Comparison of Costs to the Health Sector of Comprehensive and Episodic Health Care for Sickle Cell Disease Patients

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Synopsis

Of 391 patients with sickle cell disease known to the health care facilities of the University of South Alabama, 194 patients used these facilities in 1989. In that year, 33.5 percent of patients seen at the University of South Alabama did not attend the Comprehensive Health Care Clinics developed for sickle cell patients. There were major differences in the patterns of use and in health care costs among sickle cell patients who attended the Comprehensive Health Care Clinics and those who did not. Patients not using these clinics, although they accounted for only 33.5 percent of the total patients, constituted 71.4 percent of visits to the emergency rooms and 42.3 percent of inpatient admissions.

Patients enrolled in the Comprehensive Health Care Clinics used emergency rooms and inpatient units less frequently (P < 0.0001 and P = 0.0006, respectively) and were responsible for significantly smaller health care costs in each category (P < 0.0300). Evaluation of factors responsible for differences in the use patterns and patient education to improve use of comprehensive health care services should be considered.

RESOURCES FOR THE PROVISION of health care are scarce; there are not (and will never be) enough resources to satisfy all human desires for health care (1). This gap presents special problems in designing health care for patients with chronic diseases such as the sickle hemoglobinopathies that affect a socioeconomically poor population (2).

Sickle cell disease (SCD) is a chronic blood disorder that predominantly affects black populations in the United States. It is caused by an inherited genetic mutation that produces a defective hemoglobin. Patients with SCD suffer from a lifelong disorder characterized by recurrent and unpredictable episodes of pain (pain crises), hemolytic anemia and anemic crises, stroke, infections, renal and pulmonary problems, and numerous problems related to organ dysfunctions of varying severity (3). The symptoms caused by organ damage are accentuated or ameliorated by psychological, sociological, educational, and vocational factors and by family dynamics (4). Patients with SCD vary significantly in that some are

frequently and severely ill while others are relatively asymptomatic (5). It is estimated that about 50,000 people in the United States have sickle cell anemia, a homozygous form of the disease.

Economic disadvantages associated with inadequate medical coverage of the population at risk for SCD contribute to fragmented health care that is largely directed to treat episodic acute illnesses. Psychological, sociological, educational, and vocational factors as well as family dynamics that accentuate the illness cannot be addressed in episodic visits to emergency rooms or hospital inpatient units. Therefore, such episodes make little impact on frequency or severity of future illnesses or on overall "quality of life" of the patient. Moreover, frequent hospitalizations and emergency room visits for acute illnesses are likely to be more expensive than preventive approaches (6,7).

At the University of South Alabama Comprehensive Sickle Cell Center, we have developed a comprehensive, multidisciplinary approach to address the physical, mental, and social needs of each patient

with SCD in the region of the Alabama Gulf Coast. We have compared the economic aspects of a comprehensive health care program with episodic care rendered in emergency rooms and inpatient units. The purpose of this paper is to present our analysis to assist in future planning of health care for SCD patients.

Methods

Health care programs for sickle cell patients. There are several ways in which patients with SCD in the region of the Alabama Gulf Coast can receive health care: (a) University of South Alabama Comprehensive Sickle Cell Center, (b) emergency rooms and inpatient units of the University of South Alabama Hospitals and Clinics (without being registered with the Comprehensive Sickle Cell Center), (c) private physicians' offices in the Mobile region and health care facilities recommended by such physicians, and (d) emergency rooms and inpatient units of other hospitals in the region without specific and ongoing involvement of providers affiliated with the first three categories.

The University of South Alabama Comprehensive Sickle Cell Center was organized in 1981 and has received funding from the National Heart, Lung, and Blood Institute since April 1988. The goal of the center is to improve the quality of life of persons with SCD through basic and clinical research and demonstration activities in education, diagnosis, counseling, and social support. The center has organized comprehensive health care clinics for children and adults with SCD. In addition, a community-based program for education, counseling, and social support for SCD patients has been developed and has been an integral part of the comprehensive care program.

