Hospital Utilization Patterns and Costs for Adult Sickle Cell Patients in Illinois

Kristy Woods, MD MPH
Theodore Karrison, PhD
Mabel Koshy, MD
Ashok Patel, MD
Peter Friedmann, MD MPH
Christine Cassel, MD

Dr. Woods is an Associate Professor, Section of General Internal Medicine, Department of Medicine, Medical College of Georgia. Drs. Karrison and Friedmann are with the Section of General Internal Medicine, Department of Medicine, University of Chicago Hospitals. Dr. Karrison is a Statistician, and Dr. Friedmann is an Assistant Professor. Dr. Koshy is a Professor of Medicine, Section of Hematology, University of Illinois Hospitals. Dr. Patel is on the faculty of the Section of Hematology, Cook County Hospital, Chicago. Dr. Cassel is a Professor of Medicine and the Chief of Geriatrics, Mt. Sinai Medical Center, New York, NY.

Address correspondence to Dr. Woods, Medical College of Georgia, Section of General Medicine-HB 2010, Augusta GA 30912; tel. 706-721-2171; fax 706-721-4575; e-mail <kwoods@mail.mcg.edu>.

SYNOPSIS

Objectives. To determine population size, demographic characteristics, hospital utilization patterns, the specialties of physicians providing care, and costs for hospitalized adult sickle cell patients in Illinois.

Methods. A statewide, administrative dataset for the two-year period from January 1992 through December 1993 was analyzed retrospectively.

Results. There were 8403 admissions among 1189 individual sickle cell patients for the two-year period. Eighty-five percent of patients resided in the Chicago metropolitan area. The median age of the 1189 patients was 29; two-thirds had Medicaid or Medicare coverage. Emergency departments were the primary source of admissions (85.7%). The most common admitting diagnosis was painful crisis (97.4%), and average length of stay was four days. The median number of admissions per patient was three; most patients (85%) used only one or two hospitals. A small group used more than four hospitals and accounted for 23% of statewide admissions. Primary care physicians cared for most patients, and total hospitalization charges were more than $59 million.

Conclusions. In Illinois the adult sickle cell population is concentrated in major urban centers, primarily the Chicago metropolitan area. These patients accounted for approximately 8400 admissions and more than $59 million in hospital charges during the two-year study period. A small group of patients used multiple hospitals and accounted for more than 23% of total hospitalization charges. This study shows the necessity of and provides a useful framework for developing targeted programs for adult sickle cell patients as well as for training physicians to efficiently provide comprehensive health care services for this population.

Sickle cell disease is an inherited genetic disorder affecting more than 70,000 Americans. Sickle cell anemia, the most common form of the disease, has an estimated prevalence in African American live births of 1:375.[1] Over the past two decades, widespread incorporation of genetic screening programs in the United States has resulted in early identification and treatment of infants and children with sickle cell disease. The prognosis has improved dramatically, and presently there is a 90% chance that affected infants will survive until the age of 20.

Sickle cell patients have entered the domain of adult medicine with signifi-

cant morbidity, early mortality,[2–4] and the psychosocial issues characteristic of chronic disease sufferers.[5–8] Intermittent and unpredictable episodes of acute pain (vaso-occlusive crises) are the hallmark of the disease. Platt and colleagues observed that mortality rates increased with the number of pain crises for patients older than age 20.[9] Frequent use of the hospital emergency department by sickle cell patients for pain management has been well documented.[10–13] Evidence also suggests that a substantial number of adult patients with sickle cell disease may not receive routine outpatient care and may use multiple hospitals for inpatient services.[14–15]

Nationally, total health care costs for anemia exceed $2.9 billion annually; sickle cell anemia and related sickle hemoglobinopathies are responsible for more than 25% of all hospitalizations for anemia.[16] Cost data analyses for sickle cell disease often do not distinguish between the pediatric and adult populations. In Illinois, newborn screening has registered more than 900 infants with sickle cell disease since 1989; however, there is no record of the number of adult survivors, their demographic characteristics, their hospital utilization patterns, or the cost of their care.[17–18] In addition, there is no coordinated system of health care delivery throughout the state, and we know little about the characteristics of physicians caring for these patients. This study examined the population size, demographic characteristics, hospital utilization patterns, the specialties of physicians providing care, and costs for hospitalized adult sickle cell patients in Illinois in 1992 and 1993.

