care use within 30 d of an inpatient stay or ED T/R visit) were higher in our study cohort than in previous analyses of hospital use data.⁴ Our findings showed that the rate of ED T/R visits per person was higher than the rate of hospital admissions per person (2.60 vs 1.05), which is the opposite of what was found in a study among SCD patients in 2005-2006. That study found that hospital admission rates (1.52 encounters per patient per year) were higher than ED T/R visit rates (1.08 encounters per patient per year).⁴

Rates of acute care use among people with SCD can be analyzed in the context of acute care use among patients with similar genetic conditions, such as cystic fibrosis. Both cystic fibrosis and SCD are inherited autosomal recessive disorders that often require ongoing medical management and hospitalizations and are associated with a reduced lifespan.¹¹ One study conducted in 2016 found that the annual hospitalization rate for cystic fibrosis patients was 1072 per 1000 patients in 2013, or 1.072 per patient.¹¹ This finding aligns with our results of a hospitalization rate of 1.05 per person for patients with SCD.

Acute care use rates among adults aged 20 to 29 years offer an opportunity for further research. While our data do not allow us to identify the underlying reason for increased use rates, several age-related health complications in SCD are known. In addition, fewer hematologists treat young adults than treat children and adolescents. Both factors could contribute to increased

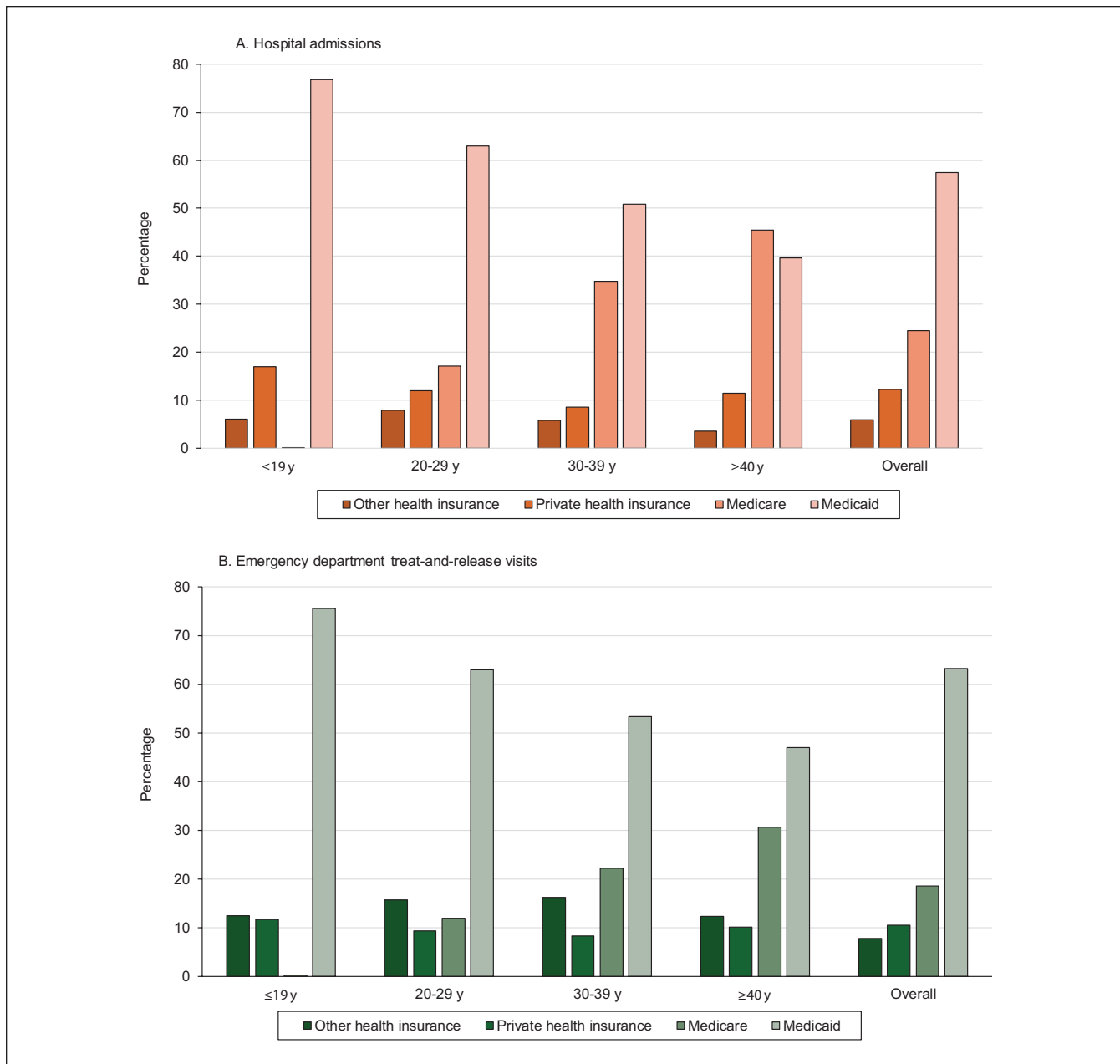


Figure 2. (A) Percentage of hospital admissions and (B) percentage of ED T/R visits, by payer and age group, among people with sickle cell disease in 6 states participating in the Centers for Disease Control and Prevention’s Sickle Cell Data Collection program, 2018. The 6 states are Alabama, California, Georgia, Indiana, Michigan, and Wisconsin. Abbreviation: ED T/R, emergency department treat and release.

use in the group aged 20 to 29 years.¹² Living with a chronic illness as a newly independent adult could also lead to an increased need for acute care in the older age group.

The ED was involved in 93.6% of all acute care encounters. High use of emergency services is costly to the individual and the health care system and often indicates poor outpatient management of care. SCDC program data from 2019-2020 were used in 2 studies to analyze the effect of

COVID-19 on acute care use among SCD patients. One study found a sharp decline in ED use in April 2020—by as much as 38% in 1 state—and although encounters increased in the following months, they had not reached prepandemic levels by December 2020.¹³ Another study of 4 states highlighted a spike in telehealth encounters in 2020 compared with the prepandemic period and found that telehealth users had more acute care use than did those who did not use telehealth.¹⁴

Limitations

