Family Caregiver Costs Of Chronically Ill And Handicapped Children: Method and Literature Review

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Synopsis

Studies to date on the costs to family caregivers of children with chronic diseases and disabilities were surveyed. The survey was conducted in the context of an economic framework, which set cost categories and definitions as well as causal factors influencing costs. Emphasis was placed on variations in costs, and in particular on identifying those categories of families whose cost burdens are high.

The analysis indicated a high cost burden for families in all disease categories studied, although a lack of uniformity in data presentation and in the variables studied prevented specific generalizations to be made about the numbers or characteristics of families with high costs. Suggestions are made for increasing the uniformity of data in future studies.

THE METHODOLOGY of medical care cost measurement has been widely studied (*1–3*) and applied, resulting in a large literature on the costs for many illnesses, including those of children. Despite the number of such studies, insufficient research has been undertaken on the magnitude of costs imposed on families as caregivers for chronically ill and handicapped children.

The costs can be considerable for both individual families and on a national basis (*4–6*), yet there is little understanding of their size and impact. From a policy standpoint it is important to know more about the costs and the circumstances which influence them. Depending upon how the burden of cost falls, a case can be made for tax deductions and credits, or subsidies.

The question of institutionalization is closely tied to family caregiving costs; if families cannot afford home care, they may choose institutionalization, which may increase the cost to society.

The issue of family caregiving costs is important for another, related reason. Policy makers are inundated with data on program costs. Legislators make decisions about policy based on program data and program contributions to public expenditures. But the costs to the family are usually hidden and overlooked. Although hidden costs are costly to assess, they are real nonetheless, and from a public welfare standpoint they deserve full recognition. We need to recognize that family costs and program (including institutionalization) costs are related.

In that context, cost cutting may be cost shifting: policies relating to programs and institutions affect the family costs of chronically ill and handicapped children. Private and public data need to be linked: the object of social policy should be to minimize the total cost, not just the cost of publicly provided services. This line of reasoning may argue for some financial support for home caregivers to help avoid unnecessary and expensive long-term institutionalizations.

We first present an overview of the methodology for estimating and analyzing family costs. Peculiarities of family care for the populations under consideration are addressed in the second section. One characteristic is the wide variations among families, making it important to know their causes or determinants. In the third section, we examine the development of cost-time profiles, as well as other determinants which influence costs. Next we review the literature on family caregiver costs for these populations. We examine the studies with regard to the method followed in establishing costs, the magnitude of the costs reported, and the determination of causes of variations in costs

among families. Lastly, we discuss some implications of the results of the studies.

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Cost Determination Methodology

Our prime concern was the incremental costs which families incur as a result of undertaking the caregiving function for chronically ill and handicapped children. Incremental costs refer to the economic burden related to caregiving functions, which are in addition to those which would have been incurred in the absence of the condition. Costs can be direct expenditures (money outlays), as well as indirect costs, which are costs resulting from lost opportunity. Direct expenditures can be for medical services (physician care, hospitalization, and the like), or for a variety of other equipment and services. We focused on all costs, direct and indirect, other than medical care costs; for a discussion of medical care costs for the populations under discussion, see references *7* and *8*.

Family caregiver costs were separated into (*a*) direct (out-of-pocket) home costs on recurring items, (*b*) direct travel costs related to the patient's condition, (*c*) costs for durable equipment and home renovation, and (*d*) indirect costs for transportation, caregiving, and other functions.

Costs in the first category, direct recurring home costs, include expenditures on adaptive aids for toileting, feeding, and learning; child care; special clothing; telephone; and supplies for incontinence, feeding, and respiration enhancement (see reference *6* for a complete listing). Costs in this category are measured by direct expenditures. When costs would be incurred for a child with or without the condition, the measured costs for the subject families should be those which are in excess of the typical level of costs. Incremental costs may not always be separable from the usual family expenditures, and in the absence of large and expensive controlled experiments, can only be roughly estimated.

Direct transportation costs include outlays for automobile fuel and maintenance. Indirect transportation costs are the costs for time spent in transporting the child. The costs are usually reported in the fourth category, indirect time costs. If, instead, the indirect costs are included in a single transportation cost figure, they need to be reported separately from the direct portion of transportation costs.