Total charges for adult sickle cell admissions in Illinois during the study period were more than $59 million, or approximately $30 million per year.

Methods

For the two-year study period from January 1992 through December 1993 we retrospectively analyzed a statewide administrative dataset, the Illinois Hospital Association-CompData file. This file contains admissions data voluntarily submitted by member hospitals that constitute approximately 91% of hospitals in the state. Data for nonmember hospitals were obtained from state agencies that require mandatory reporting of hospitalization data. Six *International Commission on Disease, Ninth Revision* (*ICD-9*), codes were used to identify admissions for sickle cell disease: 282.60 sickle cell anemia, unspecified; 282.61 hemoglobin S (Hb-S) disease without mention of crisis; 282.62 Hb-S disease with mention of crisis; 282.63 hemoglobin C (Hb-C) disease; 282.69 sickle cell anemia, other; 282.4 thalassemias.

For admissions of patients ages 18 and older, we extracted the following information: patient age at time of discharge, gender, zip code, county code, and principal payer code. Date of birth was calculated by subtracting patient age at time of discharge (reported in hundredths of a year) from the discharge date. Each hundredth of a year is roughly equivalent to 3.65 days. This method allowed for a four-day variation from actual date of birth for each patient.

Hospital utilization data consisted of hospital identification number, hospital city and zip code, admission and discharge dates, source of admission, principal diagnosis, Diagnosis-Related Group (DRG) codes, attending physician's license number and specialty code, patient discharge status, and hospital charges. We analyzed the number of admissions per patient and the number of hospitals utilized per patient.

Attending physician specialty codes were separated into three categories: (*a*) primary care (including internal medicine, family practice, general practice, general medicine, public health, geriatrics, occupational medicine), (*b*) hematology (including hematology, hematology-oncology), and (*c*) other (including surgical or other medical specialties). The state of Illinois is divided into 102 counties. For descriptive and comparative purposes, we divided the state into four service areas: the Chicago metropolitan area (composed of six northern counties), the East St. Louis area (St. Clair County), Champaign County (a mid-state region with a major state university), and a largely rural area consisting of the remaining 94 counties.

Insurance coverage was divided into three categories—Medicaid/Medicare, private insurance, and self-pay. Medicaid and Medicare are grouped together because they reflect similar age groups, level of disability, and socioeconomic status in the sickle cell population in Illinois. The private insurance category includes codes for commercial insurance, Blue Cross/Blue Shield, health maintenance organizations, other insurance, and private insurance plans administered by employers.

To look at the effects of access to medical care on hospital utilization in this population, we further analyzed the data by type of insurance. Among patients with three or more admissions, it was not uncommon for insurance type to change during the study period. Such patients were assigned to the insurance category reported most often for them.

Anonymous record linkage across admissions was required to classify individual patients. Using methods to

anonymously link records across multiple data files, we initially sorted admissions by calculated date of birth and gender.[19–21] These data were then categorized using three additional variables (zip code of residence, payer type, and hospital identification). Admissions that were perfectly matched on all five variables were considered indicative of a unique individual. Admissions matching on date of birth and gender but not the three additional variables were considered nonmatched.

Nonmatched admissions were reconciled with individual data files from four institutions having the largest number of adult sickle cell admissions: Cook County Hospital, Michael Reese Hospital, University of Illinois Hospitals, and University of Chicago Hospitals. These hospitals are all located in the Chicago metropolitan area and accounted for nearly half of total admissions in the state (3810, or 45%). The hospitals' data files contained identifiers such as date of birth, social security number, or medical record number. These identifiers allowed for verification of unique patient status among admissions to these institutions.

In more than 89% of admissions to these four institutions, actual and calculated date of birth differed by no more than 3.6 days. Together, calculated date of birth and gender were more than 93% accurate in identifying unique patients. Calculated date of birth and gender were therefore used to identify unique patients among the remaining nonmatched cases throughout the state. For patients admitted to more than one hospital, admission dates, zip codes of residence, and hospital identification codes were reviewed to determine distinct patients with the same date of birth and gender.

