

HIV-Infected Parents and Their Children in the United States

ABSTRACT

Objectives. This study sought to determine the number, characteristics, and living situations of children of HIV-infected adults.

Methods. Interviews were conducted in 1996 and early 1997 with a nationally representative probability sample of 2864 adults receiving health care for HIV within the contiguous United States.

Results. Twenty-eight percent of infected adults in care had children. Women were more likely than men to have children (60% vs 18%) and to live with them (76% vs 34%). Twenty-one percent of parents had been hospitalized during the previous 6 months, and 10% had probably been drug dependent in the previous year. Parents continued to have children after being diagnosed with HIV: 12% of all women conceived and bore their youngest child after diagnosis, and another 10% conceived before but gave birth after diagnosis.

Conclusions. Clinical and support services for people affected by the HIV epidemic should have a family focus. (*Am J Public Health.* 2000;90:1074–1081)

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HIV has a profound impact not only on the people it infects, but also on their families. Children who are dependent on their parents are particularly vulnerable. Because of the effects of HIV disease and the social conditions that are often associated with it, parents living with HIV may have limited financial, social, and emotional resources to draw upon in raising their children.^{1–9} Furthermore, if parents become incapacitated or die, others need to take over the role of caring for the children.

Children and families of people with HIV may depend on public and charitable resources that cover such services as income supplementation, health care, child care, housing, bereavement support, foster care, and adoption. These services are not always available, and the stigma associated with HIV can complicate access to such services. To address the needs of children and families affected by HIV, we need to know the magnitude and scope of the problem.

Nationally representative data have not previously been available to describe this population, although the percentage of HIV-infected adults with children has been reported for regional and convenience samples.^{10–12} Other studies have estimated the number of children with vertically acquired infection¹³ and the percentage of childbearing women who are HIV infected.^{14–16} Several researchers have used modeling techniques to estimate the number of children in the United States who have lost or will lose their mothers because of HIV.^{17,18} These studies have drawn attention to the fact that HIV affects more than just those who are infected.

To gain a better understanding of parent-hood and family responsibilities among HIV-infected adults in the United States, we used data from a national probability sample of men and women who are receiving health care for HIV to determine who had children,

the ages of the children, and with whom the children lived.

Methods

Study Design and Data Collection

The HIV Cost and Services Utilization Study used multistage national probability sampling to select a random sample of adults with known HIV infection who had at least 1 visit for health care at a facility other than a military, prison, or emergency department facility during a 2-month population definition period in early 1996. The methods have been described in detail elsewhere.^{19–21}

Briefly, we sampled geographical areas, medical providers, and then patients. In the first stage of sampling, we sampled the 8 metropolitan statistical areas with the largest AIDS caseloads with certainty, along

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with an additional 20 metropolitan statistical areas and 24 clusters of rural counties. In the second stage, we sampled 58 urban and 28 rural “known providers” from lists of all providers known by local informants to provide HIV care. To ensure that all HIV providers were represented, we also sampled 87 urban and 23 rural “other providers” who had affirmed caring for HIV patients in a screening survey of approximately 4000 physicians randomly selected from the physician master file maintained by the American Medical Association.

In the third stage, we sampled patients from anonymous lists of all eligible patients who had visited participating providers during the population definition period. To the extent possible, we removed duplicate entries across lists to minimize the possibility of persons appearing on more than one list. Women and members of staff model health maintenance organizations were oversampled.

Trained interviewers used computer-assisted personal interviewing for in-person interviews lasting about 90 minutes.²² Data collection began in January 1996 and ended 15 months later.

Our coverage rates (the population directly represented divided by the population that would have been represented with complete participation at all stages) were 68% for full interviews and 87% for people with abbreviated interviews or information supplied by others. We obtained 2864 full interviews.

Terminology

Throughout the article, “offspring” refers to all ages, and “children” refers to offspring younger than 18 years. Unless otherwise stated, children and offspring described in this article were alive at the time of the interview.