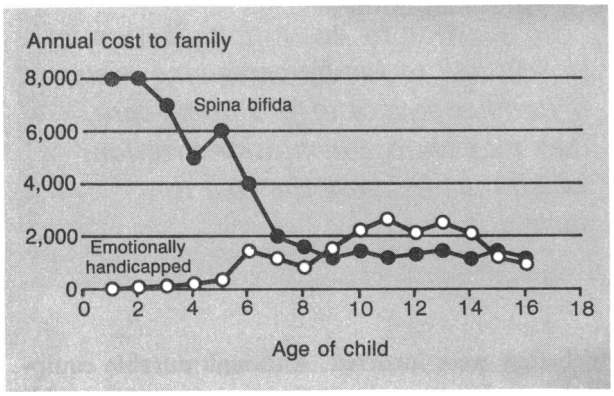
The costs of durables which last more than a year (such as wheelchairs and braces) and of home renovations were treated as outlays in the year in which they were incurred. Although durable equipment lasts for several years, our interest was with the economic burden imposed on the family, which usually occurs in the year the equipment was purchased.

The final cost category is imputed time costs. Family members give up time from work and other activities in order to provide care for the child. Usually studies focus only on the time lost from work and place a value on it equal to how much family members would have earned had they worked. Forgone leisure time is seldom included, although it has value because other activities were forgone which the family member might have preferred. There are several measurements of the value of lost leisure time, but perhaps the most reasonable is to determine the caregiving activities and apply a market price (the price which it would have cost to purchase the activities). In practice, this has not been done in this type of study (*9*).

Caregiver costs are presented either as absolute values per period (such as $67 per week, or $3,000 per year) or as relative to some total income figure (such as 20 percent of income). A frequently made error should be noted. If out-of-pocket expenditures are compared to some income figure, it is appropriate to compare them to money income earned; this ratio would then show the proportion of income earned that was paid out in caregiving expenses. It is not appropriate to view out-of-pocket expenses and foregone earnings (or foregone earnings themselves) as a proportion of money income. Foregone earnings are not part of money income; they are money income lost. Money income must be added to money income lost to create a new measure, potential or full income. Foregone income is part of this concept and can be compared to it.

Virtually all studies use logs or questionnaires, accompanied at times by interviews. Because of the time-consuming nature of record keeping, often data are collected for a very short period, such as a

Hypothetical cost-age profiles



week. If the sample is large or representative enough, an accurate picture should be obtained. However, if data are collected for unrepresentative periods, biases occur. For example, if data on the care of handicapped children are collected during summer, when children are not in school, the time and other cost estimates of caregiving will differ considerably from those obtained when school is in session. A more accurate picture results from considering both periods.

Variation in Caregivers' Costs

All studies in this area report wide standard deviations relative to mean values of family costs, indicating that some segments of the sample of families incur high costs. Much of the policy relevance of this subject is predicated on the fact that some families incur very high costs. Standard deviations and ranges do not provide sufficient information to assess policy relevance, however. It is important to know the frequency distribution of the numbers of families with regard to costs incurred. Few studies have reported this.

An important method for analyzing variations is cost-time profiles. Such profiles set out annual costs during a period of years. The profile might relate annual costs to the age of the child or annual costs to the time from the onset of the illness (as with cancer).

Two hypothetical profiles are shown in the chart. The profile for spina bifida patients shows heavy family expenditures up to about age 8, moderating after that (based on information in reference *10*). A profile of family expenditures for severely emotionally handicapped children will show a different pattern, with low expenditures until about age 8, followed by high ones until about age 14, then leveling off somewhat (*11*). Information on these profiles would be useful in determining causes of family expenditures.

An important point in developing such profiles is that chronically ill and handicapped children frequently will be cared for long after normal children have left home. An age-cost profile needs to reflect this, and to be extended to ages beyond which normal dependence ceases.

In addition to time-cost profiles, factors influencing the variation in caregiver costs can be categorized as economic, social, disease, and treatment factors. Economic factors can be broken down into out-of-pocket price, income, and other cost variables. Out-of-pocket price refers to the portion of money outlays incurred by the caregiving family. The price is influenced by the amount of insurance coverage which the family has in specific areas, by the availability of government subsidies, by the actual price charged for the services and commodities, and by the income tax deductions allowed for direct expenditures on these items. Income usually is reported as gross income, although to the extent that tax deductions exist, there may be some biases in this measure. Other costs refer primarily to time costs. Travel costs will be affected by the location of the family in relation to providers of care, as well as to whether or not the family has an automobile. The other major time costs are waiting costs, which are affected by the availability of services (for example, how crowded the services are and providers' hours of operation).