Descriptive statistics for continuous and categorical variables were calculated. Group comparisons for per-patient analyses were performed using Wilcoxon, Kruskal-Wallis, or chi-square tests as appropriate. For per-admission analyses, we used the generalized estimating equations approach for repeated measures data described by Zeger and Liang.[22] This method accounts for the potential correlation in response across multiple admissions of the same patient.[23]

Results

Demographics. Perfect matching of five variables occurred in 4792 (57%) of 8103 adult sickle cell admissions in Illinois. For admissions that did not match on all five variables (43%), individual hospital data files of the four Chicago area hospitals with the largest number of adult sickle cell admissions were used to reconcile differences and determine unique patient status. A total of 1189 individual adult sickle cell patients were identified; they accounted for 8403 hospital admissions in Illinois during the two-year study period. The majority of patients (1012, or 85.1%) were from the Chicago metropolitan area, while 3.3% were from the St. Clair area, 1.4% from the Champaign area, and 10.2% from the remaining 94 counties (Table 1).

There were roughly equal numbers of hospitalized men (47.7%) and women (52.3%). Most patients (66%) had Medicaid or Medicare coverage; 26.3% had private insurance, and 7.6% had no insurance coverage. The gender and insurance patterns were consistent across the four service areas. The study population ranged from 18 to 95 years old, with a median age of 29 years (interquartile range: 23–36 years). There was a significant age difference between service areas, with a median age of 25 in the Champaign area and 29 in the Chicago metropolitan area ($P = 0.05$). Hospitalized male sickle cell patients outnumbered female patients in the youngest age cohort (ages 18–27), with the male percentage declining in older age cohorts (Figure 1).

Hospital utilization. The 8403 admissions were distributed among 124 hospitals throughout the state (Table 2). Most admissions (89.4%) occurred among 77 hospitals within the Chicago metropolitan area. Ten hospitals in Chicago

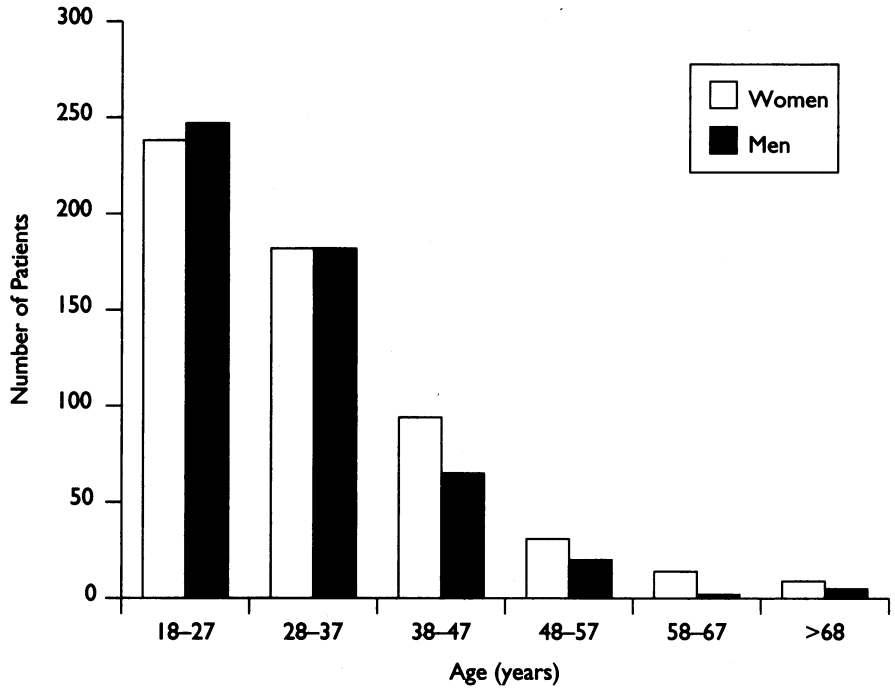
Table 1. Population size and demographic characteristics of hospitalized adult sickle cell patients in Illinois, 1992–1993

	Statewide	*Chicago area*	*East St. Louis area*	*Champaign area*	*Remainder of state*
Total number of patients	1189	1012	39	17	121
Gender [number(percent)]					
Women	622(52.3)	524(51.8)	24(61.5)	9(52.9)	65(53.7)
Men	567(47.7)	488(48.2)	15(38.5)	8(47.1)	56(46.3)
Median age in years at first admission[a]	29	29	27	25	27
Interquartile range	23–36	23–36	24–30	22–29	22–35
Range	18–95	18–95	18–95	19–37	18–75
Insurance [number(percent)]					
Medicaid or Medicare	785(66.0)	678(67.0)	28(71.8)	10(58.8)	69(57.0)
Private[b]	313(26.3)	261(25.8)	6(15.4)	6(35.3)	40(33.1)
No insurance	91 (7.6)	73 (7.2)	5(12.8)	1 (5.9)	12 (9.9)

[a]Comparison across service areas of median ages is statistically significant at $P = 0.05$ level.

