Based on a study of the cost of medical care of children with cystic fibrosis in the Yale Cystic Fibrosis Program, data was obtained on overt and hidden costs of this chronic illness, and the impact on the family was assessed. The need to protect the economic security of families with such children is stressed.

CYSTIC FIBROSIS: ECONOMIC IMPACT UPON THE FAMILY

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IN the autumn of 1969, Connecticut families of children with cystic fibrosis (C/F) were confronted by an economic crisis. This was consequent to a redistribution of funds administered by the Crippled Children Section, State Department of Health, for medical care of children with chronic illnesses, including cystic fibrosis. Termination of financial assistance for approximately one-third of children followed in the Yale Cystic Fibrosis Program aroused acute and appropriate apprehension within the clinic population. There was fear that the complex medical needs of the children could not continue to be met and that the educational, social and psychological needs of other family members would be compromised by the strain on family resources. Several families had been instrumental in influencing the legislature to enact the original bill under which public health funds were appropriated for children with cystic fibrosis. Most families had been encouraged by medical and clerical personnel to avail themselves of such funds to ameliorate the manifold stresses associated with this potentially grave disease. They had not been encouraged to explore alternate sources of assistance, and most were uninformed concerning the cost of the medication, treatment apparatus, diagnostic studies and hospital care that had been, or might in the future be, required by their children.

The medical regime recommended in the Yale Cystic Fibrosis Program included: bimonthly clinic visits for medical examination and bacteriological studies; semiannual x-rays of the chest; medications, including pancreatic enzymes, vitamin supplements, expectorants and antibiotics; a pulmonary regimen, including twice-daily postural drainage, inhalation of aerosols from a nebulizer and nightly use of a mist tent. Exacerbations of the child's symptoms necessitated even more intensive medical care.

No systematic data were available concerning the costs of such care. It was unclear what proportion of total medical costs Crippled Children Section funds had covered and what proportion had or could be covered by medical insurance benefits available to these families. A survey by questionnaire was undertaken by the Cystic Fibrosis Association of Connecticut to determine what insurance benefits were available to Connecticut families of children with cystic fibrosis. The Department of Health initiated studies directed towards establishing a scale of financial eligibility for assistance compatible with the available budget. Concurrently, a study of cost of care was

Table 1—Distribution of paid supplementary employment among study families

Pattern of employment	Percentage of families
1. Father alone earned supplementary income	38%
2. Mother alone earned supplementary income	17%
3. Both parents earned supplementary income	24%
4. Neither parent earned supplementary income	21%
Total	100%

undertaken in the Yale Cystic Fibrosis Program.

Methods

The cost of medical care of 62 children followed in this center over a one-year period (September 1, 1968 through August 31, 1969) was examined. Excluded from the study population were the following children: 1) those first known to this center during the sample year; 2) those who moved to other states during the year; 3) those who expired during the year; 4) those who were hospitalized in other centers during the year. Medical records were examined to determine the number of clinic visits, x-rays, laboratory studies and days of inpatient care associated with cystic fibrosis experienced by each child and the nature and amount of medications prescribed. Costs were computed on the basis of charges prevailing in this medical center in the autumn of 1969.

A questionnaire concerning costs of care not reflected in medical records was completed by parents of 60 per cent of the study population. Items included in the questionnaire were those which parents had indicated to be particularly significant in interviews with the author. Data concerning family composition, employment patterns and family life-style in the total study population were derived from the questionnaire and from parent interviews. Data concerning family income were derived from parent interviews and summary records of the Department of Health. Data concerning medical insurance were derived from the Connecticut Cystic Fibrosis Association survey, from parent interviews and from inquiries to the major insurance companies. (Difficulties were experienced by many parents in obtaining precise information about their policies. Responses to personal inquiries were often ambiguous. Written policy statements were difficult to interpret. Considerable assistance and clarification was given by the Executive Director of the C/F Association.)

Findings

Population Characteristics

The study population included 62 children in 54 families, 8 families having two children with C/F. Family residences were widely dispersed throughout the state. Mean size of the primary

Figure 1—Distribution by cost of medical care obtained in Yale-New Haven Medical Center