The center recommends use of emergency room facilities for true emergencies such as severe pain that cannot be controlled by oral narcotic analgesics, sudden onset of high fever, development of profound pallor and weakness, and respiratory symptoms, especially shortness of breath. The center also suggests the use of inpatient units when hospitalization is appropriate. However, the focus of this program is on teaching self-help, home health care, use of comprehensive clinics for health surveillance and for management of health problems that are considered nonemergencies, and learning to cope with the symptoms of the disease through the use of the personal, family, and community resources.

The health care services provided by the Comprehensive Sickle Cell Center are billed according to customary charges. These include physician fees,

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radiology and laboratory charges, fees for various treatments rendered in the clinic, and charges for the use of facilities. Design of the demonstration research, data analysis, and organizational costs of this project are supported by grants and, therefore, are not included in the health care costs analysis. Salaries of the sickle cell association staff who provide supportive services to our patients are added to the costs of the health care program. All patients are accepted in the program regardless of ability to pay or insurance status. It is our policy not to enforce collections from patients when the insurance payment is less than the charges.

Emergency rooms and inpatient units of the university hospitals include pediatric and adult facilities of the University of South Alabama. As parts of a nonprofit institution organized for public service, these facilities accept all patients regardless of financial capabilities. Patients not registered with the health care program of the University of South Alabama Comprehensive Sickle Cell Center (previously described) often seek assistance from the emergency rooms of the university hospitals.

Based on the known incidence of SCD, the prevalence of SCD in the population within the 150-mile radius of Mobile is estimated to be 700. However, many asymptomatic or mildly symptomatic persons with SCD are probably not known to the center or other health care facilities. There are 438 persons with SCD known to the Mobile, AL, Chapter of the Sickle Cell Disease Association of America. They include those with sickle cell anemia (Hb SS), hemoglobin sickle cell disease (Hb SC), hemoglobin S β thalassemia syndrome (Hb S β thal) of either the β + or β ° variety. Of these, 391 (or 89 percent) use the university affiliated health care programs. The remaining 11 percent of patients use private physicians, emergency rooms of private hospitals, or other

Table 1. Patients with sickle cell disease visiting health care facilities, by number of visits, University of South Alabama Comprehensive Sickle Cell Center, 1989

Frequency of visits	Comprehensive clinics		Emergency rooms		Inpatient units		Combined 1	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
0	65	33.5	120	61.9	97	50.0	10	0.0
1	36	18.6	30	15.5	40	20.6	50	25.8
2	24	12.4	20	10.3	25	12.9	35	18.1
3	19	9.8	3	1.5	10	5.2	22	11.3
4	11	5.7	3	1.5	9	4.6	18	9.3
5	8	4.1	4	2.1	4	2.1	9	4.6
6–10	14	7.2	5	2.6	5	2.6	29	15.0
11–20	13	6.7	5	2.6	4	2.0	15	7.7
21–30	2	1.0	0	0	0	0	8	4.1
31–50	2	1.0	1	0.5	Ō	Ō	4	2.1
51–70	0	0	1	0.5	Ō	Ō	2	1.0
71–100	Ö	Ö	2	1.0	Ō	Ö	2	1.0
Total	194	100	194	100	194	100	194	100

[&]quot;Combined" included comprehensive clinics, emergency rooms, and inpatient units. All patients in this study visited at least 1 of these 3 health care facilities.