[b]Includes Blue Cross/Blue Shield, health maintenance organization, commercial, employer-administered, other insurance.

Figure 1. Patient age by gender, hospitalized adult sickle cell patients in Illinois, 1992–1993



accounted for 63% of statewide admissions. The most common admitting diagnosis was sickle cell disease with vaso-occlusive crisis (97.4% of admissions). An analysis of DRG codes revealed that fewer than 1% of total admissions were for surgical procedures.

Although the hospital emergency department was the primary source of admissions for adult patients throughout the state (85.7%), there was a significant difference between regions in sources of admissions ($P < 0.001$). In the Chicago metropolitan area, 87.5% of hospital admissions were from the emergency department; in the Champaign area, 70.4% were admitted from the emergency department, and in the 94 largely rural counties, the figure was 69.3%. The source of admission was the emergency department more often for patients with Medicaid/Medicare (87.5%) or with no insurance (90.2%) than for patients with private (70.4%) or HMO (75.3%) coverage ($P < 0.001$) (Figure 2).

We separated admissions for vaso-occlusive crisis (VOC) from surgical admissions in analyzing length of stay. The median length of hospitalization for VOC was four days; this did not differ significantly across service areas. For surgical admissions, the median length of stay was 11 days, which also was consistent across service areas. Hospital discharge status was listed as "routine" for most admissions across the state (90.5%).

During the two-year study period, the median number of admissions per patient statewide was three (IQR 1–7; range 1–116 admissions); the median number of admissions did not differ significantly across regions (Table 3). Most patients (668, or 61%) used one hospital during the study period (range 1–13 hospitals per patient). Sickle cell patients in the Chicago metropolitan and East St. Louis areas used multiple hospitals more often than did patients in the combined 94 largely rural counties ($P < 0.001$).

Patients were grouped by the number of hospitals used per study period: 1–2, 3–4, and more than 4 hospitals. Approximately 85% of patients used one to two hospitals; only 3.8% (45 patients) used more than four hospitals within the two-year study period (Figure 3). The 3.8% of patients using multiple hospitals accounted for 23% of statewide admissions. Ninety percent of patients with admissions to three to four different hospitals and 100% of patients that used more than four hospitals were from the Chicago metropolitan area, as were 84% of patients using one to two hospitals. There was a significant difference across service areas in number of hospitals used ($P = 0.004$). Additionally, patients using more than four hospitals were younger ($P = 0.0003$), more often male ($P = 0.002$), and had more admissions per patient ($P = 0.0001$) than those who used fewer hospitals.

A small group of patients (3.8%) using multiple hospitals accounted for 23% of statewide admissions.

Provider specialties. Physician specialty codes were available for 84% (7098) of admissions (Table 3). Almost all (92%) of the admissions for which physician specialty codes were missing were in the Chicago metropolitan area. Across the state, primary care physicians (56%) were more often responsible for inpatient services than hematologists (21%) and other specialists (22%). Provider specialties differed between service areas ($P < 0.019$) because of the relatively large number of admissions to hematologists in the Champaign area (Table 3). Patient age did not differ significantly