Survey Content and Variables

In addition to general demographic and health characteristics, the survey covered specific items about offspring of all ages. We asked how many offspring the respondent had given birth to or fathered and whether they were alive. For each of the 5 offspring born most recently, we asked birth date and (when appropriate) age at death. We also asked HIV testing history. Because HIV antibody tests may not be accurate for children younger than 18 months,^{23,24} we asked whether testing had been performed before 18 months and, when it had, whether the respondent had been told that the child was actually infected with HIV or had AIDS.

We also asked whether offspring were living with the respondent. For children not living with the respondent, we asked who had

primary responsibility for taking care of the child. We presumed that the person with primary responsibility was also someone the child lived with. Answer options included other biological parent, grandmother, other relative, unrelated foster/adoptive parent, group home/extended care facility, and other. We also asked whether respondents were living with a spouse/partner, but we did not determine whether this person was the child’s other parent.

Most survey items covered only the 5 offspring born most recently; 3% of respondents had additional offspring. We asked these respondents how many of their additional offspring were alive and how many had a confirmed HIV/AIDS diagnosis. Because we did not know their birth dates, they were omitted from most analyses. Some were certainly younger than 18 years, so our estimate of the size of the population of children is probably a slight underestimate.

We asked participants to report their lowest CD4 count, and if they did not know their exact count, we asked whether their lowest count was 500/mm³ or more, 200 to 499/mm³, 50 to 199/mm³, or less than 50/mm³. High levels of agreement have been found between self-report and medical record CD4 counts in a hospitalized population.²⁵ We used a symptom intensity index (0–100) constructed from respondent reports of degree of discomfort and of being bothered by symptoms from a list of 14 symptoms experienced by people with HIV (e.g., weight loss, nausea). We used the Composite International Diagnostic Interview Short Form to screen for probable psychiatric disorders (major depression, dysthymia, generalized anxiety disorder, panic attacks) during the previous year.^{26,27}

We used a modified version of the Composite International Diagnostic Interview brief screener for probable drug dependence. Participants who reported use of any of a list of illicit drugs during the previous 12 months were asked whether they had to use larger amounts to obtain the same effect or whether they had experienced any emotional or psychological problems from using drugs. Those who gave affirmative responses to either question were classified as drug dependent. Because people with HIV sometimes use marijuana for medicinal purposes, we repeated analyses using the drug dependence variable with marijuana use excluded and found no substantial differences in the results. The standard drug dependence variable (with marijuana use included) is reported in this article. A heavy alcohol drinker was defined as someone who reported both drinking alcohol at least half of the days in the previous 4 weeks and typically having 3 or more drinks on those days.

In analyses comparing timing of child’s birth to timing of respondent’s diagnosis with HIV, we looked both at children conceived before the respondent was diagnosed but born after (i.e., the diagnosis was made during pregnancy) and at children conceived after the respondent had been diagnosed. We defined the latter as children born at least 10 months after diagnosis.

Data

As described elsewhere, we imputed missing values for essential variables with a standard “hot-deck” strategy.²⁸ We did not impute variables for offspring, except that when a year of birth was reported but not a month or day, we imputed “June” and “15th.” (We imputed the month and day for 3% of children and the day for 2%.)

Analysis

Adult-level analyses were based on the full sample of 2864 respondents, although many analyses were based on the 2803 (98%) respondents who reported whether they had offspring and whether their offspring were younger than 18 years. Child-level analyses were based on reports of 3138 offspring (exclusive of 209 additional offspring of respondents with more than 5), which include 1644 for analyses of living children younger than 18 years (most child-level analyses in the article are for this group), 1079 for analyses of living offspring 18 years or older, and 196 for analyses of dead offspring. The total also includes an additional 208 living offspring for whom we could not determine age and another 11 offspring for whom we could not determine living status.

