

The Economic Burden of Home Care for Children with HIV and Other Chronic Illnesses

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Approximately 10% to 18% of US children are affected by moderate-to-severe chronic illness, and the rate is increasing.^{1–4} New health care technologies, the emphasis on controlling costs, and adverse effects of hospitalization on children encourage the use of home care for chronically ill children.^{5,6} Fiscal pressures lead to costs being shifted away from publicly funded institutional care to home care, where labor is reorganized so as to make use of the no-cost services available. This restructuring simultaneously affects public health care programs, labor markets, and families, who now often have no choice but to provide informal home care. Few studies have focused on the economic or social value of pediatric home care,^{5,7,8} and none have measured time taken to care for ill children at home.^{9–12}

Home care of children, as a cost saving policy, became a national concern with the increases in numbers of pediatric HIV/AIDS cases in the 1980s. Other chronic illnesses requiring home care, however, affect a much larger portion of our nation's children. Home care viability is dependent on the continued willingness and ability of caregivers, predominantly women, to provide care.¹³ The well-documented emotional burden of caregivers calls into question the sustainability of this shift of care to families. Government systems need more information about caregiver burden, especially in regard to children's care, already considered the responsibility of the family. In this study, we compared types, amounts, and costs of care provided to HIV-positive children and chronically ill children, using healthy children to control for basic care needs.

METHODS

Sample

Data were derived from a multicenter convenience sample of maternal caregivers of 97 children with HIV, 101 children with any

Objectives. We compared types, amounts, and costs of home care for children with HIV and chronic illnesses, controlling for the basic care needs of healthy children to determine the economic burden of caring for and home care of chronically ill children.

Methods. Caregivers of 97 HIV-positive children, 101 children with a chronic illness, and 102 healthy children were surveyed regarding amounts of paid and unpaid care provided. Caregiving value was determined according to national hourly earnings and a market replacement method.

Results. Chronically ill children required significantly more care time than HIV-positive children (7.8 vs 3.9 hours per day). Paid care accounted for 8% to 16% of care time. Annual costs were \$9300 per HIV-positive child and \$25900 per chronically ill child. Estimated national annual costs are \$86.5 million for HIV-positive children and \$155 to \$279 billion for chronically ill children.

Conclusions. Informal caregiving represents a substantial economic value to society. The total care burden among chronically ill children is higher than that among children with HIV. (*Am J Public Health*. 2005;95:1445–1452. doi:10.2105/AJPH.2004.044248)

moderate-to-severe chronic disease other than HIV, and 102 healthy children at 3 sites: New York City, San Francisco, and Oakland, Calif. Participants were recruited through general and specialty pediatric clinics according to their willingness to participate. Maternal caregivers, including biological, foster, or adoptive mothers and other female kin, were defined as a child's primary female home caregiver.

Data were collected during 2 structured interviews, each 2 hours in duration, conducted 6 months apart. Participants were reimbursed \$50 per interview, and child care was provided. Eighty-six percent of the participants completed both interviews. Because our sample was composed of caregivers, we were not authorized to obtain information on children's HIV status; however, our intent was to represent a community-treated population.

Measures

We asked maternal caregivers to indicate the total number of minutes spent by all caregivers over the previous 2 weeks in providing 3 types of home care: technical, nontechnical, and health care management. These home

care estimates included both formal (paid) and informal (unpaid) care. Interviewers were trained and received computer assistance via the Sawtooth Technologies Census Q & A program (Sawtooth Technologies, Northbrook, Ill.); they were provided with a calculator for estimating care time. Interviews were audiotaped to validate any inconsistencies or suspected errors.

Technical care consisted of care in areas such as overseeing diagnostic procedures and provision of medications. In addition, we asked respondents to indicate the time taken for crisis care in the previous 3 months. Crisis care was defined as a sudden health event in which an ambulance had to be called or the child needed to go to the emergency room for immediate care. *Nontechnical care* consisted of care associated with activities of daily living and instrumental activities of daily living, such as laundry and housecleaning related to the child's illness. *Health care management* consisted of categories such as financial management and traveling for medical care.