Table 2. Hospital utilization by adult sickle cell patients, Illinois, 1992–1993

Characteristics	Statewide		Chicago area		East St. Louis area		Champaign area		Remainder of state	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total admissions	8403	...	7514	89.4	171	2.0	142	1.7	576	6.9
Admitting hospitals	124	...	77	...	4	...	3	...	40	...
Principal diagnosis										
Sickle cell disease with painful VOC	8186	97.4	7332	97.6	166	97.1	142	100	546	94.8
Sickle cell disease without crisis	15	0.2	15	0.2	0	0.0	0	0.0	0	0.0
Sickle cell anemia unspecified	111	1.3	87	1.2	4	2.3	0	0.0	20	3.5
Hemoglobin SC disease	11	0.1	9	0.1	1	0.6	0	0.0	1	0.2
Sickle beta-thalassemia	77	0.9	69	0.9	0	0.0	0	0.0	8	1.4
Other[a]	3	0.0	2	0.0	0	0.0	0	0.0	1	0.2
DRG codes										
Red blood cell disorder	8326	99.1	7447	99.1	168	98.2	142	100	569	98.8
Extensive OR procedure	39	0.5	34	0.4	1	0.6	0	0.0	4	0.7
Other OR	17	0.2	16	0.2	0	0.0	0	0.0	1	0.2
Nonextensive OR	16	0.2	12	0.2	2	1.2	0	0.0	2	0.4
Splenectomy	4	...	4	0.1	0	0.0	0	0.0	0	0.0
Bone marrow transplant	1	...	1	0.0	0	0.0	0	0.0	0	0.0
Source of admissions[b]										
Emergency department	7202	85.7	6576	87.5	127	74.3	100	70.4	399	69.3
Referral	1092	13.0	870	11.6	43	25.1	40	28.2	139	24.1
Transfer	51	0.6	44	0.6	1	0.6	2	1.4	4	0.7
Not available	58	0.7	24	0.3	0	0.0	0	0.0	34	5.9

[a]Hemoglobin SE disease or hemoglobin SD disease.
[b]Comparison across service areas of source of admissions was statistically significant at $P < 0.001$ level.
DRG = Diagnosis-Related Groups
OR = Operating room

across provider specialty; patients on a primary care or "other" service were more likely to have no insurance ($P < 0.001$) and less likely to have Medicaid or Medicare coverage than patients on a hematology service ($P < 0.001$).

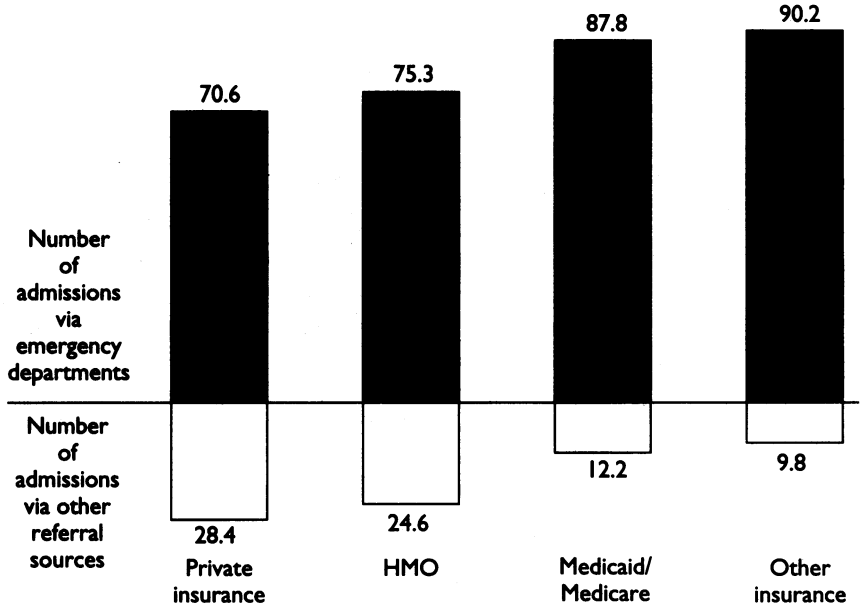
Hospital charges. The median charge for VOC admissions was $5197 (IQR $3122–$8386) and for surgical admissions $18,980 (IQR $9734–$34,339), with significant regional differences in both groups (Table 4). Adjusting for length of stay, the median charge per day for VOC admissions was $1170 (IQR $950–$1568), compared with $1679 (IQR $1288–$2311) for surgical admissions. Analyzed on a per diem basis, statistically significant regional differences remained for both VOC and surgical admissions ($P < 0.001$). Total charges for adult sickle cell admissions in Illinois during the study period were more than $59 million, or approximately $30 million per year.

Discussion

We identified 1189 individual adult sickle cell patients who were hospitalized at least once during the 24-month study period. Because more than a third of patients will not seek medical treatment for pain during an average five-year period,[9] we can estimate an adult sickle cell population of approximately 1800 patients in Illinois (1189 × 3/2 = 1783). Platt and colleagues reported a life expectancy of 42 to 48 years and a gender difference in survival for sickle cell disease favoring female patients.[4] Our study revealed a median age of 29 years for hospitalized adult patients, with the majority falling between ages 23 and 36. Roughly half (52.3%) of all hospitalized patients were female; women predominated in the older age groups. It is unclear whether the lower hospitalization rates for older male patients reflect a gender difference in access to care or care-seeking; they may also reflect early male mortality from sickle cell disease or other causes.

