Cost of Hospitalizations Associated with Sickle Cell Disease in the United States

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SYNOPSIS

Objective. This study estimated the number and cost of hospitalizations associated with sickle cell disease in the United States.
Methods. To estimate the number of hospitalizations per year in the United States of people with sickle cell disease, the authors used data for the years 1989 through 1993 from national hospital discharge surveys conducted by the National Center for Health Statistics. The authors derived cost estimates using data from a 1992 national hospital discharge survey conducted by the Agency for Health Care Policy and Research and a 1992 survey of physicians conducted by the American Medical Association.
Results. During the years 1989 through 1993, there were on average an estimated 75,000 hospitalizations per year of children and adults with sickle cell disease. The average direct cost per hospitalization (in 1996 dollars) was estimated at $6300, for a total direct cost of $475 million per year. In 66% of hospital discharge records, government programs were listed as the expected principal source of payment.
Conclusions. The cost of hospitalizations associated with sickle cell disease is substantial. Because government programs pay most of this cost, further government-funded research to develop interventions that prevent complications of the disease has great potential for cost savings as well as for reducing the suffering of those afflicted with this painful genetic disorder. These national cost estimates contribute to an understanding of the impact of sickle cell disease and should be useful in establishing research priorities.

Sickle cell disease refers to a group of genetic disorders that in the United States affect predominantly black children and adults, with other population groups affected to a much lesser extent.[1] Sickle cell disease occurs among approximately one in 350 black newborns.[1] The most common type is hemoglobin SS disease (also called sickle cell anemia), followed by hemoglobin SC disease and then by sickle beta-thalassemia.[2]

Information on the national cost of medical care for people with sickle cell disease would contribute to a better understanding of the disease's impact and would be useful in establishing research priorities. The relatively low prevalence

of sickle cell disease precludes the use of national surveys to estimate the cost of outpatient care. However, in a recent southern Alabama study, hospitalizations were found to account for 90% of the medical care costs of people with sickle cell disease,[3] suggesting that information on the national cost of hospitalizations would be very useful. To estimate the national cost of hospitalizations associated with sickle cell disease, we used data from two national hospital discharge surveys and a national survey of physicians.

Methods

We used data from the National Hospital Discharge Survey (NHDS) to derive estimates of the number of hospitalizations yearly in the United States of people with sickle cell disease. We also used NHDS data to examine the average length of stay and the expected principal sources of payment for the hospitalizations. The NHDS is conducted annually by the National Center for Health Statistics and samples hospital discharges from non-Federal short-stay hospitals in the United States.[4] Hospitalizations are coded for up to seven diagnoses, using the *International Classification of Diseases, 9th Revision, Clinical Modification* (*ICD-9-CM*).

For the years 1989 through 1993 there were an average of 75,000 hospitalizations per year of people with sickle cell disease.

We included in our study hospital discharges listed in the NHDS for the years 1989 through 1993 that had a diagnosis code for sickle cell disease (*ICD-9-CM* 282.6). This code includes hemoglobin SS disease and hemoglobin SC disease but not sickle beta-thalassemia, which is coded with other thalassemias. However, some hospitalizations of people with sickle beta-thalassemia might have been included in the study. This is because the hospital record might have listed the diagnosis as sickle cell disease, without mention of sickle beta-thalassemia. We did not distinguish hemoglobin SS disease from hemoglobin SC disease, which would have required using the *ICD-9-CM* code's fifth digit, because the authors' experience suggested that the fifth digit was not reliable.

From each hospital record, the NHDS collects data on which payer is expected to be the principal source of payment. We categorized these sources as government (including Medicare, Medicaid, and other government payments), private insurance, self-pay, and "other" (coded by the NHDS as "other").

To generate national estimates from NHDS data, it was necessary when we analyzed the data to account for a hospital discharge's probability of being included in the NHDS. In all analyses using NHDS data, we accounted for this probability by using an adjustment factor (sampling weight) that is provided on the data tape for each hospital discharge listed in the NHDS.

The average charge per hospital stay for hospitalizations with sickle cell disease as the first-listed diagnosis was obtained from the 1992 Nationwide Inpatient Sample, conducted by the Agency for Health Care Policy and Research. This survey contains data on all hospitalizations in a sample of community hospitals in 11 states. The hospital charge recorded by the survey incorporates all items except physician services, including room, laboratory, and operating room charges; x-rays; medications; and supplies. National estimates of charge per hospitalization were derived using the sampling weights provided on the data tape.

To make up for losses from partly compensated and uncompensated care, hospitals charge more than their actual costs. In 1992, hospital charges were on average 160% of costs.[5] Therefore, to estimate hospital costs, we multiplied hospital charges by 0.625.

We estimated charges for physician services by assuming one physician visit per hospital day. From the 1992 Socioeconomic Monitoring System Survey (an annual survey of physicians conducted by the American Medical Association), we obtained the estimated average charge per hospital visit.[6] The survey calculated this average by using sampling weights and including all physician specialties.

To provide costs in 1996 dollars, we used inflators based on estimates from the Congressional Budget Office.[7] The 1992 cost per hospitalization was multiplied by 1.27, and the 1992 charge per physician visit was multiplied by 1.28.