Social factors refer to other variables indicating the social circumstances of the caregivers, such as the number of children in the family, whether or not the family is a single-parent unit, and the level of education of the parents. Disease factors refer to variables relating to the diagnosis of the patient and to the stage of the disease. Treatment factors refer to the methods and timing of treatments. Timing is important since treatments may vary in degree of intensity (such as the amount of chemotherapy or physiotherapy), which influence costs.

Review of the Literature

The table shows characteristics of six studies on family costs for chronically ill and handicapped children, although not all provide sufficiently complete information to permit a full determination of costs and the factors associated with their variances.

Listed are the diseases involved in the study (such as cancer or spina bifida); the number of

Characteristics of data provided by six studies of financial burden to caregiving families

Characteristics	Gordon (10)	Lansky (12)	Bloom (13)	Houts (15)	Bodkin (16)	McCollum (14)
Disease considered	Spina bifida	Cancer	Cancer	Cancer	Cancer	Cystic fibrosis
Number of patients observed	702	70	569	139	59	62
Time period observed	7.5 years	1 week–3 months	1 week, May–Oct.	3 weeks	1 week, NS	1 year
Costs included:						
Direct home	Yes	Yes	Yes	Yes	Yes	Yes
Direct travel	No	Yes	Yes	Yes	NS	Yes
Durable equipment	Yes	No	No	No	Yes	Yes
Time cost	No	Yes, 0	Yes, 0	Yes	No, 0	No
Annual money cost	...	$3,324	$4,012	$1,121	...	$334
Annual time cost	...	$1,924	$4,697	$1,514	...	...
Money cost divided by money income	...	14 percent	15 percent	...	...	
Total cost divided by full income	...	37 percent	28 percent	...	20 percent	...

NOTE: Under costs included, *yes* indicates that the cost category was included in the study; *no* indicates it was not. *O* indicates that the cost category was included, but was placed in another cost category in that particular study. *NS* indicates not specified.

patients observed in the study; the period during which patients were observed; and the categories of costs, and whether they were included in the study.

Information on the period of the observations is important in determining biases, as in the case of observations only being recorded during the summer. Since annual costs are the average of those incurred during the school year and vacation, those which are measured should be an average as well.

The cost categories include direct home costs, travel costs, durable equipment and other capital costs, and time costs. If the cost category was included in the study, *yes* is shown; if not, *no* is indicated. A zero indicates that the time cost was included, but was placed in another cost category; for example, time costs were sometimes included with total travel costs. *NS* means the study did not specify whether the category was included.

There was no uniformity among the studies from a methodology standpoint. The four cancer studies had 1-week observation periods. The observations of Lansky (*12*) appeared to be representative of the whole year, having been taken during a longer period. The observations of Bloom (*13*) were made from May through October; this period includes summer vacations, and costs incurred during this period may be different from those incurred during school time. No study calculated potential or full income, as defined previously. We calculated this, however, when sufficient data were available. Durable expenses were calculated in two studies, McCollom (*14*), and Gordon (*10*). One study (*15*) included children and adults and did not separate children; we included it because it contains useful information, but we could not distinguish childhood costs in the results.

As seen from the table, childhood cancer was most often studied. Two studies in the United States (*12,13*) show substantial money and time costs for cancer patients. Money costs for the two samples were of the same order of magnitude (especially when allowing for the 6-year difference between the studies). The time costs reported by Bloom (*13*), however, were more than twice those shown by Lansky (*12*). Lansky's categories were perhaps broader than Bloom's, who showed losses which referred only to costs associated with accompanying the children to the hospital. Lansky referred to time losses from all illness-related functions. The fact that a large proportion of Bloom's observations were made in vacation time would cause differences in costs if all other values were the same, but the fact that the scopes of their inquiries differ makes comparisons of these studies difficult.

Differences aside, the cancer studies showed a substantial toll on families. Note that the heavy burden is not strictly a function of the welfare system in the United States; the single United Kingdom study (*16*) showed family costs as a proportion of income to be of the same order of magnitude as in the United States. Since the United Kingdom is usually believed to have a broader social welfare system than the United States, this raises some important questions about the design of welfare systems to meet the needs of specific groups.