Technical time and time spent managing care were estimated only for activities

associated with a child's illness. With the exception of 4 items, assessments of nontechnical care time (e.g., eating and bathing) were not limited to illness-related time. In the case of laundry, housecleaning, getting around in the home, and getting around outside the home, caregivers estimated only the care time devoted to the child's illness; excluded, for example, were time for additional laundry and general housecleaning, which could be highly variable.

These criteria allowed us to perform 2 calculations. First, summing the 3 care categories provided an estimate of the total cost of caring for either an ill or a healthy child in the home. Second, subtracting the care time for healthy children from that for children with illnesses produced an estimate of incremental care time associated with illness.

To determine illness severity, we measured children's functional status using the Revised Functional Status II Survey,¹⁴ developed for both chronically ill and well child populations. This instrument defines healthy children as those with the capacity to perform age-appropriate roles and tasks in the home, in the neighborhood, and at school.¹⁵⁻¹⁸

Cost Determination

Formal and informal care costs can be defined as indirect costs accrued while caring for an ill person and can broadly include loss of both paid and unpaid production.^{19,20} This definition follows a broad interpretation of the human capital approach,²¹ in which the value of lost production includes both loss of actual income from lost work and loss of leisure time. The value of lost opportunity is calculated via (1) an opportunity cost method wherein a person's care time is valued according to the wages the person could have earned if she or he were not providing home care (after adjustment for unemployment and the choice not to work) or (2) a market replacement method wherein time is valued by the market rate of the services provided. We used the market replacement method because we viewed formal and informal care as necessary care that would require substitution in the market if not provided by the caregiver.^{22,23}

Implicit in this estimate is an assumed "standard of care" for chronically ill children

that includes caregivers' assessments of the number of care hours devoted to specific tasks and their particular salaries. Other types of care could be substituted for this standard, but we assumed that children would not be placed in an institutional setting because of the advantages, in most cases, of the home care environment. Instead, we assumed that the likely substitution would be paid in-home care or a combination of respite and unpaid home care. Although institutional care is often costlier than paid home care, the market replacement values presented here could reflect higher estimates of opportunity costs if other standards of care were substituted for home care.

Market replacement estimates also tend to overestimate opportunity costs in cases in which caregivers earn less than health care workers. However, because health care workers' salaries are typically low, we expected that caregivers would earn as much as, or more than, health care workers if they pursued other full-time work as opposed to providing care. Our approach represents a good approximation of opportunity cost. The market valuation method also has the advantage of determining the value of actual care time spent.

We used 2001 national mean hourly earnings in different occupational caregiver categories to value caregiving time.²⁴ (These values included relative standard errors [RSEs], which are obtained by dividing the standard error of an estimate by the estimate multiplied by itself. This quantity is expressed as a percentage of the estimate.) The earnings values used were as follows: registered nurses, \$22.68 (RSE=1.1), licensed professional nurses, \$14.59 (RSE=1.1); nurse's aides, \$9.34 (RSE=1.2); nonnursing health aides, \$10.81 (RSE=9.3); maids, \$8.02 (RSE=2.4); welfare service aides, \$8.15 (RSE=5.0), and child-care workers, \$8.91 (RSE=2.9). Registered and licensed professional nurses were included only in analyses focusing on certain types of technical care (e.g., giving medications and working with intravenous lines). Most technical care was valued at a nurse's aide salary, most nontechnical care was valued at the aide or maid service level, and health care management was valued at the welfare service or nonnursing health aide level.

Analysis

We averaged baseline and 6-month care estimates in hours per day, summed across caregivers (paid and unpaid) and types of care, to obtain total annual home care time values. When only one time point was available, we used that estimate. In addition, we calculated annual national costs of care per child based on US prevalence rates of HIV and other chronic illnesses.

