Needs Assessment for Patients with Sickle Cell Disease in South Carolina, 2012

Alyssa M. Schlenz, PhD^a Andrea D. Boan, PhD, MSCR^b Daniel T. Lackland, DrPH^c Robert J. Adams, MD, MS^c Julie Kanter, MD^a

ABSTRACT

Objective. We conducted a needs assessment for patients with sickle cell disease (SCD) in South Carolina using statewide administrative data to examine acute care utilization during a defined 12-month period. The data were collected to provide information for state and regional service providers, managed care companies, and policy makers to identify demographic gaps in care and inform policy and educational efforts to improve care.

Methods. We obtained records on emergency department visits and hospitalizations through patient-based uniform billing data. We stratified analyses of acute care utilization and 30-day readmission rates by patient age, region, and expected payer.

Results. Young adults, those with public insurance, and those who resided in a region with the largest number of patients had the highest rates of acute care utilization and 30-day readmissions. Patients who resided in a largely rural area without access to comprehensive care also had high rates of acute care utilization and readmissions. The pattern of readmissions data suggested that data on 7- or 14-day readmission rates, in addition to data on 30-day readmission rates, could be used as benchmarks of quality of care for adult patients with SCD.

Conclusion. Administrative datasets can provide important information on demographic gaps in care for patients with SCD. The results highlight both national and regional issues in the provision of health-care services for patients with SCD.

Address correspondence to: Julie Kanter, MD, Medical University of South Carolina, Department of Pediatrics, Division of Hematology/ Oncology, 135 Rutledge Ave., MSC 558, Charleston, SC 29403; tel. 843-876-8483; fax 843-792-8912; e-mail <kanter@musc.edu>. ©2016 Association of Schools and Programs of Public Health

^aMedical University of South Carolina, Department of Pediatrics, Charleston, SC

^bMedical University of South Carolina, Departments of Pediatrics and Public Health Sciences, Charleston, SC

^eMedical University of South Carolina, Department of Neurology and Neurosurgery, Charleston, SC

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States, affecting nearly 100,000 individuals.¹ Pain is the hallmark symptom of SCD and the primary reason patients seek care. SCD also causes other potentially life-threatening complications, including infection, stroke, and organ damage, that require emergency department (ED) care or inpatient hospitalization.^{2,3} National guidelines for SCD emphasize that all affected individuals need both primary and comprehensive hematologic care to prevent severe complications,⁴ and research shows lower levels of acute care utilization and readmissions among patients who obtain comprehensive services.^{5,6}

Despite these guidelines, adherence to medical guidelines can vary by geographic region, and some research suggests disparities in patient outcomes even at the county level.7-10 Research also suggests age-based discrepancies in care. Until the advent of universal newborn screening, many children with SCD were not living into adulthood, thereby limiting the education and experience of providers in treating adults with SCD. Young adults with SCD are considered a particularly vulnerable group in terms of access to care and quality of care because of potential issues with transitioning from pediatric to adult care, lack of health-care providers for adults with SCD, and high rates of acute care utilization and mortality.¹¹⁻¹⁵ Access to quality care for patients with SCD is an especially salient issue in South Carolina and the southeastern United States because of the large number of individuals with SCD who reside in the region and the unique demographics that may influence access to care. South Carolina, Alabama, Georgia, and North Carolina each has an estimated 2,500 to 5,000 patients with SCD, and most identify as African American.¹ Each of these states also has a large percentage (close to 20%) of residents who live below the federal poverty level and a large number of patients who reside in rural areas that are far from comprehensive specialty centers.^{7,16,17}