Table 2. Comparison of sickle cell patients who never visited the Comprehensive Health Care Clinics (group 1) and patients with one or more clinic visits (group 2), University of South Alabama, 1989

Characteristics	Group no clinic		Group 1 or more cli		Total		
	Number	Percent	Number	Percent	Number	Percent	
1 or more emergency room visits	39	52.7	35	47.3	74	100	
1 or more inpatient admissions	48	49.5	49	50.5	97	100	
Total clinic visits	0	0	649	100	649	100	
Average clinic visit per patient	0		5.0		3.3		
Total emergency room visits	367	71.4	147	28.6	514	100	
Average emergency room visit per patient	5.6		1.1		2.6		
Total inpatient admissions	114	42.9	152	57.1	266	100	
Average admissions per patient	1.8		1.2		1.4		
Total hospital days	757	42.3	1,033	57.6	1,790	100	
Average hospital days per patient	11.6		8.0		9.2		
Total clinic cost	0	0	\$24,544	100	\$ 24,544	100	
Average clinic cost per patient	0		\$190		\$127		
Total emergency room cost	\$86,380	69.4	\$38,067	30.6	\$124,446	100	
Average emergency room cost per patient	\$1,329		\$295		\$641		
Total inpatient cost	\$721,613	53.7	\$622,982	46.3	\$1.344.594	100	
Average inpatient cost per patient	\$11,102		\$4,829		\$ 6,931		
Total cost	\$807,993	54.1	\$685,592	45.9	\$1,493,584	100	
Average total cost per patient	\$12,431		\$5,315	• • •	\$7,699		
Total patients	65	33.5	129	66.5	194	100	

health care clinics in the area. Since there are more than 600 physicians, 3 nonuniversity hospitals, and other health care clinics in the area, the number of sickle cell patients being followed at any of these provider facilities is extremely small. For the purpose of this analysis, therefore, we have chosen to compare the health care programs at the University of South Alabama facilities only.

Economic analysis. The economic analysis was performed by the staff (M.W.) of the Statistical Support Unit under the supervision of its director

(A.S.). Assistance from the financial departments of the hospitals, emergency rooms, and comprehensive health care clinics was requested. Of 391 SCD patients known to the University of South Alabama facilities, 194 patients used the university facilities during 1989, a year after the Comprehensive Sickle Cell Center was funded by the National Institutes of Health. Data were obtained in the following categories:

- 1. Use patterns: number of visits to each facility;
- 2. Generated charges: fees of physicians and other

This resulted in no patient with zero combined visit.

health care professionals, charges for use of facilities, laboratory and radiology charges, and costs of treatment administered and recorded on the charge sheets for each patient:

- 3. Collected charges: collections from the insurance companies, Medicaid, Medicare, other governmental programs, and payments by the patient or his or her family;
- 4. Reasons for each visit determined from the presenting complaint in the medical record, and discharge diagnoses.

Health care costs described in the results section are generated charges unless specified otherwise.

Statistical analysis. The statistical techniques used in this research include a test for the binomial proportion, two group t tests, and basic descriptive procedures.

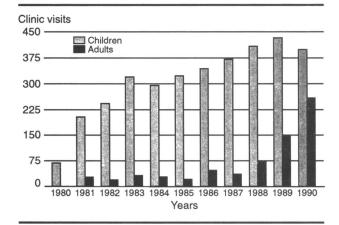
Results

Increase in attendance. As shown in the chart, the attendance (that is, total number of visits) at the Comprehensive Health Care Clinics at the University of South Alabama Comprehensive Sickle Cell Center has steadily increased since 1981 when the program was organized. The growth in the clinic attendance since Federal funding of the program can be partly attributed to expansion of the multidisciplinary team in 1988 and announcements to the community.

Use of health care facilities. Use patterns for emergency rooms, inpatient units, and the Comprehensive Health Care Clinics (combined for children and adults) are shown in table 1. The following results deserve to be emphasized:

- Although the attendance at the clinics has increased steadily (see chart), 33.5 percent of patients seen at the University of South Alabama facilities use the services of the emergency room and inpatient units exclusively and do not attend the Comprehensive Health Care Clinics. The reasons for their choice of emergency room as the primary health care facility are not known.
- A small number of patients visit the emergency room very frequently. For example, during 1989 only 2 percent of patients had a range of emergency room visits of 31 to 100 per year.
- A small number of patients account for a large number of hospitalizations. For example, the hospitalizations of only 2 percent of patients ranged between 11 and 20 in 1989.