Distributions of most of the time variables were highly nonnormal, with large numbers of zero values and some very large values. Accordingly, we tested pairwise differences between groups using the bootstrap method. SAS PROC MULTTEST (SAS Institute Inc, Cary, NC) was used (without centering) in conducting these tests, which involved 100 000 resamples of the same size as the original sample.²⁵ We tested variables individually to avoid severe adjustments for a large and arbitrary number of variables. Rather than adjust the alpha level for the large number of comparisons, we interpreted results only when they exhibited a meaningful pattern. The bootstrapped *t* distribution was more leptokurtic than the raw *t* distribution and yielded more extreme significance levels, but in most cases values were very similar to each other.

RESULTS

Caregivers of HIV-positive children were slightly older than caregivers of children with chronic illnesses (Table 1); in addition, they had less education and had been providing care for a slightly longer duration than caregivers in both of the other groups. Caregiving durations were sufficiently long (6 to 7.6 years), however, that all of the caregivers could be expected to be at equal skill levels. Although chronically ill children had significantly poorer functional status scores (mean=83.5) than children with HIV (mean=92.2) and healthy children (mean=95.0) ($F_{2,296}=23.61, P<.0001$), these status scores were comparable to those of other samples of chronically ill and healthy children.¹⁴

We expected the control group of healthy children to differ from the other 2 groups in terms of some of the variables relating to disease, including functional status, type of

TABLE 1—Demographic Characteristics of Caregivers and Children, by Type of Child Illness

Characteristic	HIV-Positive Children	Chronically Ill Children	Healthy Children	Statistic
Male child, %	44	50	44	$\chi^2 = 1.06, P = .59$
Age of child, y, mean	8.2 _x	7.6 _{xy}	6.8 _y	$F_{2,297} = 2.86, P < .06$
Functional status score of child, mean (SD)	92.2 _x (9.3)	83.5 _y (17.1)	95.0 _x (11.1)	$F_{2,296} = 23.61, P < .0001$
Race/ethnicity of caregiver, %				$\chi^2_6 = 7.42, P = .28$
White	25	41	37	
Black	46	30	36	
Hispanic	21	21	22	
Other	8	8	6	
Biological mother is caregiver, %	56 _x	69 _y	54 _x	$\chi^2_2 = 5.94, P = .05$
Months caregiving, mean	91.4 _x	87.8 _x	71.6 _y	$F_{2,245} = 4.01, P < .0193$
HIV serostatus of caregiver, %				
HIV positive	50	0	1	
HIV negative	45	98	99	
Not reported	2	3	2	
Insurance coverage, % ^a				$\chi^2_6 = 43.74, P < .0001$
None	1 _x	1 _y	5 _z	
Private	3	23	37	
Public	90	65	54	
Both	6	11	4	
Primary illness, no.				
HIV	97			
None			102	
Neurological		37		
Gastrointestinal		25		
Hemophilia		6		
Sickle cell		18		
Other		13		
Unknown		2		
Age of caregiver, y, mean (SD)	43.3 _x (11.2)	40.5 _{xy} (11.1)	39.4 _y (11.1)	$F_{2,292} = 3.15, P < .04$
Caregiver education, y, mean (SD)	12.4 _y (2.6)	13.0 _{xy} (3.6)	13.6 _x (4.2)	$F_{2,291} = 3.09, P < .05$
Median household income, thousands	20-25 _x	40-50 _y	40-50 _y	$F_{2,291} = 9.94, P < .0001^b$

Note. Values in the same row with different subscripts are significantly different from each other at $P \leq 0.05$; values in the same row with identical subscripts are not significantly different. No subscripts indicate no significant differences.

^aIn this category, differences indicated with subscripts refer to all within-category column values.

^bWilcoxon test.

insurance coverage, and income level. We did not attempt to control for illness severity, in that doing so would have resulted in our variables of interest (care time and cost) also being controlled. Instead, the goal was for our sample to represent average levels of illness severity in different patient groups, allowing cost to be used as a surrogate measure of average severity of either HIV or chronic disease.

We did control statistically for children's age, family income, and functional status. Adjusting for age and income made very little difference in amount of caregiving time. Adjusting for functional status reduced differences among the groups in some of the paid nontechnical care categories, suggesting that paid help with nontechnical tasks such as housecleaning and moving the child was used more by fami-

lies with children at lower functional status levels.