Hospital costs and charges for physician services were added together to calculate the cost of medical treatment during hospitalizations, which we termed the direct cost of hospitalizations.

Data were analyzed by five-year age groups for children under 10 years old and by 10-year age groups for people 10 years old and older.

Results

Using the methodology described above, we estimated that for the years 1989 through 1993 there were an average of 75,000 hospitalizations per year of people with sickle cell disease (see Table). People under 60 years old accounted for an estimated 99% of these hospitalizations. The estimated average length of stay was 6.1 days, resulting in a total of 456,000 days of care per year. The estimated mean length of

Estimated number of hospitalizations per year, average length of stay, and cost of hospitalizations per year, by age group—people with sickle cell disease, United States, 1989–1993

Age group (years)	Estimated number of hospitalizations per year (thousands)[a]	Estimated average length of stay (days)	Estimated average direct cost per hospitalization (in 1996 dollars)[b]	Estimated total direct cost of hospitalizations per year (in 1996 dollars)[c]
0 – 4	8	4.2	4,200	34,600,000
5 – 9	5	4.9	4,900	24,300,000
10 – 19	21	4.9	5,600	119,800,000
20 – 29	17	7.0	6,900	119,600,000
30 – 39	15	7.4	7,400	111,700,000
≥40	8	7.5	8,300	65,200,000
All ages	75	6.1	6,300	475,200,000

NOTE: Sickle beta-thalassemia is not included in the definition of the *International Classification of Diseases, 9th Revision, Clinical Modification* code for sickle cell disease used in this study.

[a]Rounded to nearest 1000 hospitalizations following publication guidelines of the National Center for Health Statistics.

[b]Rounded to nearest $100 because these figures were based on estimates.

[c]Calculated by multiplying non-rounded estimates of average yearly number of hospitalizations by non-rounded estimates of average direct cost per hospitalization. The results were then rounded to the nearest $100,000.

stay for people 20 years of age or older was longer than that for younger people (see Table).

The average direct cost per hospitalization (in 1996 dollars) was an estimated $6300; costs increased with increasing age (see Table). The estimated total direct cost of hospitalizations per year for people with sickle cell disease was $475.2 millon. We also found that the expected principal source of payment was a government program in 66% of hospitalizations, private insurance in 20%, self-payment in 7%, another source in 4%, and was not stated in 3%.

Discussion

Using data from national surveys, we found that the national cost of hospitalizations associated with sickle cell disease is substantial and that government programs pay most of this cost. These national cost estimates contribute to an understanding of the disease's impact and should be useful in establishing research priorities.

The national cost of hospitalizations associated with sickle cell disease is substantial, and government programs pay most of this cost.

Limitations. Sickle cell disease varies greatly in severity, with some people relatively asymptomatic while others are often and severely ill. A possible indicator of variability in severity is the number of times an individual is hospitalized. However, because the NHDS samples discharge events and not individuals, this study could not determine how many times an individual was hospitalized.

The current study estimates the direct cost of hospitalizations of people with sickle cell disease, but not indirect and intangible costs. Indirect costs include the patient's and family members' time lost from school, wages lost from work, transportation expenses, and income lost from premature death. Intangible costs include pain, disruption of family life, and stress on the patient and family.

Sickle beta-thalassemia is not included in the definition of the *ICD-9-CM* code for sickle cell disease used in this study. However, some hospitalizations of people with sickle beta-thalassemia might have been included in the study. This is because the hospital record might have listed the diagnosis as sickle cell disease, without mention of sickle beta-thalassemia. Because probably not all hospitalizations of people with sickle beta-thalassemia were included in this manner, the study mildly underestimates the costs of hospitalizations of people with sickle cell disease.

Availability of comprehensive care. The costs of inpatient and outpatient care for sickle cell disease are lower among people receiving comprehensive care. Yang et al. describe a comprehensive care program for sickle cell disease in southern Alabama that focuses on home health care, use of comprehensive clinics for health surveillance and non-emergency health problems, and helping patients learn to cope

with symptoms using personal, family, and community resources.[3] Yang and colleagues found that people with sickle cell disease who used the comprehensive clinics had 33% fewer hospitalizations than people with the disease who did not use them. Compared with people not using the clinics, the clinic users had an average direct cost per person that was 56% lower for inpatient care, 78% lower for outpatient care (clinics and emergency rooms), and 57% lower for all health care. Differences in disease severity did not appear to account for these findings.

New drug treatments. Among adults with sickle cell disease, the rate of hospitalizations for painful crises can be reduced with a drug, hydroxyurea. In 1995, a multicenter study showed that among adults with three or more painful crises per year, hydroxyurea reduced the median number of crises requiring hospitalization by 58%.[8] As hydroxyurea is used more widely, the number and cost of hospitalizations for sickle cell disease nationwide will probably decrease.

Public funding. The hydroxyurea study is an example of government-funded research that can be expected to lead to savings in health care costs. In 1995, Federal funding for research on sickle cell disease was $47 million (National Institutes of Health, unpublished data). In the current study we estimate that during 1989 through 1993, government programs paid for 66% of hospitalizations of people with sickle cell disease. Because states and the Federal government pay substantial sums to treat complications of sickle cell disease, government-funded research into interventions that prevent complications or result in better outpatient management of them has great potential for cost savings.

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