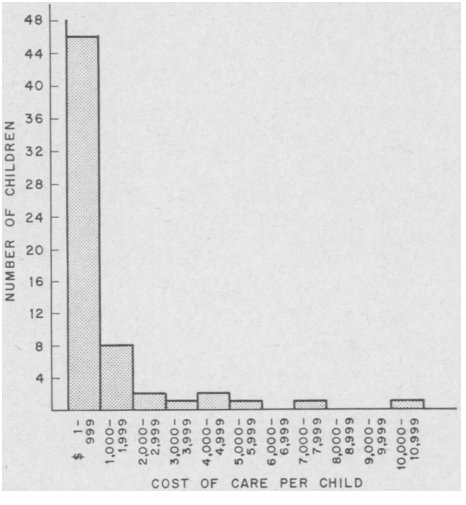

Table 2—Mean costs of medical care by category

Nature of charges		Mean cost
Comprehensive inpatient care		$ 522
Comprehensive outpatient care		$ 703
Outpatient visits	$ 74	
X-ray (outpatient)	$ 48	
Laboratory (outpatient)	$ 51	
Medications (outpatient)	$530	
Total		$1,225

family unit (parents and children) was 5.0 persons. Mean age of the father was 36 years. Mean age of the oldest child was 11.6 years. Mean gross family income was $9,700. Proportions of families engaged in paid employment supplementary to the father's base full-time employment are shown in Table 1.

It is seen that in 79 per cent of families one or both parents engaged in supplementary employment (fathers either engaged regularly in paid overtime work at the primary place of employment or held second jobs).

Costs of Care of Children with Cystic Fibrosis

The distribution of costs of medical care in this center among the study population is shown in Figure 1. The median cost for the total group was $619. The mean cost was $1,225. The disparity between the two figures reflects the influence of costs for children requiring intensive care and hospitalization during the study period. To illustrate, a significant disparity was demonstrated between costs for children requiring outpatient care only and those also requiring hospitalization. The mean cost for the 51 children requiring only outpatient care was $603. The mean for the 11 children requiring outpatient care and hospitalization was $4,111. Unfortunately, it must be expected that a C/F Center population will include a proportion of children requiring intensive care during any sampling period. Furthermore, the mean cost is in fact lower than that required for optimal medical care, since some families failed to comply fully with medical recommendations. Their children had fewer clinic visits and diagnostic studies than was advised.

An analysis of the mean cost of $1,225 for the total study population in terms of separate categories of medical care is shown in Table 2.

Mean costs of medical and paramedical care incurred outside of this center are shown in Table 3.

Items 1 and 2 in Table 3 reflect the geographic dispersal of the population or, viewed alternately, the centralization of specialized medical care for C/F patients. That is, when concern about the child was aroused, families living far from the medical center might consult their local physician either prior to or instead of bringing the child to the center. Expenses associated with clinic visits included loss of pay to either or both wage earners, car expenses, parkway tolls and parking fees and cost of care of siblings of the patient. Item 3 represented cost of operating the mist tent and associated air conditioner if required, replacement or repair of the equipment and repair of moisture and mildew damage in the environment. Item 4 reflected the large appetite and poor tolerance of

Table 3—Mean costs incurred outside of medical center

Source of cost	Mean cost
1. Medical care outside medical center	$130
2. Expenses associated with clinic visits	$106
3. Expenses associated with pulmonary therapy	$195
4. Extra cost of food	$227
Total	$658

Table 4—Variable costs of paramedical care

1. Premiums paid on medical insurance
2. Premiums paid on life insurance for child or equivalent savings
3. Purchase of therapeutic equipment (electronic nebulizer, mist tent, tilt-table for postural drainage, electric vibrator)
4. Fees to visiting nurse to give intramuscular injections of antibiotics
5. Long-distance phone calls to physicians at medical center
6. Dental care associated with tooth staining from medication
7. Transportation and loss of pay to visit child when hospitalized
8. Custom clothing for children with severe growth retardation
9. Increased cost of housing to provide child in mist tent with separate bedroom

foods with high fat content observed in many children with C/F. In particular, the cost of high quality, lean meats was cited.

In addition to the above costs which occurred with regularity in the C/F population, additional expenses are listed in Table 4. These are items which could become extremely significant but were too variable within the population to be reflected in meaningful averages.

Although the need for medical insurance is not exclusive for children with cystic fibrosis, it is particularly urgent for such a group. Families not covered by group insurance plans made available through their employers found the cost of premiums to run as high as $40–$50 per month for policies purchased independently. Life insurance was unavailable for most children with cystic fibrosis. A program of systematic savings to serve an equivalent purpose was viewed by some families as essential. Items 3–7, highly variable in cost, are self-explanatory. Item 8 reflected the growth retardation often associated with cystic fibrosis. In a survey of growth attained by 24 patients 12 years and over followed in this center, it was determined that 47 per cent of males were at or below the 3rd percentile for weight and 27 per cent were at or below the 3rd percentile for height. Among females, 67 per cent were at or below the 3rd percentile for weight and 56 per cent for height.[1] An occasional patient could, in young adulthood, have the stature and foot-size of an elementary school child. Clothing and shoes combining correct size and appropriate style were costly.