Total Home Care

Chronically ill children required significantly more total home care time (mean=7.8 hours per day, SE=0.72) than either HIV-positive (mean=3.9 hours per day, SE=0.48) or healthy (mean=2.7 hours per day, SE=0.26) children ($P < .001$). After control for healthy children's care time, children with chronic disease required 5.1 extra care hours per day, while children with HIV required only an additional 1.3 care hours per day (Table 2).

The largest time expenditure was that for nontechnical care, which accounted for 56% of the total care time for HIV-positive children, 57% for chronically ill children, and 88% for healthy children. In the case of technical care, percentages were 33% for chronically ill children, 28% for children with HIV, and 5% for healthy children. Health care management accounted for 16% of total care time for HIV-positive children and 10% for chronically ill children (Table 2).

Technical Care

Caregivers of chronically ill children spent more than twice as long providing technical care as did caregivers of HIV-positive children (Table 2). Relative to the time caregivers of healthy children spent on technical care, caregivers of HIV-positive children spent an additional hour per day, and caregivers of chronically ill children spent more than 2 additional hours per day. Giving medications was the only type of technical care for which caregivers of HIV-positive children spent significantly more time than caregivers of chronically ill children (38 vs 17 minutes per day), which can be readily explained by the complex combination HIV drug therapy that is today's standard of care. Caregivers of both HIV-positive and chronically ill children spent an average of 34 hours per year (SEs=12.4 and 14.7, respectively) on crisis care.

Nontechnical Care

Most caregiving time was spent on nontechnical care (Table 2). Caregivers of chronically ill children spent 2 additional hours per day on nontechnical care simply because of

TABLE 2—Average Number of Minutes per Day of Home Care, by Child Illness Group and Type of Care