Total number of visits by children and adults with sickle cell disease to the Comprehensive Care Clinics of the University of South Alabama Medical Center, 1980–90



Differences in the use patterns and health care costs among sickle cell patients. To examine differences in patterns of use between clinic patients and those who use emergency rooms exclusively, we divided the patients into two groups. Patients who had never visited the Comprehensive Health Care Clinics were included in group 1. Patients with one or more clinic visits were included in group 2. These patients may use emergency rooms and may be admitted to the hospitals for acute illnesses. Table 2 shows results of the analysis of 194 SCD patients who used the health care facilities of the University of South Alabama in 1989.

- Patients in group 1, who do not visit the Comprehensive Health Care Clinics, use the emergency rooms (P = 0.0001) and inpatient units (P = 0.0006) at a disproportionately higher rate than patients in group 2, the clinic group.
- Group 1 also exhibits disproportionately higher health care costs in the emergency rooms (P = 0.0162), inpatient unit (P = 0.0211) and total costs (P = 0.0142). This implies that the health care cost per patient in group 1 is significantly higher than that in group 2.

Sex and age patterns and hemoglobin phenotypes.

There is no sex difference in the patient population between groups 1 and 2 (47 percent males in group 1 and 51 percent in group 2). There are significantly more adult patients in group 1 (mean age = 23.2 years) compared with group 2 (mean age = 12.5 years) (P = 0.0001). This difference is probably attributable to the earlier establishment of the comprehensive pediatric sickle cell patient service at the University of South Alabama Medical Center.

Table 3. Top 10 users (sickle cell disease patients coded by tetter) of health care facilities in number of visits and hospital days,
University of South Alabama Comprehensive Sickle Cell Center, 1989

Rank		ncy reen y patient		ent stays patient		c visits patient		l visits patient		ital days patient
1	A B C D E F G H	99 83 59 44 18 17 17	G D K C L B M N O	19 13 11 11 8 7 7	Q K N R S T U V	36 32 22 22 20 19 19	A B C D K G Q R	101 90 70 58 47 38 36 34	G B L N K R D O	255 109 95 81 76 75 66
9 10 Total	10	13 9 373	10	7 5 95	10	17 16 221	N F 10	29 28 531	M P 10	53 50 916
All users 1	74 13.5	514 72.6	97 10.3	2 66 35.7		649 34.2		1,429 37.2		1,790 3 51.2

¹ Total patients in study who used the facility. 2 Percent of total attributed to top 10 users.

Table 4. Dollar costs incurred by top 10 users (sickle cell disease patients coded by letter) of health facilities, University of South Alabama Comprehensive Sickle Cell Center, 1989

Rank	Emergency reom vielts by patient			inpatient stays by patient		Clinic visits by patient		Total visits by patient	
1	В	\$20,827	G	\$161,985	Q	\$1,566	G	\$166,259	
2	· A	29,001	R	144,405	K	1,054	R	144,405	
3	C	12,336	В	81,558	Т	1,022	В	102,385	
4	Ð	7,655	X	53,432	N	812	D	53,823	
5	F	6,172	L	46,498	Z	725	Х	53,432	
6	8	4,194	D	46,143	Х	609	L	47,477	
7	Æ	3,804	. K	43,543	S	587	K	47,466	
8	H	3,245	. Y	37,543	Σ	575	Υ	37,543	
9	Z	3,196	P	36,826	W	559	Р	37,468	
10	J	3,006	М	35,515	0	551	С	36,432	
Total	10	\$64 ,4 5 3	10	\$6 87,447	10	\$8,060	10	\$726,689	
Total patients 1		124,446 3.5 \$7.8		1,344,594 0.3 51.1	129	9 24,544 8 32.8		1,493,584 5.2 48.7	

¹ Total patients in study who used the facility. 2 Percent of total attributed to top 10 users.

