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Children of HIV-Infected Parents: Custody Status in a Nationally Representative Sample

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ABSTRACT -

OBJECTIVE. The purpose of this work was to determine the rates and predictors of custody status for children of HIV-infected parents.

PARTICIPANTS AND METHODS. Data came from interviews of 538 parents with 1017 children (0–17 years old) from a nationally representative sample of HIV-infected adults receiving health care in the United States. Outcomes were collected at 2 survey waves and included child custody status and who, other than the HIV-infected parent, had custody of the child. Child custody status was categorized as (1) in custody of HIV-infected parent at both survey waves, (2) infected parent had custody at first survey wave but not second survey wave, (3) not in custody of infected parent at either survey wave, and (4) infected parent gained custody between survey waves. Potential custodians included (1) other biological parent, (2) state, foster, or adoptive parent, (3) grandparent, and (4) relative, friend, nonbiological parent, or other. Multinomial logistic regression modeled both outcomes.

RESULTS. Forty-seven percent of the children were in the custody of their HIVinfected parent at both survey waves, 4% were in the parent's custody at the first but not second survey wave, 42% were not in custody at either survey wave, and the parent of 7% gained custody between survey waves. Parents cited drug use (62%) and financial hardship (27%) as reasons for losing custody. Children of HIV-infected fathers, older parents, parents living without other adults, parents with low CD4 counts, drug-using parents, and parents with ≥ 1 hospital stay were less likely to be in their parent's custody at either survey wave.

CONCLUSIONS. More than half of the children were not in custody of their HIVinfected parent at some time during the study period. Pediatricians and others taking care of children with HIV-infected parents may be able to offer counseling or referrals to assist parents with child custody issues. www.pediatrics.org/cgi/doi/10.1542/ peds.2006-3319

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Key Words

HIV, children and adolescents

Abbreviations

HCSUS—HIV Cost and Services Utilization Study

IDU—injection-drug user MSM—men who had sex with men HAART— highly active antiretroviral therapy

OR— odds ratio CI— confidence interval

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IV-INFECTED PARENTS FACE the dual challenge of coping with their disease and raising their children.¹⁻⁴ As more women of childbearing age are becoming infected with HIV in the United States, the number of HIV-infected parents may increase^{5,6}; many HIV-infected men are also parents.7 The stress and strain of being a patient and a parent could potentially jeopardize an HIV-infected parent's ability to maintain custody of a child.8-10 One study of HIV-infected mothers in New Orleans, Louisiana, found that 14% of children were separated from their mothers¹¹; another study of HIV-infected, drug-using mothers in New York City reported that 58% lost custody of ≥ 1 child.^{11,12} In a French prospective cohort study, children's cumulative risk of long-term or permanent separation from their mother (including because of maternal death) was 37% after 5 years.13

Although clinicians and researchers often advocate the importance of guardianship planning,14-18 we know relatively little about why HIV-infected parents retain or lose custody of their children. Often, HIV-infected parents do not lose custody as a direct consequence of their illness. For example, initial studies using convenience samples of HIV-infected mothers found that they were more likely to be separated from their children if they used illegal drugs or alcohol, suffered from mental health problems, or had lower CD4 counts.11,13 Older children were more likely to be separated from their HIV-infected mothers than younger children.¹¹ HIV-infected mothers participating in a New York City methadone program reported the following reasons for losing custody of their children: voluntary surrender to a family member, removal by social services, housing/financial difficulties, family initiated removal, or incarceration/drug treatment.¹² Although these studies provide some information regarding factors associated with parental custody, they focus on results from convenience samples rather than on HIV-infected parents in general. Furthermore, they have only included mothers, and some questions remain; for example, do HIV-infected parents regain custody, and who has custody when the parent does not?

By better understanding why HIV-infected parents lose custody of their children, physicians treating HIVaffected families can provide referrals to services that can help parents plan for temporary or permanent loss of custody of their children. Using a nationally representative sample of HIV-infected adults who received medical care during a 6-month period in the United States, we investigate the extent to which HIV-infected parents have custody of their children and, when they do not have custody, who is the custodian. Unlike past studies, this study includes HIV-infected fathers, as well as mothers.