Type of Care	Home Care, Average min/d								
	HIV Group (n = 97)			Chronic Group (n = 101)			Healthy Group (n = 102)		
	All Caregivers: Paid and Unpaid	All Caregivers: Paid Only	Primary Caregiver Only: Paid and Unpaid	All Caregivers: Paid and Unpaid	All Caregivers: Paid Only	Primary Caregiver Only: Paid and Unpaid	All Caregivers: Paid and Unpaid	All Caregivers: Paid Only	Primary Caregiver Only: Paid and Unpaid
Technical care	65.05 _x	7.70 _x	41.56 _x	151.73 _y	32.46 _y	97.55 _y	7.83 _z	0.13 _z	6.29 _z
Diagnostic procedures	18.86 _x	2.79 _x	10.18 _x	97.47 _y	24.14 _y	59.63 _y	6.30 _z	0.04 _z	5.10 _x
Medications	38.00 _x	4.37 _x	24.78 _x	17.28 _y	3.46 _x	13.08 _y	1.20 _z	0.07 _y	0.95 _z
Intravenous lines	0.00	0.00	0.00	0.62	0.02	0.62	0.00	0.00	0.00
Care of nasogastric or feeding tubes	2.08 _x	0.51 _x	0.71 _x	16.97 _y	3.80 _y	10.99 _y	0.00 _x	0.00 _x	0.00 _x
Skin	0.04 _x	0.00	0.04 _x	1.34 _y	0.18	1.12 _y	0.04 _x	0.00	0.04 _x
Other tubes/equipment	0.00	0.00	0.00	2.76 _x	0.83	1.36	0.00 _y	0.00	0.00
Crisis	5.53 _x	0.00	5.48 _x	5.53 _x	0.01	4.83 _x	0.14 _y	0.00	0.11 _y
Other	0.54 _x	0.02	0.38 _x	9.76 _y	0.02	5.94 _y	0.14 _x	0.01	0.10 _x
Nontechnical care	131.51 _x	9.37 _x	91.63 _x	266.90 _y	37.53 _y	200.01 _y	140.63 _x	5.81 _x	102.17 _x
Feeding	22.86 _x	1.56 _x	16.55 _x	61.12 _y	11.80 _y	46.47 _y	29.30 _x	1.64 _x	22.26 _x
Bathing	12.46 _x	1.56 _x	9.10 _x	16.00 _x	2.20 _x	11.74 _x	8.60 _y	0.40 _y	6.14 _y
Skin care	5.65 _x	0.46	4.50 _x	8.85 _y	1.31 _x	7.18 _y	4.93 _x	0.25 _y	4.15 _x
Grooming	10.55 _x	0.81	8.31 _x	18.53 _y	1.84	15.00 _y	12.43 _x	0.93	10.01 _x
Bowels/bladder	5.51 _x	0.95 _x	2.78 _x	22.22 _y	3.52 _y	15.70 _y	6.69 _x	0.54 _x	4.36 _x
Using toilet	2.18	0.12	1.60	4.66	0.50	3.56	3.27	0.25	2.14
Getting around house	8.10 _x	0.20	4.49 _x	30.12 _y	4.80 _x	22.15 _y	13.40	0.07 _y	5.43 _x
Getting other places	35.35	1.62	22.00 _x	49.53	4.75 _x	33.15 _y	45.51	1.35 _y	34.98 _y
Transfer bed/chair	0.70 _x	0.05 _x	0.29 _x	7.30 _y	0.90 _y	5.19 _y	1.03 _x	0.00 _x	0.87 _x
Laundry due to illness	9.47 _x	0.34 _x	7.65 _x	13.71 _x	2.41 _y	11.98 _x	3.03 _y	0.02 _z	2.13 _y
Housecleaning due to illness	7.28 _x	0.67 _x	4.77 _x	14.67 _x	1.27 _x	11.92 _y	1.06 _y	0.00 _y	0.91 _z
Dressing	6.52 _x	0.39 _x	5.00 _x	16.49 _y	1.38 _y	12.73 _y	8.22 _x	0.34 _x	6.23 _x
Other	4.82	0.64	4.70	3.67	0.85	3.24	3.14	0.00	2.55
Health care management	39.72 _x	1.91 _x	32.01 _x	48.16 _x	6.09 _x	42.16 _x	11.86 _y	0.26 _y	10.34 _y
Arranging care	13.61 _x	0.82	12.07 _x	17.60 _x	3.24 _x	16.32 _x	4.73 _y	0.14 _y	4.13 _y
Arranging finances/insurance	2.40	0.10	1.82	4.12 _x	0.28	3.92 _x	0.73 _y	0.01	0.67 _y
Education/training	4.57	0.02	3.27	4.27	0.38	3.78	2.28	0.03	1.94
Travel/waiting	18.70 _x	0.92 _x	14.38 _x	20.20 _x	1.91 _x	16.18 _x	3.78 _y	0.08 _y	3.30 _y
Other	0.44	0.04	0.44	1.96	0.28	1.96	0.34	0.00	0.29
Total daily technical/ nontechnical care									
Minutes	196.56 _x	17.07 _x	133.19 _x	418.63 _y	70.00 _y	297.56 _y	148.46 _x	5.94 _z	108.46 _x
Hours	3.28	6.98	2.47
Total daily all care									
Minutes	236.28 _x	18.97 _x	165.20 _x	466.79 _y	76.08 _y	339.73 _y	160.32 _z	6.20 _z	118.80 _z
Hours	3.94	7.78	2.67
Total daily all care after control for healthy children									
Minutes	76.00	12.78	46.40	306.47	69.89	220.92			
Hours	1.27	5.11			

Note. Groups in the same row with different subscripts are significantly different from each other at $P \leq .05$; groups in the same row with identical subscripts are not significantly different. No subscripts indicate no significant differences.

the child's illness, significantly more than the nontechnical care time devoted to either healthy or HIV-positive children. Amounts of nontechnical time spent were similar for healthy and HIV-positive children, which was not unexpected given that this time included the normal daily care needs of children.

Health Care Management

Caregivers of both groups of ill children spent significantly more time managing care than caregivers of healthy children. After healthy care time had been controlled, caregivers of HIV-positive children spent an additional 170 hours per year (28 minutes per day) on care management, while caregivers of chronically ill children spent an additional 219 hours per year (36 minutes per day).