The cystic fibrosis study (*14*) showed a significant burden as well, although less than for cancer.

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No firm conclusions could be reached from the spina bifida study.

All studies reported great variations in the distribution of costs and their causes. Only McCollum (for cystic fibrosis patients) showed an actual frequency distribution by level of expenditures (*14*). The distribution showed that, for 62 patients in the sample, 7 incurred annual expenditures in excess of $2,000, and 8 incurred from $1,000 to $2,000. Although the figure lumps both medical and nonmedical expenditures, this shows that (at 1969 price levels) a substantial number of families with children with cystic fibrosis incurred significant cost burdens.

The data for families with children having cancer are impressive. Although none of the studies for this disease reported actual frequency distributions, some idea of the orders of magnitude can be inferred from specific cross-tabulations. Lansky (*12*) reported that the 12 families with the longest distances to medical centers incurred costs in excess of $6,000 a year, while the 10 families whose children had the most severe restriction of activity averaged nonmedical, out-of-pocket expenditures in excess of $4,000 a year. Bloom reported that families with children with Hodgkins disease, bone cancer, and soft tissue carcinoma averaged annual, out-of-pocket expenditures of between $15,000 and $17,000 (*13*). Gordon showed high standard deviations for 7-1/2 year costs for wheelchairs, disposables, and braces (*10*), but the lack of explicit reporting precludes drawing any inference about the actual distribution.

Several studies identified one or two key causes of variations. However, since in none of the studies were the methods reported explicitly, it was impossible to assess the studies fully in this regard or to draw generalizations from them. Lansky reported distance from care, the size of the family, marital status, degree of disability of the patient, and mode of treatment (whether or not hospitalized), as being important (*12*). Bloom was the only researcher to give time profiles (*13*), reporting a significant drop in mean annual total costs with increasing time since diagnosis. Costs increased with annual family income, but the authors noted a lack of statistical relationships between causal variables and costs. The Houts study highlighted the importance of the treatment regimen (in this case whether or not chemotherapy was being administered) (*15*).

Summary and Conclusions

Our results show, first, the small number of studies that have been undertaken on cost burdens of families. Yet, those that have been done showed the enormous burden of certain childhood illnesses on family caregivers. In the case of cancer, even the mean value showed an enormous burden on families with children with that disease. However, the mean is not always a good indication of the burden. For example, 8 families out of a sample of 62 observed by McCollum incurred overall costs (including medical) related to cystic fibrosis of more than $2,000. Mean out-of-pocket costs for children with selected types of cancer were more than $15,000.

There has been a trend in analyzing Medicare costs toward focusing on high-cost patients (*17–20*). The facts emerging from the studies, which indicate a crippling financial burden for a small but significant portion of the population, have influenced the recent enactment of catastrophic health insurance for Medicare patients. The burdens on families with handicapped or chronically ill children are no less real. Once additional evidence on the magnitudes and incidence of these burdens is made clear, a case for similar type policies may be made (*21*).

One problem uncovered in the present survey, which must be overcome before generalized results may be obtained, is the lack of uniformity among the studies with regard to the categories of costs, survey methods, and variables used to explain cost variations. From a methodology standpoint, the studies were probably strongest in reporting costs by categories, although in some cases it was difficult to distinguish between categories. Categorizing costs is important because different categories of costs, such as time and durable equipment costs, may be influenced by different causal variables. The survey methods are important, because a nonrandom survey can result in a biased result.

Variations in costs should be explicitly reported, preferably using frequency distributions. The statis

tics on high cost burden families are of particular policy significance. Finally, underlying causal factors should be examined more explicitly and systematically. Not being able to apply uniform methods of analysis eliminates the ability to assess results and to generalize. Subsequent investigators will not have a roadmap from which to work if they do not have access to the research methods of previous investigators. We have suggested a classification of causal variables, and have highlighted those we believe to be of particular significance (especially the age-time profile).

As of now, only rough guesses can be made regarding the distribution of costs as well as cost-age profiles and other causal variables. Yet this information is important from a policy standpoint, in that it can help to identify target groups concerned with specific diseases for which public assistance of some form is important. Until more studies are undertaken in a systematic way, we will not have a clear idea of how public policy can be framed where it appears to be negligent.

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