METHODS

Study Design

Respondents participated in the HIV Cost and Services Utilization Study (HCSUS), which selected a national probability sample of adults with known HIV infection who made ≥ 1 visit to a nonmilitary, nonprison medical provider other than an emergency department in the contiguous United States during the first 2 months of 1996. We used 3 survey waves of data: (1) baseline (January 1996 to April 1997), (2) first follow-up (December 1996 to June 1997), and (3) second follow-up (September 1997 to January 1998). The primary outcome of child custody status comes from the first and second follow-up surveys. Respondents completed informed-consent forms. Complete details of the HCSUS design and methods are available elsewhere.^{7,19-21}

The primary analytic sample for this study includes 538 parents (with 1017 children <18 years old) who participated in the 3 survey waves and who had complete responses on custody items from both follow-up surveys. The secondary analytic sample consists of the 270 parents (with 442 children) who lacked custody of \geq 1 child at first follow-up. For both analyses, the child is the unit of analysis. The term "parent" refers to respondent parents throughout the results and discussion sections.

Trained interviewers used computer-assisted personal interviewing for in-person interviews lasting ~90 minutes.²² Rand's institutional review board and local boards approved the study; some sites signed single-protection assurances.

Measures

Predictor Variables

Baseline variables include the following: parent's age at interview, gender, educational attainment, household income, household composition, HIV exposure/risk group (injection-drug user [IDU], men who had sex with men [MSM], heterosexual, or other), year of HIV diagnosis, interview language (English or Spanish), geographic region (Northeast, Midwest, South, or West), and metropolitan statistical area (rural to 1.5 million, 1.5-2.5 million, 2.5-4.5 million, or >4.5 million). Parents reported their race/ethnicity (black, Latino, white/ other). White/other includes groups that were too few to analyze separately. Household composition included living with spouse/partner, living with adult(s) other than the spouse/partner, or living without other adults in the household. Child age was calculated for first follow-up. Mean imputation was used for 1 missing observation for year of diagnosis and 3 missing observations for child age. We derived a dichotomous variable indicating whether parents reported using any illegal drugs from a list of 8 categories in the past 12 months.

At first follow-up, parents reported their lowest CD4

count. If parents did not know the exact measurement, they were asked whether their lowest count was \geq 500/ μ L, 200 to 499/ μ L, 50 to 199/ μ L, or <50/ μ L. High agreement has been found between self-reported and medical chart CD4 counts in a hospitalized population.²³ Parents also reported their number of overnight hospital stays during the previous 6 months. Respondents reported their use of any highly active antiretroviral therapy (HAART) during the previous 6 months. Respondents were asked at each survey wave about the HIV status of each of their children (HIV-positive or HIV-negative/unknown status).

We measured parents' social support by averaging 3 sources of support (someone to give money to respondent, to help with daily chores, to love and make respondent feel wanted); each had a 5-point scale from "none of the time" to "all of the time." We created a dichotomous variable (1 if social support was in the lowest decile and 0 otherwise). Complete details regarding this variable are available elsewhere.²⁴

Outcome Variables

The outcome variables come from the first and second follow-up surveys.

Custody Status

For \leq 5 children, respondents were asked at both follow-up survey waves, "Who has legal custody of the child born on [date]?" From these responses, 4 outcome categories were created: (1) child was in the custody of the respondent at both follow-ups (in custody both survey waves); (2) child was in the custody of the respondent at first follow-up but not at second follow-up (did not maintain custody between survey waves); (3) child was not in the custody of the respondent at either follow-up (not in custody either survey wave); and (4) child was not in the custody of the respondent at first follow-up but was at second follow-up (gained custody between survey waves).

Other Custodians

For children who were not in respondent's custody at first follow-up, we asked, "Who has legal custody of the child born on [date]?" Response options were clustered into 4 possible outcome categories: (1) other biological parent; (2) the state or unrelated foster/adoptive parent; (3) grandparent; and (4) friend, other relative, spouse/ partner who is not biological parent, or other.

Reasons for Losing Custody

Respondents who reported they had ever had any of their children taken away from them were asked, "Was your child or children taken away from you because of": (1) "your HIV status or illness?"; (2) "you couldn't afford to care for the child?"; (3) "mental illness?"; (4) "drug

use?"; and/or (5) "some other reason?" Respondents could list >1 reason.

Data Analysis

For the primary analysis of the child's custody profile from first to second follow-up (n = 1017), we used multivariate multinomial logistic regression, with the child as the unit of analysis. This model included predictors for which bivariate multinomial logistic regressions had an overall 2-sided P value of <.20, a standard screening threshold.25 This threshold is less stringent than the *P* value of <.05 used to ultimately evaluate statistical significance to avoid inappropriately removing predictors that have stronger multivariate than bivariate effects. The outcome category representing children who were in the custody of the respondent parent at both follow-ups was used as the reference outcome. We report the odds ratio (OR) and 95% confidence interval (CI) for a given predictor and outcome, relative to the reference category of the predictor (if applicable) and the reference outcome category.