Because no national registry exists for following patients with SCD across the lifespan, as there is for such diseases as cystic fibrosis,⁹ other methods must be used to identify the needs of patients in regions with a high prevalence of SCD to tailor educational programs, enhance clinical services, and track outcomes. The objective of this study was to examine the patient population with SCD in South Carolina by evaluating acute care utilization patterns by age, region, and expected payer using administrative data. The study was conducted to inform state and regional service providers, managed care organizations, and policy makers on current patterns of utilization and to identify gaps in care that may be related to demographic variation within the state. In contrast to a summative evaluation, which evaluates changes resulting from specific programs or policies, this study is a formative evaluation, which assessed the needs of patients with SCD to inform educational and policy efforts. In particular, this study was interested in answering the following questions about individuals with SCD in South Carolina: (1) How old are the majority of patients who utilize acute care services? (2) Is there regional variation in utilization? (3) Does utilization vary by type of insurance, and does variation in type of insurance by age account for differences in utilization? and (4) What is the status of readmissions in South Carolina, and is a 30-day readmission rate an appropriate benchmark for measuring quality of care?

METHODS

Data source

Data were obtained from the South Carolina Revenue and Fiscal Affairs Office, which monitors all uniformed billing data for emergency department (ED) and inpatient discharges in the state, except for discharges from hospitals in the Veterans Affairs or military health system. We obtained encounter-level data with a primary or secondary discharge diagnosis of SCD (282.41, 282.42, 282.60, 282.60–282.64, 282.68, or 282.69) based on the International Classification of Diseases, Ninth Revision (ICD-9)¹⁸ from January 1 through December 31, 2012 (the most recent year for which all patient data were available). We also obtained data on patient age, sex, expected payer, and county of residence. Patients with fatal cases (n=42) and patients not residing in South Carolina for encounters in 2012 (n=111) were excluded.

Variables

Region of residence. Region of residence was determined for each patient according to the county in which the patient resided for the majority of encounters. The South Carolina Department of Health and Environmental Control divides the state into four regions: Lowcountry, Midlands, Pee Dee, and Upstate. These regions differ from each other in rurality and proximity to comprehensive care.

Age. Age of patient was determined as the age at the patient's first encounter in 2012. Consistent with previous research,¹¹ age was categorized into the following groups: 0–9, 10–17, 18–30, 31–45, 46–64, and ≥ 65 years.

Expected payer. Expected payer was determined according to the third-party payer listed for each patient

for the majority of encounters, including Medicaid, Medicare, private insurance, and self-pay/uninsured.

Outcomes

Emergency department (ED) visits and hospitalizations. Rates of ED visits, hospitalizations, and total acute care encounters per patient were calculated for the 12-month period. An ED visit that resulted in a hospitalization was classified as a hospitalization for that encounter to ensure that an ED visit represented only a treat-and-release encounter. Encounters had to be at least 24 hours apart to be considered separate encounters.

Readmissions. A readmission was defined as either a treat-and-release ED visit or a subsequent inpatient hospitalization occurring more than one day after but within 30 days after a hospital discharge (index point). Time between encounters was calculated in days from date of index point to date of subsequent ED or hospital admission. A readmission within 30 days was assessed as a rehospitalization, an ED visit following a hospitalization, or an encounter consisting of any acute care (ED or inpatient hospitalization) separately. Encounters in January were considered the first encounter. An encounter in December could count as a readmission for a hospitalization in November, but it was excluded as a hospitalization eligible for a subsequent readmission (n=310) because 30-day follow-up information would not be available.

Data analysis

Descriptive analyses were completed in SAS[®] version 9.4.¹⁹ Rates and 95% confidence intervals (CIs) for acute care encounters per patient were stratified by age, expected payer, region of residence for ED visits, hospitalizations, and total visits. Rates and 95% CIs for hospitalizations resulting in a subsequent readmission to the ED or inpatient care within 30 days were calculated at the encounter level. Kaplan-Meier estimator was used to plot age, expected payer, and region-specific cumulative event curves during a 30-day period to understand patterns of readmissions and to examine alternative benchmarks for quality of care (i.e., 7- and 14-day readmission rates).