We constructed analytic weights to adjust the sample to represent the entire reference population, and we calculated weighted sample means and proportions to estimate population parameters for early 1996. To adjust standard errors and statistical tests for the differential weighting and complex sample design, we used linearization methods²⁹ in SUDAAN (Research Triangle Institute, Research Triangle Park, NC) and Stata (Stata Corp, College Station, Tex).²⁸

We report unadjusted proportions of dichotomous outcomes (e.g., presence of children) by covariates (e.g., geographic region) with χ^2 tests of association. We report adjusted odds ratios resulting from multivariate logistic regression models. We also report whether each subgroup differed significantly from the omitted subgroup defined for a particular covariate as determined by a Wald *t* test. To limit multiple testing, we performed

the Wald *t* tests only with variables for which there was a statistically significant overall difference between odds ratios for population subgroups defined by each covariate (i.e., whether the odds of having the outcome varied across age categories, as determined by an *F* test).

Results

HIV-Infected Adults With Children Younger Than 18 Years

Twenty-eight percent of HIV-infected adults in care had 1 or more children younger than 18 years. Using population weights, we estimated that this represents about 62 800 HIV-infected adults with about 120 300 children. Women were more likely than men to have children (60% vs 18%; $P < .001$). Table 1 shows variations by demographic and other characteristics; men had more such variations than women.

Fifty-three percent of people with children had more than 1 child: 29% had 2, 14% had 3, and 10% had 4 or more. Among people with children, 16% had children aged 0 to 2 years, 24% had children aged 3 to 5 years, 59% had children aged 6 to 12 years, and 45% had children aged 13 to 17 years.

Timing of Child's Birth in Relation to Parent's Diagnosis

Twelve percent of women and 2% of men (including 6% of men who were not in one of the HIV exposure/risk categories that included men who had sex with men) had a child conceived after their diagnosis with HIV (i.e., the child was born 10 or more months after diagnosis). An additional 10% of women and 1% of men (including 4% of men not in the exposure/risk categories just described) had a child who was born after diagnosis but probably conceived before. These percentages were notably higher among women younger than 30 years at the time of diagnosis: 26% conceived after diagnosis, and another 15% conceived before but gave birth after diagnosis.

Living Arrangements for Children

Fifty-two percent of children lived with the respondent, and 28% lived with their other parent (but not with the respondent), for a total of 80% living with at least 1 parent (Table 2). The remaining children lived with their grandmother (9% of all children), with another relative (5%), with an unrelated foster or adoptive parent (4%), or in another situation (e.g., group home, living independently; 2%) (Table 2). Living situation varied greatly by

TABLE 1—Percentages of HIV-Infected Adults With Children Younger Than 18 Years, by Sex: HIV Cost and Services Utilization Study, 1996–1997

Respondent Characteristic	Female, % (N ^a)	Male, % (N ^a)
Age, y		
18–29	69 (12 100)	13 (17 300)
30–39	71 (22 600)	19 (80 900)
40–49	48 (12 900)	20 (55 700)
≥50	8 (4 200)**	15 (19 600)*
Race/ethnicity		
African American	61 (27 900)	31 (44 400)
Hispanic	66 (9 500)	28 (23 200)
White	54 (13 100)	11 (99 600)
Other	51 (1 200)	13 (6 200)**
Geographic region		
Midwest	70 (5 500)	16 (19 700)
Northeast	59 (19 900)	33 (34 600)
South	58 (21 700)	21 (58 600)
West	59 (4 800)	8 (60 500)**
Size of community, millions		
0–1.5 ^b	64 (18 800)	19 (59 100)
1.5–2.5	51 (5 900)	14 (27 200)
2.5–4.5	57 (7 800)	17 (27 800)
>4.5	60 (19 300)	21 (59 400)
Employment		
Full/part time	54 (12 300)	15 (72 900)
Unemployed	70 (6 300)	26 (9 600)
Disabled	57 (25 800)	21 (79 800)
Not working	70 (7 400)**	15 (11 100)*
Annual income, \$		
0–5000	58 (15 500)	22 (28 500)
5001–10 000	63 (17 600)	23 (39 400)
10 001–25 000	59 (13 400)	20 (45 300)
>25 000	54 (5 400)	13 (60 200)**
Education		
Less than high school	61 (22 300)	32 (31 500)
High school	65 (15 300)	21 (46 700)
Some college	52 (11 700)	16 (53 300)
College	51 (2 400)*	8 (42 000)**
Exposure/risk category ^c		
MM/IDU	...	10 (17 800)
MM	...	8 (111 300)
IDU	53 (14 500)	51 (20 900)
Heterosexual	66 (26 500)	54 (14 200)
Other	53 (10 900)**	35 (9 300)**
CD4 count, per mm ³		
≥500	64 (7 300)	20 (14 300)
200–499	59 (22 200)	16 (62 500)
50–199	59 (13 200)	19 (52 800)
0–49	60 (9 100)	21 (43 800)
Total	60 (51 800)	18 (173 400)