Primary Caregiver

Most total care time (70% for HIV-positive children, 73% for chronically ill children, and 74% for healthy children) was accounted for by the primary maternal caregiver. Time spent by other caregivers varied according to type of care, with the primary caregiver receiving the most help for different types of technical care. Even so, the primary caregivers of chronically ill children provided 64% of total technical care, significantly more than for either HIV-positive or healthy children. Chronically ill children's primary caregivers also provided 75% (significantly more care time than the HIV-positive or healthy group) of nontechnical care and 88% (significantly more care time than the healthy group) of care in regard to health management, while primary caregivers of HIV-positive children provided slightly, but not significantly, less nontechnical care time than caregivers in the other 2 groups (70%).

Paid Versus Unpaid Care

Paid care accounted for only small percentages of total care time: 16% among caregivers of chronically ill children and 8% among caregivers of HIV-positive children. Most (49%) paid time involved nontechnical care. Only 7% of total nontechnical care for HIV-positive children and 14% of nontechnical care for chronically ill children represented paid care.

Value of Total Care

Among HIV-positive children, the total cost of all home care was \$53 per day (\$19 335 per year). The cost for chronically ill children was \$98 per day (\$35 897 per year), nearly twice the figure for the HIV-positive group. After control for healthy children's care, additional costs due to illness were \$25 per day (\$9298 per year) for children with HIV and

\$71 per day (\$25 860 per year) for children with other chronic illnesses (Table 3).

Employment

Additional family burdens occur when a caregiver elects to withdraw from the workforce (as many of the present respondents did) to care for a sick child (Table 4). Thirty-one percent of caregivers worked either full

TABLE 3—Cost Burden of Home Care Hours, by Type of Care and Illness Group

Type of Care	Unit Cost per Hour, \$	Cost Burden, \$					
		HIV Group (n=97)		Chronic Group (n=101)		Healthy Group (n=102)	
		Mean Cost per Day	Mean Cost per Year	Mean Cost per Day	Mean Cost per Year	Mean Cost per Day	Mean Cost per Year
Technical care	...	22.04	8 044	44.03	16 071	2.11	768
Diagnostic procedures	14.59	4.59	1 673	23.70	8 651	1.53	559
Medications	22.68	14.36	5 243	6.53	2 384	0.46	166
Intravenous lines	22.68	0.00	0	0.23	84	0.00	0
Care of nasogastric or feeding tubes	22.68	0.79	286	6.41	2 341	0.00	0
Skin	14.59	0.01	3	0.33	118	0.01	3
Other tubes/equipment	22.68	0.00	0	1.04	381	0.00	0
Crisis	22.68	2.09	763	2.09	763	0.05	20
Other	22.68	0.20	73	3.69	1 346	0.05	19
Nontechnical care	...	20.09	7 334	40.92	14 936	21.80	7 957
Feeding	9.34	3.56	1 298	9.52	3 472	4.56	1 664
Bathing	9.34	1.94	708	2.49	909	1.34	488
Skin care	9.34	0.88	320	1.38	502	0.77	279
Grooming	9.34	1.64	599	2.88	1 053	1.94	706
Bowels/bladder	9.34	0.86	313	3.46	1 262	1.04	380
Using toilet	9.34	0.34	124	0.73	264	0.51	185
Getting around house	9.34	1.26	460	4.69	1 711	2.09	761
Getting other places	9.34	5.50	2 008	7.71	2 814	7.08	2 585
Transfer bed/chair	9.34	0.11	39	1.14	414	0.16	58
Laundry due to illness	8.02	1.27	462	1.83	669	0.41	147
Housecleaning due to illness	8.02	0.97	355	1.96	715	0.14	51
Dressing	9.34	1.02	370	2.57	937	1.28	467
Other	9.34	0.75	273	0.58	207	0.49	178
Health care management	...	10.84	3 908	13.34	4 868	3.59	1 311
Arranging care	22.68	5.14	1 851	6.64	2 424	1.79	653
Arranging finances/insurance	10.81	0.43	156	0.74	269	0.13	47
Education/training	22.68	1.73	623	1.61	588	0.86	314
Travel/waiting	10.81	3.37	1 215	3.60	1 315	0.68	248
Other	22.68	0.17	60	0.74	270	0.13	47
Total technical/nontechnical, all caregivers	...	42.13	15 378	84.95	31 008	23.91	8 725
Total care, all caregivers	...	52.97	19 335	98.34	35 897	27.50	10 036
Incremental cost after controlling for healthy children	...	25.47	9 298	70.84	25 860