RESULTS

The final dataset consisted of 2,313 patients and 10,727 encounters (Table 1). Most (84%) patients were aged 45 years or younger. The Lowcountry (n=808) had the highest number of patients with acute care encounters, followed by Midlands (n=613), Pee Dee (n=541),

Table 1. Characteristics of patients with sickle
cell disease (n=2,313) and their hospital encounters
(n=10,727), South Carolina, January 1–
December 31, 2012 ^a

Patient characteristics	Number (percent ^b)
Total number of patients	2,313 (100.0)
Sickle cell genotype	_/- · · · (· · · · · /
HbSS	1,314 (56.8)
HbSC	54 (2.3)
HbSβ ^{+/0} thalassemia	226 (9.8)
HbSD/HbSE	49 (2.1)
Not specified	670 (29.0)
Age (in years)	070 (27.0)
0_9	473 (20.5)
10–17	272 (11.8)
18–30	713 (30.8)
18–24	410 (17.7)
25–30	303 (13.1)
31–45	478 (20.7)
46–64	
40−04 ≥65	290 (12.5)
	87 (3.8)
Sex	
Male	984 (42.5)
Female	1,329 (57.5)
Race	0.047 (05.0)
African American	2,217 (95.9)
White	80 (3.5)
Other	16 (0.7)
Patients by region	
Lowcountry	808 (34.9)
Midlands	613 (26.5)
Pee Dee	541 (23.4)
Upstate	351 (15.2)
Expected payer	
Medicaid	1,057 (45.7)
Medicare	559 (24.2)
Private insurance	486 (21.0)
Self-pay/uninsured	211 (9.1)
Patients with ED visit	1,736 (75.1)
Patients with hospitalization	1,404 (60.7)
Readmissions within 30 days	788 (35.6)
Encounter characteristics	
Total number of acute care encounters	10,727 (100.0)
Number of ED visits	7,125 (66.4)
Number of ED visits resulting in	417 (3.9)
hospitalization	
Number of treat-and-release ED visits	6,708 (62.5)
Number of hospitalizations	4,019 (37.5)
Mean (SD) length of hospitalization, days	5.0 (5.0)

^aData were obtained from the South Carolina Revenue and Fiscal Affairs Office, which monitors all uniform billing data for ED and inpatient discharges in the state, except for discharges from hospitals in the Veterans Affairs or military health system.

^bPercentages may not total to 100 due to rounding.

Hb = hemoglobin

HbSS = hemoglobin SS (sickle cell anemia)

HbSC = hemoglobin SC

 $HbS\beta^{+/0} =$ hemoglobin S/beta thalassemias

HbSD/HbSE = hemoglobin SD/SE

ED = emergency department

and Upstate (n=351) regions. By type of insurance, 45.7% of patients were insured by Medicaid, followed by Medicare (24.2%), private insurance (21.0%), and self-pay/uninsured (9.1%).

Acute care encounters by age, region, and expected payer

By age, rates of acute care encounters were relatively stable in childhood and adolescence, spiked in young adulthood, and then declined in middle age (Table 2). The spike in acute care encounters was largely due to higher rates of ED visits for adults aged 18–45 years, who had rates approximately three to four times the rates for children and adolescents.

By region, the Lowcountry had the highest rate (3.8 visits per patient) of ED visits, followed by the Pee Dee (2.7 visits per patient). Hospitalization rates were similar across regions, although the Pee Dee had the highest rate (2.1 visits per patient). The Upstate had the lowest rates of both ED visits (1.8 visits per patient) and hospitalizations (1.4 visits per patient).

By type of insurance, rates of acute care encounters for patients with public insurance were approximately two to three times the rates for those who had private insurance or were self-pay/uninsured. Patients with Medicare had the highest rates of acute care encounters, followed by Medicaid, private insurance, and self-pay/uninsured.

Most patients with Medicaid were children, adolescents, or young adults, whereas almost all patients with Medicare were aged >18 years (Table 3). Private insurance was more evenly distributed across all age groups up to age 65 years. The self-pay/uninsured group consisted mostly of young adults, followed by adults aged 31–64 years. Rates of acute care encounters were relatively stable across insurance types for children and adolescents. In contrast, adults aged 18–45 years with Medicare or Medicaid had approximately two to four times the number of encounters as those who had private insurance or were self-pay/uninsured.