Note. Values refer to children who were alive.

^aRepresented population of adults with HIV, derived with analytic weights. Unweighted sample sizes were 840 for women and 1963 for men.

^bIncludes rural areas not incorporated into the metropolitan statistical area classification system.

^cMM/IDU: men who had sex with men and who were injection drug users; MM: men who had sex with men; IDU: injection drug users. The list is hierarchical, so a respondent who fit in more than 1 category was placed in the highest of those categories.

* $P < .05$; ** $P < .01$; *** $P < .001$ for χ^2 test for cross tabulations.

sex of the respondent. Sixty-nine percent of children of a female respondent lived with the respondent and 6% lived elsewhere with their father, whereas 32% of children of a male respondent lived with the respondent and 53% lived elsewhere with their mother (Table 2).

There was no significant decrease in the proportion of children who lived with their parent as a function of stage of the parent's

disease, as measured by CD4 counts (Table 3) and other variables, such as symptom intensity or days in the hospital (data not shown).

HIV-Infected Adults Living With Their Children

Women were much more likely than men to be living with their children: 76% of

TABLE 2—Percentages of Children Younger Than 18 Years in Various Living Arrangements, by Sex of Respondent: HIV Cost and Services Utilization Study, 1996–1997

Living Arrangement	Total (n = 119 900 ^a), %	Female (n = 65 700), %	Male (n = 54 200), %
Respondent parent ^b	52	69	32
Other parent ^c	28	6	53
Grandmother	9	10	8
Another relative	5	6	3
Unrelated adoptive/foster parent	4	6	2
Other	2	2	2

^aRepresented population of children derived with analytic weights. Unweighted sample size was 1640.

^bMay have been living with other parent.

^cNot living with respondent.

women with children (and 45% of all women) and 34% of men with children (and 6% of all men) lived with at least 1 child. Among women and men living with children, 15% and 21%, respectively, had at least 1 child living elsewhere.

The likelihood that a respondent lived with his or her children varied by household income for women and men and by respondent's level of education and exposure/risk category for women (Table 3). These variables remained significant in logistic regression, and several other variables were found to be significant as well (Table 3).

Among respondents living with children, 31% also lived with a spouse, and 20% lived with a partner (including a boyfriend or girlfriend); 1% were homeless and were not asked about living with a spouse or partner. Twenty-four percent lived with at least 1 other HIV-infected adult (including infected spouses and partners).

Health of and Available Support for Parents Living With Children

Many parents were at a fairly advanced stage of illness that could have been affecting their ability to take care of their child. Twenty-three percent of parents living with children reported that their lowest CD4 count was 50 to 199, and 22% reported less than 50. Sixty percent of parents living with their children had symptomatic HIV, and another 30% had AIDS.