This project had several limitations. First, 2018 is the most recent year of comprehensive data from all participating SCDC states, which limited our ability to reflect current trends in SCD. In addition, the onset of the COVID-19 pandemic in early 2020 may have been associated with shifts in the patterns of acute care use among SCD patients who were not represented in this analysis. Second, the SCDC program relies on data linkages from state-level datasets and provides data to CDC based on the Common Data Model.¹⁵ States have limited genotype data through clinical records and newborn screening, and genotype data are not included in the Common Data Model. Therefore, we did not include genotype-specific analyses in our study. Third, methods to identify cases may underreport people who lack health insurance, are privately insured, were born before newborn screening for SCD was implemented in 2006, and are infrequent users of acute care.⁵ Fourth, data on the type of hospital admission (ie, chief concern or reason for the visit) were not collected, which precluded analysis of these data. Fifth, while all states participating in SCDC must adhere to case definition criteria, each state applies its own method to link available data sources, leading to potential methodologic differences in what was reported in each data source, including differences in data completeness and case misclassification that may make cross-state comparisons unreliable or misleading. Sixth, no uniform method of calculating readmissions across all states exists. Seventh, data were derived from the SCDC report submitted annually to CDC; these annual data are aggregated, which did not allow for additional analyses at the individual level. Finally, our analysis did not account for the survival effect, which may have resulted in a population with fewer acute care use events in later age cohorts.

Conclusions

Acute care use was high in 2018 among people with SCD. The percentages of patients with hospital admissions and ED T/R visits indicate that SCD patients are more likely to use the ED than to be admitted to the hospital. This article represents a large subset of SCD patients who rely on acute care. While acute care use was high among people with SCD, less than half of the population living with SCD were admitted to the hospital. However, more than half used the ED. Further assistance may be needed for children and adolescents with SCD as they transition to adult care, and more acute care resources may need to be allocated to the adult population. We also found that most acute care encounters involved the ED. These findings necessitate further research to better understand differences in acute care use between age groups, high rates of ED T/R visits, and treatment of SCD in an outpatient setting. In addition, public health insurance bears the primary cost associated with acute care

among people living with SCD. This onus could provide incentive for public payers to invest in innovative models of care aiming to improve access to coordinated care for those living with SCD.





Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The work was supported by a cooperative agreement from the Centers for Disease Control and Prevention Sickle Cell Data Collection program (CDC-RFA-DD-23-0002).

ORCID iDs

Joshua I. Miller, MPH  <https://orcid.org/0009-0001-6345-585X>
 Brandon K. Attell, PhD  <https://orcid.org/0000-0002-4370-3924>
 Brandon M. Hardesty, MD  <https://orcid.org/0000-0001-6819-3898>
 Angela B. Snyder, PhD, MPH  <https://orcid.org/0000-0002-5149-6355>

Supplemental Material

Supplemental material for this article is available online. The authors have provided these supplemental materials to give readers additional information about their work. These materials have not been edited or formatted by *Public Health Reports's* scientific editors and, thus, may not conform to the guidelines of the *AMA Manual of Style*, 11th Edition.

References

1. Hassell KL. Population estimates of sickle cell disease in the U.S. *Am J Prev Med*. 2010;38(4 suppl):S512-S521. doi:10.1016/j.amepre.2009.12.022
2. Ballas SK, Lusardi M. Hospital readmission for adult acute sickle cell painful episodes: frequency, etiology, and prognostic significance. *Am J Hematol*. 2005;79(1):17-25. doi:10.1002/ajh.20336
3. Phillips S, Chen Y, Masese R, et al. Perspectives of individuals with sickle cell disease on barriers to care. *PLoS One*. 2022;17(3):e0265342. doi:10.1371/journal.pone.0265342
4. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA*. 2010;303(13):1288-1294. doi:10.1001/jama.2010.378
5. Snyder AB, Lakshmanan S, Hulihan MM, et al. Surveillance for sickle cell disease—Sickle Cell Data Collection program, two states, 2004-2018. *MMWR Surveill Summ*. 2022;71(9):1-18. doi:10.15585/mmwr.ss7109a1
6. Snyder AB, Zhou M, Theodore R, Quarmyne M-O, Eckman J, Lane PA. Improving an administrative case definition for longitudinal surveillance of sickle cell disease. *Public Health Rep*. 2019;134(3):274-281. doi:10.1177/0033354919839072

7. US Department of Agriculture, Economic Research Service. Rural–urban continuum codes. 2025. Updated January 7, 2025. Accessed May 20, 2023. <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes>
8. Johnson KM, Jiao B, Ramsey SD, Bender MA, Devine B, Basu A. Lifetime medical costs attributable to sickle cell disease among nonelderly individuals with commercial insurance. *Blood Adv*. 2023;7(3):365-374. doi:10.1182/bloodadvances.2021006281
9. Nouraie M, Gordeuk VR. Blood transfusion and 30-day readmission rate in adult patients hospitalized with sickle cell disease crisis. *Transfusion*. 2015;55(10):2331-2338. doi:10.1111/trf.13155
10. Benenson I, Jadotte Y, Echevarria M. Factors influencing utilization of hospital services by adult sickle cell disease patients: a systematic review. *JBI Database System Rev Implement Rep*. 2017;15(3):765-808. doi:10.11124/JBISRIR-2016-002983
11. Chatterjee K, Goyal A, Shah N, Kakkera K, Jagana R, Anderson P. Contemporary national trends of cystic fibrosis hospitalizations and co-morbidities in the United States. *Adv Respir Med*. 2016;84(6):316-323. doi:10.5603/ARM.2016.0041
12. Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD. Exploring adult care experiences and barriers to transition in adult patients with sickle cell disease. *Int J Hematol Ther*. 2015;1(1). doi:10.15436/2381-1404.15.003
13. Attell BK, Plaxco AP, Zhou M, et al. Emergency department utilization before and during the COVID-19 pandemic among individuals with sickle cell disease. *BMC Emerg Med*. 2024;24(1):134. doi:10.1186/s12873-024-01043-5
14. Reeves SL, Plegue M, Patel PN, et al. Assessing patterns of telehealth use among people with sickle cell disease enrolled in Medicaid during the start of the COVID-19 pandemic. *Telemed J E Health*. 2024;30(7):e1971-e1979. doi:10.1089/tmj.2023.0422
15. Smeltzer MP, Reeves SL, Cooper WO, et al. Common Data Model for sickle cell disease surveillance: considerations and implications. *JAMIA Open*. 2023;6(2):ooad036. doi:10.1093/jamiaopen/ooad036