Rates of 30-day readmission

The overall 30-day readmission rate for any acute care encounter (ED or inpatient hospitalization) was 45.6% (Table 4). The 30-day rehospitalization rate was 31.5%, and the 30-day readmission rate to the ED was 18.2%. The patterns of readmission rates based on age, region, and expected payer were similar to patterns of overall acute care utilization. Readmission rates were relatively stable in childhood and adolescence and doubled in young adulthood. The readmission rate remained high among those aged 31–45 years and dropped among

Table 2. Rates of acute care encounters among patients with sickle cell disease (*n*=2,313), by patient characteristics, South Carolina, January 1–December 31, 2012^a

		Encounters per patient			
Characteristic	Number of patients	Emergency department N (95% CI)	Inpatient hospitalization N (95% Cl)	Total N (95% CI)	
Total	2,313	2.9 (2.6, 3.2)	1.7 (1.6, 1.8)	4.6 (4.3, 5.0)	
Age (in years)				,	
0–9	473	1.1 (1.0, 1.2)	1.3 (1.2, 1.5)	2.4 (2.2, 2.6)	
10–17	272	1.3 (1.1, 1.5)	1.3 (1.1, 1.5)	2.6 (2.3, 2.9)	
18–30	713	4.9 (4.2, 5.6)	2.2 (2.0, 2.5)	7.2 (6.3, 8.0)	
31–45	478	3.8 (3.0, 4.8)	1.9 (1.6, 2.2)	5.7 (4.8, 6.6)	
46–64	290	1.8 (1.3, 2.2)	1.5 (1.2, 1.7)	3.2 (2.6, 3.8)	
≥65	87	0.3 (0.2, 0.4)	1.0 (0.8, 1.2)	1.3 (1.2, 1.5)	
Region					
Lowcountry	808	3.8 (3.2, 4.4)	1.8 (1.6, 2.0)	5.6 (4.9, 6.4)	
Midlands	613	2.4 (2.1, 2.8)	1.5 (1.3, 1.7)	3.9 (3.4, 4.4)	
Pee Dee	541	2.7 (2.2, 3.3)	2.1 (1.9, 2.4)	4.9 (4.2, 5.6)	
Upstate	351	1.8 (1.4, 2.2)	1.4 (1.2, 1.6)	3.2 (2.7, 3.7)	
Expected payer					
Medicaid	1,057	2.8 (2.5, 3.2)	2.0 (1.8, 2.1)	4.8 (4.3, 5.3)	
Medicare	559	4.6 (3.8, 5.4)	2.5 (2.2, 2.7)	7.0 (6.1, 8.0)	
Private	486	1.6 (1.3, 1.9)	1.0 (0.9, 1.2)	2.7 (2.3, 3.1)	
Self-pay/uninsured	211	1.7 (1.4, 2.0)	0.3 (0.2, 0.4)	2.1 (1.8, 2.4)	

^aData were obtained from the South Carolina Revenue and Fiscal Affairs Office, which monitors all uniform billing data for emergency department and inpatient discharges in the state, except for discharges from hospitals in the Veterans Affairs or military health system.

CI = confidence interval

	Me	Medicaid	Me	Medicare	Privat	Private insurance	Self-pay	Self-pay/uninsured
Age group (in years)	Total number of encounters	Number of encounters per patient (95% Cl)	Total number of encounters	Number of encounters per patient (95% CI)	Total number of encounters	Number of encounters per patient (95% Cl)	Total number of encounters	Number of encounters per patient (95% Cl)
00	386	2.5 (2.3, 2.7)	m	1.0 (NC ^b)	80	2.1 (1.8, 2.4)	4	1.8 (NC ^b)
10-17	185	2.6 (2.3, 2.9)	4	2.2 (NC ^b)	76	2.7 (1.8, 3.5)	7	2.1 (NC ^b)
18–30	315	8.0 (6.8, 9.3)	154	12.2 (9.8, 14.5)	136	3.5 (2.4, 4.6)	108	2.1 (1.7, 2.5)
31–45	131	6.8 (4.9, 8.6)	181	8.0 (6.3, 9.8)	101	2.6 (1.6, 3.6)	65	1.9 (1.5, 2.3)
5-64	40	5.0 (2.9, 7.2)	135	3.5 (2.7, 4.4)	88	2.1 (1.4, 2.8)	27	2.4 (0.7, 4.1)
≥65	0	NC ⁶	82	1.4 (1.2, 1.5)	Ð	1.0 (NC ^b)	0	NC ⁶
_	1,057	4.8 (4.3, 5.3)	559	7.0 (6.1, 8.0)	486	2.7 (2.3, 3.1)	211	2.1 (1.8, 2.4)