Many of the parents may have been too sick to tend to their children's needs or may have had other conditions that interfered with their ability to take care of their children. For example, 21% of parents living with children had been hospitalized during the previous 6 months, including 10% who had been hospitalized for 7 or more days. Of note, 50% of parents who had been hospital-

ized during the previous 6 months were also living with a spouse or partner. Eighteen percent of parents living with children had needed home health care in the previous 6 months; 45% had symptoms consistent with a psychiatric disorder; 10% showed evidence of probable past drug dependence; 5% had been heavy alcohol drinkers in the previous 4 weeks; and 10% had needed drug or alcohol treatment in the previous 6 months.

Although many parents appeared to have resources available to draw upon, some parents lacked social networks that could pick up the slack if they were unable to take care of their children's needs, and some had limited financial resources. Twenty percent had no close friends, and 16% saw family members once a month or less. Twenty-five percent had no one to lend them money, and 16% had no one to help with chores. Thirteen percent had gone without needed health care at least once in the previous 6 months, because they needed the money for basic necessities such as food, clothing, and housing, and 8% had gone without basic necessities because they needed the money for health care.

Some put off going to the doctor because they were too sick (19%), they were taking care of someone else (16%), or they did not have a way to get there (23%). Twenty percent had had to find a place to live in the previous 6 months. Sixty-seven percent were participating in 1 or more government supplemental income programs: 31% received Supplemental Security Income, 31% received Social Security Disability Insurance, and 39% received Aid to Families with Dependent Children. In addition, 49% had Medicaid coverage, 13% had Medicare coverage, 21% had private insurance (including health maintenance organizations), and 17% had no health insurance.

HIV Infection Status of Children

Forty-nine percent of children had been tested for HIV, including 4% who were found to be infected and 1% who had ambiguous or uncertain test results (e.g., infants for whom testing was not definitive). Forty-two percent had not been tested, and 99% of untested children were at least 18 months old (old enough so that even HIV antibody tests could be expected to produce definitive results). Respondents did not know the testing status of 9% of the children, although almost all of these children (94%) were not living with the respondent. The likelihood that children had been tested was much greater among those born after or just before the respondent had had his or her first positive HIV test, and there are large differences in testing based on the sex of the respondent (Table 4).

Offspring 18 Years or Older

Nineteen percent of respondents had offspring 18 years or older. Some of these offspring were living with the respondent, including 23% of offspring aged 18 to 20 years, 12% of offspring aged 21 to 25 years, and 3% of older offspring.

Deceased Offspring

Thirteen percent of women and 3% of men had deceased offspring, for a total of about 14 000 offspring who had died. Sixty-five percent of deceased offspring had died between birth and the age of 2 years; 10%, between 3 and 5 years; 9%, between 6 and 12 years; 5%, between 13 and 17 years; and 11%, at 18 years or older. Sixteen percent of deceased offspring had been diagnosed with HIV, 4% had tested negative, 2% had ambiguous results, 74% had not been tested, and 4% were reported as "don't know."

Discussion

Twenty-eight percent of HIV-infected adults in the HIV Cost and Services Utilization Study population had children younger than 18 years; this translates to about 62 800 adults with 120 300 children. Because it is reasonable to consider the minor children of HIV-infected parents as part of the HIV-affected population, this indicates a much larger disease burden than has been commonly recognized.

The total number of children in the United States with HIV-infected parents is even larger. The study was limited to adults in the 48 contiguous states who receive at least some care in settings other than emer-

TABLE 3—Percentages of Parents Living With Children Younger Than 18 Years and Odds Ratios (ORs) From Logistic Regressions Predicting Whether Parents Live With Children: HIV Cost and Services Utilization Study, 1996–1997