The adult sickle cell population was responsible for 8403 hospital admissions, with more than 90% in the major urban areas of Chicago and East St. Louis. Across the state, the median number of admissions per patient was three, and 75% of patients had between one and seven admissions during the two-year study period. Previous studies that included pediatric patients found that 90% of sickle cell

Figure 2. Source of admissions by insurance status, hospitalized sickle cell patients in Illinois, 1992–1993



admissions were for painful crises.[14,24] Our findings reveal an even greater percentage of admissions (97%) due to painful vaso-occlusive crises among adults.

The emergency department was the primary source of admissions statewide, and this pattern was most pronounced in urban areas. Two recent studies have examined the relationships among insurance status, use of outpatient services, and hospitalization rate in patients with sickle cell disease. Yang and colleagues reported that sickle cell patients using comprehensive ambulatory clinics have lower rates of emergency department and inpatient visits.[15] Conversely, Hand and coworkers observed that high frequency emergency room use was independent of insurance status and was positively correlated with the use of primary care clinics.[25] Our statewide survey in Illinois reveals that sickle cell patients with Medicaid, Medicare, or no insurance used the emergency department as a source of admission more often than patients with private insurance coverage.

An earlier report on emergency room utilization patterns for sickle cell patients at an urban outpatient medical center noted that approximately 10% of patients accounted for 43% of visits.[14] Our analysis of adult admissions found that, similarly, a small group of 45 patients (3.8%) accounted for 23% of total admissions across the state. In contrast to the majority of patients, this group used multiple health care facilities (5 to 13 different hospi-

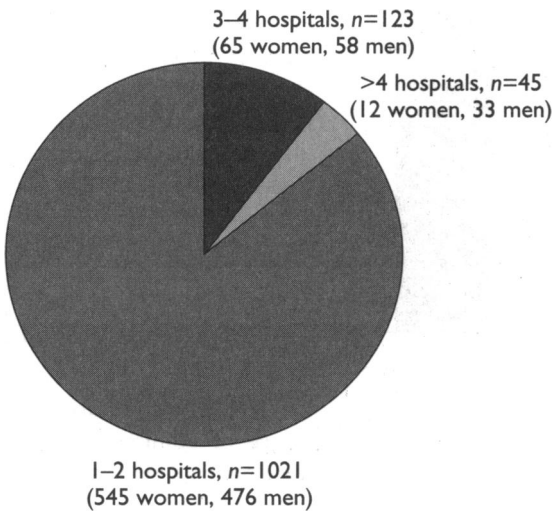
Table 3. Hospital admissions per patient, number of hospitals per patient, and physician specialties, by service area, for adult sickle cell patients, Illinois, 1992–1993

	Statewide		*Chicago area*		*East St. Louis area*		*Champaign area*		*Remainder of state*	
	Number	*Percent*	*Number*	*Percent*	*Number*	*Percent*	*Number*	*Percent*	*Number*	*Percent*
Number of patients	1189	...	1012	...	39	...	17	...	121	...
Median number of admissions per patient[a]	3	...	3	...	3	...	4	...	3	...
Interquartile range	1–7	...	1–8	...	1–8	...	2–11	...	1–5	...
Range	1–116	...	1–116	...	1–17	...	1–37	...	1–45	...
Median number of hospitals per patient[a,b]	1	...	1	...	1	...	1	...	1	...
Interquartile range	1–2	...	1–2	...	1–2	...	1–1	...	1–1	...
Range	1–13	...	1–13	...	1–4	...	1–3	...	1–4	...
Mean number of hospitals per patient[a]	1.6	...	1.7	...	1.6	...	1.3	...	1.2	...
Physician specialties										
Primary care	4009	...	3549	56.2	127	77.0	37	26.6	296	61.8
Hematology	1555	...	1348	21.4	34	20.6	97	69.8	76	15.9
Other	1534	...	1418	22.4	4	2.4	5	3.6	107	22.3

[a]For the two-year study period.