Table 3. Rates of acute care encounters among patients with sickle cell disease (n=2,313), by age group and expected payer, South Carolina, January 1–December 31, 2012ª

discharges from hospitals in the Veterans Affairs or military health system.

^bSample size was too small to reliably calculate 95% Cl.

CI = confidence interval

NC = not calculated

Characteristic	Number of encounters	Readmission to emergency department N (95% Cl)	Readmission to inpatient hospitalization N (95% CI)	Readmission for any acute care encounter N (95% Cl)
Total	3,709	18.2 (16.9, 19.4)	31.5 (30.0, 33.0)	45.6 (44.0, 47.2)
Age (in years)				,,
0–9	567	3.7 (2.4, 5.6)	19.0 (16.0, 22.5)	24.7 (21.4, 28.5)
10–17	320	7.8 (5.4, 11.3)	15.9 (12.4, 20.4)	25.0 (20.6, 30.1)
18–30	1,489	26.0 (23.8, 28.3)	38.2 (35.7, 40.7)	57.6 (55.1, 60.1)
31–45	862	23.0 (20.3, 25.9)	39.8 (36.6, 43.1)	54.6 (51.4, 58.0)
46–64	389	10.8 (8.1, 14.3)	23.6 (19.7, 28.2)	34.7 (30.2, 39.7)
≥65	82	0	8.5 (4.2, 17.1)	8.5 (4.2, 17.1)
Region				
Lowcountry	1,346	20.9 (18.8, 23.2)	32.6 (30.2, 35.2)	48.6 (46.0, 51.3)
Midlands	846	16.3 (14.0, 19.0)	28.1 (25.2, 31.3)	42.7 (39.4, 46.1)
Pee Dee	1,068	19.5 (17.2, 22.0)	34.7 (32.0, 37.7)	47.6 (44.6, 50.6)
Upstate	449	10.2 (7.8, 13.4)	27.0 (23.1, 31.3)	37.4 (33.1, 42.1)
Expected payer				
Medicaid	1,909	18.1 (16.4, 19.9)	32.9 (30.8, 35.0)	47.0 (44.8, 49.2)
Medicare	1,280	21.4 (19.3, 23.8)	35.6 (33.0, 38.2)	51.8 (49.1, 54.6)
Private	460	10.9 (8.4, 14.1)	18.0 (14.8, 21.9)	27.2 (23.4, 31.5)
Self-pay/uninsured	60	6.7 (2.6, 16.8)	5.0 (1.6, 14.7)	10.0 (4.6, 20.9)

Table 4. Rates of 30-day readmissions among patients with sickle cell disease (n=2,313), by patient
characteristics, South Carolina, January 1–December 31, 2012ª

^aData were obtained from the South Carolina Revenue and Fiscal Affairs Office, which monitors all uniform billing data for emergency department and inpatient discharges in the state, except for discharges from hospitals in the Veterans Affairs or military health system.

CI = confidence interval

those in middle age before declining dramatically for patients aged ≥ 65 years. Patients with public insurance had higher readmission rates than patients with private insurance or those who were self-pay/uninsured. Patients in the Lowcountry and Pee Dee regions had higher readmission rates than did patients in the Midlands or Upstate.