Respondent Characteristic	Female Parents		Male Parents	
	% (N ^a)	OR	% (N ^a)	OR
Age, y				
18–29	80 (8 400)	1.00	38 (2 200)	1.00
30–39	75 (16 100)	0.73	35 (15 600)	0.48
40–49	71 (6 200)	0.66	36 (11 200)	0.59
≥50	77 (300)	0.63	22 (2 900)	0.33
Race/ethnicity				
African American	76 (16 900)	0.92	28 (14 000)	0.57
Hispanic	76 (6 300)	0.95	35 (6 500)	0.75
White	77 (7 100)	1.00	42 (10 500)	1.00
Other	44 (600)	0.09 ^{**f}	47 (800)	1.79
Geographic region				
Midwest	78 (3 800)	0.87	41 (3 100)	0.81
Northeast	74 (11 700)	0.98	28 (11 600)	0.41 ^d
South	74 (12 600)	1.00	40 (12 200)	1.00
West	86 (2 800)	2.26	30 (5 000)	0.47 ^d
Size of community, millions				
0–1.5 ^b	77 (12 000)	0.93	41 (11 100)	1.01
1.5–2.5	77 (3 000)	0.93	24 (3 700)	0.53
2.5–4.5	71 (4 500)	0.56	37 (4 700)	0.90
>4.5	77 (11 500)	1.00	30 (12 300)	1.00
Employment				
Full/part time	78 (6 700)	0.61	33 (10 900)	0.61
Unemployed	79 (4 400)	0.99	18 (2 500)	0.40
Disabled	73 (14 800)	1.00	36 (16 700)	1.00
Not working	80 (5 200)	1.29	43 (1 700)	1.44
Annual income, \$				
0–5 000	68 (9 100)	0.32 ^e	33 (6 200)	0.33 ^d
5 001–10 000	76 (11 100)	0.51	21 (9 100)	0.20 ^f
10 001–25 000	80 (7 900)	0.40	33 (8 900)	0.36 ^d
>25 000	89 (2 900) ^{***}	1.00 [*]	53 (7 600) ^{**}	1.00 [*]
Education				
Less than high school	70 (13 700)	1.00	33 (10 200)	1.00
High school	74 (10 000)	1.12	37 (9 600)	1.10
Some college	87 (6 100)	3.06 ^d	29 (8 500)	0.88
College	96 (1 200) [*]	10.92 [*]	42 (3 400)	1.29
Exposure/risk category ^c				
MM/IDU	24 (1 900)	0.30
MM	32 (8 400)	0.43
IDU	55 (7 600)	1.00	36 (10 700)	1.00
Heterosexual	81 (17 600)	3.19 ^f	34 (7 600)	0.76
Other	87 (5 800) ^{***}	6.65 ^{***f}	42 (3 200)	0.83
CD4 count, per mm ³				
≥500	79 (4 700)	2.51	38 (2 900)	1.20
200–499	79 (13 100)	1.98	37 (10 000)	1.02
50–199	73 (7 800)	1.52	24 (9 800)	0.53 ^d
0–49	71 (5 400)	1.00	41 (9 000)	1.00 [*]
Total	76 (31 000)		34 (31 800)	

^aRepresented population of parents with HIV, derived with analytic weights. Unweighted sample size was 502 for women and 346 for men.

^bIncludes rural areas not incorporated into the metropolitan statistical area classification system.

^cMM/IDU: men who had sex with men and who were injection drug users; MM: men who had sex with men; IDU: injection drug users. The list is hierarchical, so a respondent who fit in more than 1 category was placed in the highest of those categories.

^d $P < .05$ for t test comparing the indicated variable with the omitted variable, which had an odds ratio of 1.0.

^e $P < .01$ for t test comparing the indicated variable with the omitted variable, which had an odds ratio of 1.0.

^f $P < .001$ for t test comparing the indicated variable with the omitted variable, which had an odds ratio of 1.0.

^{*} $P < .05$; ^{**} $P < .01$; ^{***} $P < .001$ for χ^2 test for cross tabulations and global F tests for variables within the regressions.

gency rooms, prisons, or military facilities. In particular, adults with poor access to health care, who might not obtain care or who might only go to emergency rooms, were omitted from the sample frame. Poor access is generally associated with demographic characteristics, such as low income, non-White race/ethnicity, younger

age, unemployment, and less education³⁰; in our study, these characteristics were associated with a higher likelihood of having children.