Hemoglobin phenotypes of patients in this study includes Hb SS, Hb SC, Hb S β ° that, Hb S β ° that. Hb S β ° that. Hb SS and Hb SC are the predominant hemoglobin phenotypes of patients in both groups, which account for 89 percent (Hb SS = 75 percent) in group 1 and 87 percent (Hb SS = 70 percent) in group 2. No statistical difference was detected in patients with these two phenotypes between these two groups (P = 0.7700).

Types of sickle cell complications that were treated in emergency room and hospital. The most common sickle cell complication that was treated in both the emergency room and hospital was vasoocclusive pain crisis. Painful attacks account for 94 percent of emergency room visits in group 1 and 79 percent in group 2. This difference is statistically significant

(P < 0.0001). It reflects the difference in patterns of using health care facilities by these two groups of patients. Those who had no clinic visits (group 1) utilized emergency rooms as their primary facility for the care of pain crises much more often than those who had clinic visits. Twelve percent of patients in group 2 visited emergency rooms because of infectious complications compared with only 2.3 percent in group 1. Most of group 2 are pediatric patients who are more likely to have infectious complications. Parents of young sickle cell patients are instructed to seek immediate medical attention when the child develops fever or other symptoms of early infections. Fifty-nine percent of the hospitalizations in group 1 were due to pain crisis, compared with 68 percent in group 2. There was no statistical difference between these two groups (P = 0.1600).

Identification of high utilization-expense group. To identify a group that uses the more expensive health care facilities, we examined several categories of high utilization and expenses: (a) most frequent visitors to the emergency rooms, (b) persons most frequently hospitalized, (c) persons with most hospitalization days, and (d) those with high health care costs. In each of these four categories, the top 10 persons were identified and compared with others. Most patients in tables 3 and 4 had at least one overlap with other categories. Thus, it is possible to identify a small group of people who use the emergency room and inpatient units more frequently and contribute to high health care costs. Six of the 10 users with the highest overall cost were from group 1, people who had never visited the comprehensive care clinics. Some persons may be in the top 10 because they have a more severe form of the disease that requires assistance from the emergency room and the hospital. However, reasons why persons attend only the emergency rooms but are not part of the comprehensive health care programs are not known. Eightyeight to 100 percent of the top 10 users by cost visited the emergency room because of pain crisis. Almost all hospitalizations (92 out of 95) of these 10 patients were for the management of a pain crisis.

Description of health care costs. The mean clinic care expenditure was \$190 per patient per year, or \$43 per visit. In addition, the expenditure by the sickle cell association to provide social services, career counseling, and supportive services was \$63 per patient seen in the Comprehensive Health Care Clinics. Inclusion of sickle cell association costs did not change the interpretation of the overall health care costs data analysis. Emergency room visits cost \$1,682 per patient per year, or \$270 per visit. Average hospitalization costs were \$13,862 per patient, or \$4,417 per hospitalization.

Total health care costs billed in 1989 were \$1,494,584. Of these, \$657,737 (or 44 percent) were collected. Fifteen percent of patients were responsible for 77 percent of the total health care costs related to sickle cell disease. Although 75 percent of patients had health care costs below \$6,054 per year per person, one patient accounted for \$166,259 of health care costs in 1989.

Discussion

Consideration of health care costs is necessary for health planning and policies on a national scale (1). On superficial analysis, the services of multidisciplinary teams and social support of a community program

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may appear to be more expensive compared with a single physician providing care to a patient in a clinic, in an emergency room, or a hospital. Health care in the emergency rooms and inpatient units, however, is more expensive compared with comprehensive health care in the special outpatient clinics, as shown in this study. National health policy decisions such as limitations on expenditures of Medicare and Medicaid funds and payments according to Diagnosis Related Groups influence an individual patient's health care and presumably his or her quality of life (8). Limits on outpatient visits, services of multidisciplinary teams, preventive care, and psychosocial support may be counterproductive to the national health care expenditures if such decisions result in increased overall costs.