The cumulative readmission rate had a largely linear pattern during a 30-day period (Figure A), with a slight initial curve during the first 7-14 days. This pattern varied by age group (Figure B); a linear pattern in days to readmission was found for children and adolescents, whereas a more curvilinear pattern, with an initial peak in the first 7-14 days, was found for adults aged 18-45 years. By 14 days, approximately 30% of adults aged 18-45 years were readmitted to the hospital or ED vs. approximately 10% of children and adolescents. By expected payer (Figure C), a slight curvilinear pattern was found for those with public insurance; however, the data for those with private insurance or who were selfpay tended to plateau after the first 7 days. By region (Figure D), patterns of readmissions were fairly similar, with a slight curvilinear pattern for the Lowcountry, Midlands, and Pee Dee regions.

DISCUSSION

This study used a statewide administrative dataset to perform a needs assessment for people with SCD in South Carolina by assessing demographic variation in acute care utilization. The information gained will help to inform state and regional policy and clinical educational efforts to improve care and can be modeled in other states with a similar intent.

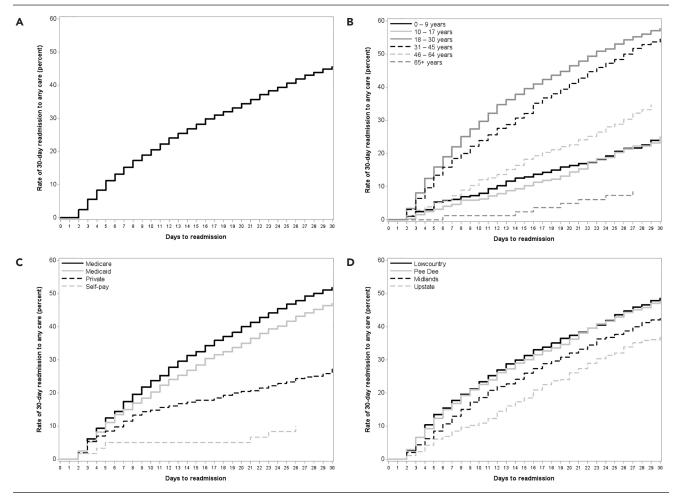
Most patients using acute care services were adults aged 18-45 years, who also had the highest rates of ED visits and hospitalizations. That most patients were younger than 45 years of age was expected based on the anticipated lifespan of individuals with SCD. These findings are consistent with previous studies that used both state-specific and nationally representative databases and suggest that acute care utilization is consistently high across adulthood, which may be the result of changes in the pathophysiology of SCD over time or differences in access to specialty care in adulthood vs. childhood or both.^{11,12,20,21} The latter explanation is particularly important given discrepancies in pediatric care and adult care in South Carolina during the study period. In 2012, pediatric hematologic care was available in the Lowcountry, Midlands, and Upstate, but no adult specialty care was available in any region.

In most age groups, the rate of acute care encounters was higher than national population-based estimates. The rate of ED visits was approximately two to three times as high as the rate reported by Brousseau and colleagues, who provided encounter estimates per year based on eight states in various geographic areas.¹¹ For example, the rate of ED visits per patient for young adults in South Carolina was 4.92 (95% CI 4.24, 5.60) vs. 1.59 (95% CI 1.50, 1.68) reported by Brousseau and colleagues. The reason for the higher rate of ED visits in our study is unclear but may reflect patient use of the ED as a substitute for comprehensive care, either because comprehensive care was not available or was too far from the patient's residence.¹⁰ This finding may also suggest that patients are being discharged from the hospital too quickly, resulting in frequent ED readmissions.