However, our study also underrepresents infected parents who are asymptomatic and who are therefore less likely to receive HIV-related health care. About 85% of adults

with a diagnosis of AIDS were represented in our sample.¹⁹ Therefore, children of adults who were not represented may be less likely to experience the major effects of their parent's illness, and so, from a policy perspective, our sampling strategy tended to focus more on families with the greatest disease burden.

TABLE 4—Percentages of Children With Various HIV Testing Results, by Timing of Child's Birth: HIV Cost and Services Utilization Study, 1996–1997

Month of Child's Birth in Relation to Month of Respondent's First HIV Diagnosis	Respondent (Parent) Sex	N ^a	No Test, %	HIV+, %	HIV-, %	Exposed ^b , %	Don't Know, %
≥36 Months before diagnosis	Female	41 100	49	1	45	<0.05	5
	Male	40 500	57	1	27	<0.05	15
13–35 Months before diagnosis	Female	6 600	25	10	60	1	5
	Male	5 100	42	2	48	0	9
0–12 Months before diagnosis	Female	4 200	20	12	61	5	3
	Male	2 600	23	11	51	5	11
0–9 Months after diagnosis	Female	6 400	3	12	79	2	4
	Male	2 700	32	0	44	8	16
≥10 Months after diagnosis	Female	7 300	1	14	76	5	5
	Male	3 400	34	8	51	2	5

Note. Percentages do not always add to 100 horizontally because of rounding.

^aRepresented population of children derived with analytic weights. Unweighted sample size for all children in this table was 1635.

^bChild <18 months at time of test and no confirmation of child's infection status via more precise means.

Just over half of parents in our study lived with at least 1 of their children. In comparison with men, women not only were more likely to have children (60% vs 18%) but were more likely to live with their children if they had them (76% vs 34%). Previous studies on regional and convenience samples revealed both higher and lower percentages of women with children and generally higher percentages of men with children than found in our study.^{10–12} Although only a small percentage of children are infected, most (and virtually all who live with their parent) will be affected by their parent's illness. The needs of these children are often addressed by public programs and private, nonprofit organizations, making it important from a policy perspective to understand these needs. Yet, such children represent a little-studied aspect of the HIV epidemic.

Our study provides answers to some questions about children affected by HIV, including the characteristics of their households, who is taking care of them, and their history of HIV testing. For example, our study showed that HIV-affected children are found in all regions of the country and in communities of all sizes (not just in urban centers). Indeed, many live in small communities where there would typically be limited experience with HIV-affected families and an appropriate range of services might be unavailable.

Our data allowed us to examine whether children remained with infected parents through the full course of the illness or whether they tended to be placed in other living situations as the disease progressed. The percentage of children living with their parent did not vary much with the severity of the parent's illness, whether measured by lowest CD4 count, by symptom intensity, or by number of days in the hospital. Thus, many

children remain with parents in circumstances that may be especially challenging. An HIV-infected parent may not always have much energy, and medical costs and loss of income can drain resources that would otherwise be available for children.

Most parents experience at least some physical symptoms, and many have symptoms consistent with psychiatric disorders. (The rate of screening positive for psychiatric disorders in our sample was several times higher than that revealed in a nationally representative non-HIV-positive adult sample.^{27,31}) Twenty-one percent of the parents who live with children have been hospitalized in the previous 6 months. Many children have parents who are drug or alcohol dependent or homeless. Some parents and children are also living with at least 1 other infected adult, which may create even more stress in the household. Parents reported a broad range of competing needs as well. Our study and other studies have indicated that HIV-infected parents may have only limited social support from families and friends^{32–35}; by comparison, previous studies conducted with physically ill and general samples found that only 2% of the people had no close friends or relatives.^{36,37}

About 20% of the children lived with neither the respondent nor the other parent. Grandmothers most often filled the gap for these children, followed by other relatives and unrelated adoptive or foster parents, all of whom could need extra support. Government funds are available for formal foster and adoptive care, but informal care arrangements that occur when a relative takes in a child often do not qualify for financial assistance.³⁸