TABLE 4—Caregiver Work Reductions and Losses, by Illness Group

	HIV Group	Chronic Group	Healthy Group	Statistic
Reduced work for child care, %	23	14	13	$\chi^2_2 = 1.55, P = .46$
Retired, %	12 _x	6 _{xy}	4 _y	$\chi^2_2 = 5.54, P = .06$
Employment status, %				$\chi^2_4 = 24.36, P < .0001$
Full time ^a	11	23	39	
Part time	20	19	22	
Unemployed	69	58	39	
Quit work to care for child, %	36	47	33	$\chi^2_2 = 2.28, P = .32$
Days of missed work in past month, ^a mean (SD)	2.9 (4.3) _x	6.7 (3.4) _y	1.1 (1.3) _x	$F_{2,18} = 5.37, P = .015$
Hours of reduced work, mean (SD)	8.7 (6.1)	9.8 (4.8)	5.5 (6.0)	$F_{2,18} = 1.11, P = .35$

Note. Values in the same row with different subscripts are significantly different from each other at $P \leq 0.05$; values in the same row with identical subscripts are not significantly different. No subscripts indicate no significant differences.

^aSignificant at the .05 level.

or part time while caring for a child with HIV, as compared with 42% of caregivers of children with chronic illnesses and 61% of caregivers of healthy children.

DISCUSSION

This is the first study to examine, at a significant degree of detail, the economic burden associated with the home care of ill children. There were 2 primary findings. First, rates of use of home care among ill children, and the costs of this care, were high, especially in the case of children with chronic illnesses. Even after control for time spent caring for healthy children, chronically ill children received 36 more hours of care per week than these children, more than the 31.4 hours per week required by disabled adults according to one national survey¹² and comparable to the 28 to 39.9 hours per week estimated for frail elderly individuals in another study.²⁶ This is important because national policies that restructure public health care systems, shifting costs from publicly financed institutions to the home, will have both economic and social consequences for labor markets, communities, and families.

The sustainability of home care as a policy is dependent on the continued willingness of caregivers.^{13,27} The economic and emotional burden of caring for ill children in the home is often hidden under the veil of care already provided for healthy children. Time spent raising children represents a value to society that is desirable, and society acknowledges

this value with certain benefits, such as tax credits, to help families with children. However, we have demonstrated the extent to which the cost of hiring paid health or domestic workers to provide in-home care for ill children (ranging from approximately \$19 000 to \$36 000) is higher than that of hiring caregivers for healthy children (approximately \$10 000).

Our second major finding was that the care needs of children who are HIV positive are similar to those of healthy children with the exception of the time necessary for giving medications, and this may be reflective of the success of highly active antiretroviral therapy (HAART) treatment. Although we were unable to obtain CD4 or viral load data, we did use functional status to indicate severity. Care times reported were consistent with children's functional status ratings, indicating that the chronically ill children involved in this study were sicker or more disabled than the children with HIV.

The differences in functional status and care time between the HIV and chronic illness groups cannot be attributed to a particularly low functioning, chronically ill sample; the functional status of the chronically ill children in our sample was comparable to that of chronically ill children in 3 other previous samples.^{14,28} Instead, we believe that our findings are due primarily to advances in HIV treatments. Today, children in the United States with HIV are much like healthy children in the care they require with the exception of time spent giving medications.

Survival rates among HIV-infected children have improved since combined antiretroviral therapy was introduced in the mid-1990s.^{29,30} The findings of this study with respect to the care time spent on children with HIV may be indicative of these children's improved health and may represent a positive outcome of their improved drug treatment.