Our study found regional variation in utilization. The data on number of patients with acute care

encounters by county were consistent with data on newborn screenings in the state (Unpublished data, South Carolina Department of Health and Environmental Control, 2012-2013). The Lowcountry had the highest rate of acute care utilization, followed by the Pee Dee, Midlands, and Upstate. The primary differences between these regions are the size of the total population of patients and the degree of rurality. The Lowcountry may have a larger catchment area because of the presence of a major academic (and tertiary care) center, which may draw patients with more severe complications. The large number of patients and high rate of acute care utilization in the Pee Dee is also notable because it is the only region that lacks comprehensive sickle cell care. The Pee Dee also has a large number of rural counties, which may limit patients' ability to travel to specialized physicians in other regions. The large number of patients with SCD in this region utilizing acute care services necessitates

Figure. Rate of 30-day readmission to any care for sickle cell disease, overall, by age group, by expected payer, and by region, South Carolina, 2012



Public Health Reports / January-February 2016 / Volume 131

expanded education and specialty services and highlights the need for southeastern states and other areas with large or numerous rural areas to evaluate the current status of care.⁷

Utilization varied by type of insurance, and variation in type of insurance by age accounted for differences in utilization. Patients with public insurance had higher rates of acute care utilization than those with private insurance or those who were self-pay/ uninsured, consistent with the findings of Brousseau and colleagues.¹¹ The subgroup analysis of acute care utilization by age and expected payer also suggested an age-based discrepancy in utilization between publicly insured and privately insured individuals. Utilization was similar among children and adolescents with Medicaid and children and adolescents with private insurance. In contrast, adults with public insurance had higher rates of acute care utilization than adults with private insurance. Given the high rate of acute care utilization among those with public insurance, state and regional policy makers might consider expanding comprehensive services for adult patients to improve care and save costs.10,20,22

Young adults comprised about half of the individuals in the sample who were self-pay/uninsured. Surprisingly, these patients had the lowest rates of overall acute care utilization, regardless of age. This finding suggests that patients without insurance may forego necessary but expensive health care or that patients with more complications from SCD are more likely to have insurance in South Carolina.

The overall 30-day readmission rate (including both hospital and ED encounters) in South Carolina was higher than national population-based estimates.¹¹ This discrepancy was largely the result of readmissions to the ED, which were higher in South Carolina (18.2%; 95% CI 16.9, 19.4) than nationally (15.0%; 95% CI 14.7, 15.3). The pattern of readmissions during a 30-day period suggests that multiple benchmarks may be important for understanding and improving care. This observation was particularly true for adults aged 18-45 years, who demonstrated an initial peak in utilization during the first 7-14 days. As noted by previous researchers,¹¹ multiple benchmarks may be helpful for evaluating data on SCD, with 7- to 14-day benchmarks potentially representing the quality of acute care utilization and a 30-day benchmark representing the quality of comprehensive hematological care.

Limitations

This study had several limitations. It used an administrative dataset that did not include data on certain forms of health-care utilization, such as urgent care. This study was also limited to using ICD-9 codes to designate an individual as having SCD; thus, patients who were not listed with an SCD diagnosis would not be represented in the analysis. In addition, it was not possible to verify the accuracy of patient demographics entered into the billing system; previous studies have documented the challenges of accurately capturing certain forms of information (e.g., SCD subtype) from billing data.¹¹ Finally, the administrative dataset restricted our focus to a limited set of demographic variables; other variables that would be helpful to examine in future studies include more specific measures of socioeconomic status, patient-reported barriers, and availability of primary care providers.

CONCLUSION

This study highlights important national and regional issues for care of people with SCD. Recent research suggests that the discrepancy between pediatric and adult health outcomes in SCD is a national issue resulting, in part, from a paucity of providers willing and able to treat adult patients with SCD.14,15 In South Carolina and similar southeastern states, this issue may be compounded by a large number of patients residing in rural areas and fewer resources for accessing care at comprehensive centers in urban settings.⁷ Improvements in care for patients with SCD will require a combination of national educational efforts to increase the number of providers who can provide quality care for people with SCD as well as local, state, and regional efforts to improve access. As part of these efforts, the use of multiple quality benchmarks may be useful for adult patients, including the use of 7- and 14-day readmission rates in combination with 30-day readmission rates.

This study was supported by the Southeastern Virtual Institute for Health Equality and Wellness from U.S. Army Medical Research and Materials Command/Telemedicine and Advanced Technology Research Center (W81XWH-10-2-0057). This study was approved by the Medical University of South Carolina's Institutional Review Board.