[b]Comparison across service areas of median number of hospitals per patient was statistically significant at the $P < 0.001$ level.

Figure 3. Number of different hospitals to which individual sickle cell patients were admitted over a two year period, Illinois, 1992–1993 (*n* = 1169 patients)



tals per patient) during the two-year study period. Definable characteristics of these patients include younger age, male gender, and residence in an urban area.

The atypical pattern observed among this identifiable cohort may be indicative of the acute and unpredictable nature of painful crises. It may also reflect a high frequency of admissions among patients in urban areas with a large concentration of available hospitals; patients may use more hospitals because more are available. Conversely, such a pattern may reflect the lack of available or accessible outpatient services for the adult sickle cell population. And finally, we cannot exclude the possibility of inappropriate manipulation of an urban health care system by chronically ill patients who have substance abuse or other psychosocial problems.

The median length of hospitalization was four days for painful crises and 11 days for surgical admissions. Attending physicians were most often (56%) primary care physicians; hematologists were listed in 21% of admissions, and other physicians in 22% of admissions. Charges per admission reflected regional billing trends and average lengths of stay. During the study period, total hospitalization charges for 1189 patients in Illinois were $59 million, or approximately $30 million per year. This figure is staggering given that it does not include the cost of outpatient services or emergency room visits. Based on previous reports that only 32% to 38% of sickle cell patients seen in emergency departments are admitted as inpatients, we estimate more than 12,000 emergency department visits per year during the study period.[14,15,25]

The use of an anonymous, administrative dataset limits the accuracy of our population estimate. Although we used a systematic method to identify unique patients, it is possible that we failed to identify some individual patients and

Table 4. Hospital charges for adult sickle cell patients, Illinois, 1992–1993

Hospitalization	*Statewide*	*Chicago area*	*East St. Louis area*	*Champaign area*	*Remainder of state*
Painful vaso-occlusive crisis					
Number of admissions	8326	7447	168	142	569
Median charge per admission[a]	$5197	$5311	$3881	$4739	$4537
Interquartile range	$3122–8386	$3181–8550	$2709–5718	$3054–7812	$2637–7020
Range	$0–227,618	$300–117,618	$1118–18,403	$565–69,263	$0–38,295
Median charge per day	$1170	$1206	$925	$883	$1071
Range	$0–15,381	$150–1538	$457–2016	$559–1860	$0–7943
Total charges	$57,265,520				
Sickle cell disease without crisis or surgical diagnosis					
Number of admissions	77	67	3	0	7
Median charge per admission[a]	$18,980	$21,948	$8967	0	$10,883
Interquartile range	$9734–34,339	$10,079–35,108	$5415–17,055	0	$6981–14,058
Range	$0–141,599	$1707–141,599	$5415–17,055	0	$0–24,105
Median charge per day	$1679	$1747	$1421	0	$1172
Range	$0–6874	$786–6874	$527–1805	0	$0–1728
Total charges	$1,965,573				
Total charges for all admissions	$59,231,093				

[a]Comparison across service areas of hospital charges was significant at the $P < 0.0001$ level.

thereby underestimated population size. This could have resulted in overestimating the average number of admissions per patient and admissions to multiple hospitals. Therefore, an even smaller percentage of patients could be high users and health care resources could be distributed more evenly.

Provider specialty data were available on 84% of admissions. Most of the missing provider data (14%) were from the Chicago metropolitan area. If all missing data were for hematologists, primary care physicians would still predominate in the Chicago area and throughout the state. Additionally, we looked at attending physician of record and did not consider the role of inpatient hematology consultants. And, finally, our findings may be unique to the state of Illinois and not applicable to areas with larger rural sickle cell populations or different systems of health care delivery, such as the Comprehensive Sickle Cell Centers that exist in some states.

In summary, we have described important demographic and population characteristics for adult sickle cell disease in the state of Illinois. Utilization patterns, provider specialties, and hospitalization expenditures for this population have been delineated. A small group of adult sickle cell patients had frequent hospitalizations. While total hospitalization expenditures were enormous, they were disproportionately distributed, with 3.8% of the population accounting for 23% of total hospitalizations and approximately that proportion of total costs.