Item 9 reflected several aspects of life with a child with cystic fibrosis. Families whose child slept in a mist tent reported marked difficulties in obtaining housing on a rental basis. Certain models of the compressor produced intrusive noise and the moisture resulted in environmental damage. Thus, the purchase of housing assumed urgency. There was difficulty in assigning a shared bedroom to a child with cystic fibrosis and a sibling. Not only the mist tent, but the nocturnal coughing often associated with the illness could constitute serious disturbances for a "roommate."

The majority of items in Table 3 and Table 4 can be viewed as hidden costs of this chronic illness. Many cannot be covered by insurance or listed as deductions in computing income tax.

Insurance Coverage

Distribution of coverage by medical insurance is shown in Table 5.

It is seen that 69 per cent of the study population were covered by primary and/or major medical insurance covering hospitalization and were therefore reasonably well-protected against catastrophic expenses. Thirty-one per cent had no such protection. Only one child in the latter group was eligible for Medicaid benefits during the study period.

Among those covered by major med-

ical policies, only 46 per cent (25% of the total study population) had benefits available for comprehensive outpatient care including clinic visits, diagnostic studies and medication, the mean cost of which was $703 (Table 2). In these instances, the family was responsible for a deductible base varying from $60–$500 per annum. Benefits covered a proportion (usually 80%) of the balance.

Discussion

Having an estimated incidence between 1 per 1,000 and 1 per 2,000 live births, and with life expectancy being extended by increasingly effective medical management, cystic fibrosis is now an important public health concern. A picture of the average family of a child followed in the Yale Cystic Fibrosis Service between September 1, 1968 and August 31, 1969 has emerged. The father was 36 years of age, and had two children in addition to the child with C/F. The oldest child was 11.6 years of age. Father and/or mother was engaged regularly in employment supplementary to father's basic occupation.

Total gross family income averaged $9,700. This income was above the level allowed for a family of five under Crippled Children Section eligibility standards in the autumn of 1969. Therefore, the industriousness of such a family could, in effect, be penalized. That is, the increment in earnings derived from supplementary employment could render such a family ineligible for assistance. Medical expenses for the child could then readily offset the increment in earnings. The average income compared unfavorably, however, with the amount of $12,574 which the Bureau of Labor Statistics deemed necessary for an urban Connecticut family of comparable composition (family of five persons, age of head 35–54 years, age of oldest child 6–15 years) to maintain an "Intermediate Standard of Living" in the spring of 1969.[2]

Such a family endured the chronic grief and apprehension associated with having a child with a potentially grave disease which could pervade every aspect of family life.[3,4] With each successive phase of childhood development, the family faced new challenges in helping the child with C/F adapt to his illness and its complex treatment. Almost 1½ hours each day had to be devoted to the therapeutic regimen, in addition to the time invested in obtaining medical care. The needs of the children free of C/F had nonetheless to be met. Although such a family could afford few (if any) luxuries, household appliances, such as an electric clothes dryer and a bedroom air conditioner were necessary to offset the effects of the mist tent. With the limited availability of adequate public transportation within the state, such a family might find it essential to operate two cars so that the mother could have prompt access to medical care for the child while the father was employed.

Recreational activities were essential for psychological replenishment. However, one parent was likely to be employed during the evening hours. Therefore, opportunities for gratifying marital interaction were reduced and the par-

Table 5—Distribution of coverage by medical insurance among study population

Nature of coverage	Percentage of population
Children covered by primary medical insurance only	14%
Children covered by major medical insurance	55%
Children excluded from family medical insurance	9%
Children in families without medical insurance	22%
Total	100%

ents seldom enjoyed an evening out together. For financial reasons, and because of the complexity of the child's symptomatology and treatment, such a family took vacations away from the household only once in many years.

Coping with these continuous stresses, such a family was confronted with the depleting financial drain of the illness. According to a recently published formula, cost of medical care should be considered catastrophic when it equals 15 per cent of gross family income less $50 for each family member.[5] Therefore, cost of medical care for the *entire family of five* with an income of $9,700 would be considered catastrophic at the level of $1,205. In fact, average cost of medical care (private and in the medical center) *for the child with C/F alone* was $1,355 excluding cost of medical care for conditions unrelated to C/F. Including paramedical expenses, the total amount equaled nearly one-quarter of such a family's low moderate income.

It was noted that almost one-third of study children were unprotected by medical insurance (Table 5), and only one-fourth had sufficiently comprehensive coverage to include outpatient expenses and medication. It is therefore evident that whatever system of distribution will prove most effective, it is essential that medical care funds not subject to the vicissitudes of the political climate be made available for such families. Appropriate attention is currently being directed towards the health needs of those living in poverty. However, grave danger exists that while this segment of the population is being assisted, families who have been able to attain a moderate income by full utilization of their earning capacity may be reduced to the poverty level by chronic health problems such as cystic fibrosis.

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