In comparison with our study, previous studies have shown somewhat larger percentages of children living with someone other than a parent.^{1,8} The difference may re-

fect a shift with time or a difference in the population represented. Unlike previous studies, our study included children of men as well as women with HIV. Indeed, about 45% of the children in our study were reported by their fathers, so studies that focus only on mothers will omit a large percentage of children affected by HIV. Fathers were less likely to be living with their children, and respondents of either sex who were not living with their children might have been less likely to provide accurate answers about their children. Finally, our study omitted children whose HIV-infected parent or parents were deceased. We expect that these children would be more likely than the children in our study to be cared for by someone other than a parent.

Because the HIV epidemic is spreading at a faster rate among women than among men (and especially among young women³⁹), and because it is also spreading faster among heterosexual men than among gay men,⁴⁰ we may see an increase in the percentage of HIV-infected adults who have children. In addition, HIV-infected people are now living longer, so the number of children with at least 1 infected parent is likely to continue to grow.

Our study shows that 26% of the women younger than 30 years had conceived children after being diagnosed with HIV. Antiretroviral therapies and other advances have increased the life expectancies of HIV-infected people,^{41–43} and recently developed antiviral prophylactic regimens for pregnant HIV-infected women have reduced the risk that babies will be infected.^{44,45} These developments could increase the percentage of women who decide to give birth. People with HIV could benefit from counseling to know about options to prevent unintended pregnancies and to reduce perinatal transmission of HIV.⁴⁶ There are also benefits to having

their potentially infected children tested for HIV, because early treatment can improve quality and length of life.^{23,47-49} Although almost all of the children born or conceived after the female respondents were diagnosed with HIV had been tested, 20% of the children born during the year before diagnosis had not been tested, and an even higher percentage of children born in the several years before their mother's diagnosis had not been tested. Given the probable lag between infection and diagnosis⁵⁰ for many of these parents, many of the children born before their parent's diagnosis are probably also at risk for infection. Possible reasons for lack of training include access barriers, fear of disclosure, and lack of knowledge on the part of parents or clinicians. The much higher percentage of fathers who reported that their children had not been tested may also reflect that the mothers had tested negative and, therefore, their children were not at high risk for HIV infection. Another possibility is that the fathers had not disclosed their infection to the mothers, so the mothers did not recognize that both they and their children were at risk. Therefore, both the parents and their children could be at risk. Further research would be necessary to determine why so many fathers report untested children.

Conclusions

In this broad and representative sample of HIV-infected adults in care, we have shown that many throughout the country have children and some continue to conceive and have children after diagnosis. HIV-infected parents generally continue to live with their children even as their disease progresses. Any planning for the future of the epidemic will need to consider the impact on parents of having responsibility for children and the impact on children of having parents with a chronic, stigmatizing, and potentially fatal condition. Parents may need support in meeting the sometimes conflicting responsibilities of looking after their own health needs while also taking care of their children.⁵¹ The children, as well, have needs related to their parent's HIV infection, including financial assistance, emotional support, and supervision when the parent is incapacitated or dies.^{51,52} HIV-infected adults could also benefit from counseling and support when making decisions about having children.

Given the epidemiology of HIV, this issue will not go away soon. Even if we succeed in decreasing transmission rates, many parents are already infected, and the disease will continue to have a large impact on families and on how society treats them. □

Contributors

M. A. Schuster drafted the child-specific survey items, designed the analysis, and wrote the paper. D. E. Kanouse worked on the analysis and helped write the paper. S. C. Morton oversaw the statistical and weighting issues and contributed to the analysis and writing. S. A. Bozzette and M. F. Shapiro oversaw the drafting of adult-specific items, designed the overall HIV Cost and Services Utilization Study, and contributed to the analysis and writing. A. Miu performed the programming. G. B. Scott contributed her clinical pediatric HIV expertise.

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