The US economic burden associated with childhood illnesses is substantial. However, because of the use of drugs to prevent maternal transmission of HIV, fewer children in the United States now carry HIV. In 2002, only 92 new cases of pediatric AIDS were reported. Still, about 9300 children younger than 13 years live with HIV or AIDS.³¹ On the basis of our estimated figures, the value of the illness-specific home care provided to HIV-positive children is \$86.5 million each year.

The numbers of children affected by other chronic pediatric illnesses are of another magnitude. It is estimated that 10% to 18% of US children (6 to 10.8 million children) are chronically ill. According to our cost estimates, the total value of their care ranges from \$155 to \$279 billion per year.^{2-4,32,33} Even if one considers only our lower cost estimate, which takes into account the fact that our sample may overrepresent chronic illnesses requiring labor-intensive home care, this figure constitutes a significant societal cost. The national economic value of informal caregiving provided to adults was only \$196 billion in 1997.³³

Study Limitations

Many factors contribute to amounts of care provided, including the characteristics of the caregiver, illness, and child. A limitation of this study is that these factors could have accounted for some of the differences in care and costs among the groups. We think our patient groups were typical of each disease category and that the time and cost differences observed were actually surrogate indicators of illness severity. However, our data should be interpreted with this limitation in mind and may not apply to all children with HIV or chronic illnesses. Future studies should measure HIV status and its relationship to caregiving time.

Another potential limitation of this study involves the reliability of our respondents'

self-reports of time spent caregiving. In regard to self-reports of health-related information, data from the National Health Interview Survey show that rates of underreporting of hospitalizations are 5% and 10% in the case of 6-month and 12-month recall periods, respectively.^{34–36} Adults are more reliable in reporting significant health care events such as hospitalizations and physician visits.^{37–43} We attempted to minimize recall bias by using short recall times, 2 weeks for home care time and 3 months for hospitalizations. These shortened recall times allowed us to make more reliable annualized estimates. In addition, we averaged care time across 2 data collection points to provide a more accurate assessment of average care across time, even if the child's disease was progressing or improving. Future studies could measure disease progression over time and relate it to care provided.

In our replacement approach to valuing care time, we attempted to reflect the societal approach—especially that of the large insurance systems that might be responsible for paying for care provision—to valuing such time. However, measures of forgone opportunities may better reflect the costs of caring from the perspective of family caregivers themselves. Future researchers should consider alternative perspectives in measuring care burden.

Conclusions

Measures of economic burden in health care are used to determine the value of new treatments and technologies and to direct public health expenditures. As broad new health care policies are created, shifting public expenditures to families to cut costs, it is important to determine the economic effects on families. This study demonstrates the high economic value of caregivers of chronically ill children, and, along with the findings of other studies indicating the high personal stress of caregiving, our results should alert public payers of the need to lend support to these caregivers if home care is to be sustained as a viable strategy.

In addition, the present study exhibits the success of HAART treatment for children with HIV by demonstrating that their care needs are similar to those of healthy children. This also represents an example of how im-

proved medical treatments can affect the burden of home care. Future studies should continue to explore the home care burden of other groups of chronically ill children, including those with stable physical or mental disabilities, and the effects of treatments on caregiving. ■

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Contributors

L.S. Wilson originated and supervised the economic portions of the study and its analysis and led the writing. J.T. Moskowitz supervised the implementation of the study and the writing and synthesized the analysis. M. Acree originated, conducted, and synthesized the data analysis. M.B. Heyman, P. Hartz, and S.J. Ferrando assisted with the study, especially the medical aspects, and synthesized the analysis. S. Folkman originated the study and supervised all aspects of implementation, analysis, and writing. All of the authors helped to conceptualize ideas, interpret findings, and review drafts of the article.

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Human Participant Protection

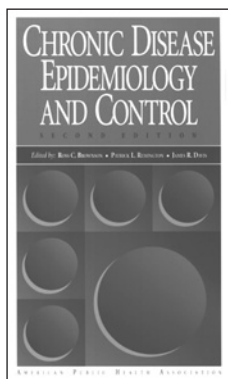
Informed consent and institutional review board approval were obtained at all sites.

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