Costs of health care are usually supported by a variety of methods including (a) personal resources of the patient or his or her family, (b) private insurance organizations, or (c) governmental programs supported by taxes. Since the personal resources of the patients with SCD and their families are usually limited, and private insurance coverage is available to only a very small proportion of SCD patients, governmental programs are usually necessary to support the institutions providing health care to SCD patients. Only 44 percent of health care costs were collected through third party payments, including those from governmental programs such as Medicaid and Medicare at the University of South Alabama. Improved funding for health care for chronic diseases, especially in the socioeconomically disadvantaged populations, should be seriously and urgently considered.

In this study, patients enrolled in the comprehensive health care program used emergency rooms and hospitals less often and utilized fewer health care dollars compared with patients who never attended the clinics. The reasons for differences in the utilization patterns and health care costs among sickle cell patients enrolled in the clinic and those not subscribing to the clinic are not clear. It is possible

that the two groups differ in severity of their disease; those not attending the clinic may be more severely ill and, therefore, exhibit increased utilization and costs. However, this explanation is unlikely. The Comprehensive Health Care Clinics are open to all patients, including those severely affected. An informal analysis of patients seen in the emergency rooms and Comprehensive Health Care Clinics fails to reveal obvious differences in the physical status of patients in the two settings. Other reasons for differences in utilization patterns could include lack of awareness about the comprehensive health care program (despite numerous announcements), lack of appreciation of the advantages of the program, lack of transportation, inability to attend the clinics due to inconvenient working hours, or lack of referral from emergency room staff.

A very small proportion of patients may visit the emergency room to obtain prescriptions for controlled narcotic agents that may be managed differently in the Comprehensive Health Care Clinics. A survey of patients and their families and the staff of the emergency room is planned to investigate the causes of the current utilization patterns.

Economic analysis of health care programs is quite complex. In the most complete schema, inputs should include (a) direct costs to the health care sector and to the patients and their families, (b) indirect costs in production losses when people are withdrawn from the work force to receive treatment, and (c) the intangible costs associated with therapy such as pain and suffering. Measurement of indirect and intangible costs is quite complex and, although desirable, is controversial and expensive. Sickle cell patients with varying degrees of physical abilities and skills may be able to work in certain situations but are unable to find employment for various reasons. Actual lost wages of a never-employed sickle cell patient may be considered zero. However, "potential" lost wages of a patient who should be employed but is not able to find employment because of misinformed employers are difficult to calculate.

The *output* or results of this health care program may be considered in a variety of ways. Benefits, usually expressed in dollars, although not without controversy, would include savings in direct medical care costs resulting from improved health or production gained from an earlier return to work. Pediatric patients are usually not employed immediately after receiving health care and, therefore, present a unique challenge in terms of determining the potential benefit over their life time. One can use life tables to determine survival and income tables for various populations to calculate such benefits. Income dis-

parities exist, however, between white and black populations.

Further, reliable data concerning survival and potential income of sickle cell patients in varying states of health are not available. Similarly, intangible benefits such as patients or families feeling healthier are quite difficult to convert into dollars just as is converting the cost of pain and suffering into money units. One way around the problem of valuation of health improvements is not to attempt converting them into money units but to measure "effectiveness" of the treatment and describe "cost-effectiveness." This can be further simplified by limiting the calculation of costs to direct costs.

Since charges by health care providers and payment policies in various States are nonuniform, it is not possible to extrapolate our experience to sickle cell programs in other areas. The general principles demonstrated in this study, however, are probably applicable in other situations. We are currently in the process of assessing "quality of life" of sickle cell patients enrolled in the Comprehensive Health Care Clinics and will attempt to evaluate improvement in "quality of life" in relationship to the direct costs of the program.

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