These findings have important implications in terms of allocation of services and physician resources. Additional targeted and comprehensive programs that will serve as models for other chronic conditions such as diabetes are needed to ensure the delivery of cost-effective and quality care to the expanding adult sickle cell population. Primary care physicians must be recognized as key providers in the management of adult sickle cell disease in conjunction with hematologists. To enhance medical outcomes and decrease excessive utilization patterns, efforts must focus on primary prevention education of primary care physicians, intensive case management, and further investigation of the small subgroup of high risk patients.

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References

1. Agency for Health Care Policy and Research [US]. Sickle cell disease: screening, diagnosis, management, and counseling in newborns and infants. Clinical Practice Guidelines No. 6. Rockville (MD): AHCPR; 1993 Apr. AHCPR Pub. No. 93-0562.
2. Leikin SL, Gallagher D, Kinney TR. Mortality in children and adolescents with sickle cell disease. Pediatrics 1989;84:500–508.
3. Vichinski E. Comprehensive care in sickle cell disease: its impact on morbidity and mortality. Semin Hematol 1991;28:220–226.
4. 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;330:1639–1644.
5. Farber MD, Koshy M, Kinney TR. Cooperative study of sickle cell disease: demographic and socioeconomic characteristics of patients and families with sickle cell disease. J Chronic Dis 1985;38:495–505.
6. Bobo L, Miller S, Smith W. Health perceptions and medical care opinions of inner-city adults with sickle cell disease or asthma compared with those of their siblings. South Med J 1989;82:9–12.
7. Weissman DE, Haddox JD. Opioid pseudoaddiction—an iatrogenic syndrome. Pain 1989:36:363–366.
8. Belgrave FZ, Molock SD. The role of depression in hospital admissions and emergency treatment of patients with sickle cell disease. J Natl Med Assoc 1991;83:777–781.
9. Platt OS, Thorington BD, Brambilla DJ, Milner PF, Rosse WF, Vichinsky E, et al. Pain in sickle cell disease: rate and risk factors. N Engl J Med 1991;325:11–16.
10. Powers RD. Management protocol for sickle cell disease patients in acute pain: impact on emergency department and narcotic use. Am J Emerg Med 1986;4:267–269.
11. Gonzalez ER, Bahal N, Hansen LA, Ware D, Bull DS, Omato JP. Intermittent injection vs patient-controlled analgesia for sickle cell disease pain in the emergency department. Arch Int Med 1991;151:1373–1378.
12. Pollack C, Sanders D, Severance H. Emergency department analgesia without narcotics for adults with sickle cell pain crises: case reports and review of crisis management. J Emerg Med 1991;9:445–452.
13. Brookoff D. A protocol for defusing sickle cell crisis. Emerg Med 1992;15:131–140.
14. Koshi M, Leiken J, Dorn L, et al. Evaluation and management of sickle cell disease in the emergency department (an 18-year experience): 1974–1992. Am J Ther 1994;1:309–320.
15. Yang Y, 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;110:80–86.
16. Morbidity and mortality: chartbook on cardiovascular, lung, and blood disorder. Bethesda (MD): National Heart, Lung, and Blood Institute; 1994 May.
17. Genetics Section, Illinois Department of Public Health. Annual report: fiscal year 1993 (July 1992–June 1993). Springfield (IL): Department of Public Health: 97–115.
18. Sickle cell report. Illinois Health Care Cost Containment Council. Springfield (IL):1991.
19. Roos LL, Wadja A, Nichol JP. The art and science of record linkage: methods that work with few identifiers. Comput Biol Med 1986;16:45–57.
20. Newcombe HB. Handbook of record linkage: methods for health and statistical studies, administration, and business. New York: Oxford University Press, 1988.
21. Muse AG, Mikl J, Smith PF. Evaluating the quality of anonymous record linkage using deterministic procedures with the New York State aids registry and a hospital discharge file. Stat Med 1995;14:499–509.
22. Zeger SL, Liang KY. Longitudinal data analysis for discreet and continuous outcomes. Biometrics 1986;42:121–130.
23. Davis CS. A computer program for regression analysis of repeated measures using generalized estimating equations. Comput Methods Programs Biomed 1993;40:15–31.
24. Brozovic M, Davies SC, Brownwell AI. Acute admissions of patients with sickle cell disease who live in Britain. BMJ 1987;295:1206–1208.
25. Hand R, Koshi M, Patel M. Health insurance status and the use of emergency and other outpatient services by adults with sickle cell disease. Annals Emerg Med 1995;25:224–229.