REFERENCES

- Hassell KL. Population estimates of sickle cell disease in the U.S. Am J Prev Med 2010;38:S512-21.
- Gill FM, Sleeper LA, Weiner SJ, Brown AK, Bellevue R, Grover R, et al. Clinical events in the first decade in a cohort of infants with sickle cell disease. Cooperative Study of Sickle Cell Disease. Blood 1995;86:776-83.
- Platt OS, Brambilla DJ, Rosse WF, Milner PF, Castro O, Steinberg MH, et al. Mortality in sickle cell disease. Life expectancy and risk factors for early death. N Engl J Med 1994;330:1639-44.
- National Heart, Lung, and Blood Institute, Division of Blood Diseases and Resources. The management of sickle cell disease. Bethesda (MD): National Institutes of Health (US); 2002.

- Frei-Jones MJ, Field JJ, DeBaun MR. Risk factors for hospital readmission within 30 days: a new quality measure for children with sickle cell disease. Pediatr Blood Cancer 2009;52:481-5.
- Yang YM, Shah AK, Watson M, Mankad VN. Comparison of costs to the health sector of comprehensive and episodic health care for sickle cell disease patients. Public Health Rep 1995;110:80-6.
- Telfair J, Haque A, Etienne M, Tang S, Strasser S. Rural/urban differences in access to and utilization of services among people in Alabama with sickle cell disease. Public Health Rep 2003;118:27-36.
- Davis H, Gergen PJ, Moore RM Jr. Geographic differences in mortality of young children with sickle cell disease in the United States. Public Health Rep 1997;112:52-8.
- 9. Smith LA, Oyeku SO, Homer C, Zuckerman B. Sickle cell disease: a question of equity and quality. Pediatrics 2006;117:1763-70.
- Nietert PJ, Abboud MR, Zoller JS, Silverstein MD. Costs, charges, and reimbursements for persons with sickle cell disease. J Pediatr Hematol Oncol 1999;21:389-96.
- Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. JAMA 2010;303:1288-94.
- Platt OS, Thorington BD, Brambilla DJ, Milner PF, Rosse WF, Vichinsky E, et al. Pain in sickle cell disease. Rates and risk factors. N Engl J Med 1991;325:11-6.
- 13. McPherson M, Thaniel L, Minniti CP. Transition of patients with sickle cell disease from pediatric to adult care: assessing patient readiness. Pediatr Blood Cancer 2009;52:838-41.

- Crosby LE, Quinn CT, Kalinyak KA. A biopsychosocial model for the management of patients with sickle-cell disease transitioning to adult medical care. Adv Ther 2015;32:293-305.
- Jordan L, Swerdlow P, Coates TD. Systematic review of transition from adolescent to adult care in patients with sickle cell disease. J Pediatr Hematol Oncol 2013;35:165-9.
- Census Bureau (US). Small area income and poverty estimates, year 2012 [cited 2015 May 9]. Available from: http://www.census .gov/did/www/saipe/data/statecounty/maps/2013.html
- Centers for Disease Control and Prevention (US). Registry and surveillance system for hemoglobinopathies (RuSH) [cited 2015 May 9]. Available from: http://www.cdc.gov/ncbddd/sicklecell /freematerials.html
- 18. Medicode. ICD-9-CM: international classification of diseases, 9th revision, clinical modification. Salt Lake City: Medicode; 1996.
- SAS Institute, Inc. SAS[®]: Version 9.4. Cary (NC): SAS Institute Inc.; 2013.
- Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. Am J Hematol 2009;84:323-7.
- Shankar SM, Arbogast PG, Mitchel E, Cooper WO, Wang WC, Griffin MR. Medical care utilization and mortality in sickle cell disease: a population-based study. Am J Hematol 2005;80:262-70.
- Davis H, Moore RM Jr, Gergen PJ. Cost of hospitalizations associated with sickle cell disease in the United States. Public Health Rep 1997;112:40-3.