For the secondary analysis of who had custody of the child when the respondent parent did not at first follow-up (n = 442), a similar modeling strategy was used. In this case, the other biological parent was used as the reference outcome. We report ORs with 95% CIs from the multivariate multinomial logistic regression.

We report weighted percentages for categorical outcomes, both overall and by covariate level. Within multivariate analyses, we perform a joint test for the overall significance of categorical predictors. To limit multiple testing, we report an adjusted Wald test of whether each category of a given variable differed significantly from its corresponding reference category only when there is evidence of overall significance for that categorical variable.

Analytic weights that are modifications of previous HCSUS weights²⁶ account for differential selection probabilities, the number of children within families, nonresponse, attrition, and a computer error that prevented 5% of eligible parents from receiving parenting questions. All of the analyses use these weights and account for their effects and the multistage sample design (including the clustering of children within families) using Stata (Stata Corp, College Station, TX) survey commands.²⁷

RESULTS

Characteristics of Respondent Parents

Weighted parent characteristics include mothers (51%), black parents (51%), white/other parents (29%), and Latino parents (19%); living with a spouse/partner (47%), other adults (38%), and without other adults (16%); and mean age of 35.7 years. Parents reported on 1 (43%), 2 (30%), 3 (18%), 4 (4%), and 5 (5%) chil-

dren (Table 1). Children had a mean age of 9.6 years at first follow-up.

Patterns of Parental Custody Over Time

At first follow-up, 52% of children were in the parent's custody compared with 54% at second follow-up. Of the 442 children not in the parent's custody at first follow-up, 14% returned to that parent's custody by second follow-up. Of the 575 children in the parent's custody at first follow-up, 10% were not in that parent's custody at the second follow-up.

In bivariate analyses (Table 2), mothers were more likely than fathers to have custody of their children (P <.001). For example, 71% of children lived with mothers in both survey waves compared with 23% with fathers. Younger parents were more likely to have custody (P <.001), as were parents who lived with a spouse/partner or with other adults compared with parents who lived without other adults (P < .001). Fifty-one percent of children whose parents lived with a spouse/partner were in that parent's custody at both survey waves, whereas only 5% of children whose parents lived without other adults were in the parent's custody at both survey waves. Parents in the heterosexual and "other" exposure/risk groups were more likely to have custody of children than parents in the MSM or IDU risk groups (P < .001). In general, lower CD4 counts decreased the probability that parents would have custody of children (P = .003). Parents who reported drug use in the past 12 months were less likely to have custody of children than those who did not (P < .001). There was significant regional variation in custody (P < .001): 67% of children living in the Midwest were in the parent's custody compared with 41% to 47% of children in other regions. Younger children were more likely to be in their parent's custody (P < .001).

In multivariate analysis (Table 3), parent gender, age, lowest CD4 count, household composition, drug use in the past 12 months, geographic region, and child age remained significant predictors for the child's custody profile, and any hospital stay in the previous 6 months was significant only in multivariate analysis. Older children were more likely to have been in the custody of the parent at neither survey wave, as were children of fathers, those who lived without other adults (compared with living with their spouse/partner), those who used drugs in the past 12 months, or those who reported any hospital stays in the previous 6 months. Children of parents residing in the Midwest (compared with those from the Northeast) were less likely to have been out of the custody of the parent at both survey waves.

Predictors of Other Custodians

Children were more likely to be in the custody of the state or an unrelated foster/adoptive parent if the HIVinfected parent was their mother or reported an annual

TABLE 1 Distribution of HIV-Infected Parent's and Children's Characteristics

Characteristic	Weighted %
Parent characteristics ($N = 538$) ^a	Weighted A
Mother (335)	51
Age, v ^b	51
18-29 (n = 103)	20
30-39(n = 282)	50
40-49 (n = 239)	26
\geq 50 (n = 14)	4
Race/ethnicity	
Black ($n = 205$)	51
Latino ($n = 101$)	19
White/other ($n = 172$)	29
Education	
Some high school ($n = 212$)	40
High school graduate ($n = 165$)	29
Some college $(n = 125)$	24
College graduate ($n = 36$)	/
Annual nousenoid income, \Rightarrow (1996)	25
0-5000 (7 = 140)	25
5001 - 10000(n - 107)	5Z 20
10001-23000(77 - 155)	20
\geq 23 001 (17 – 78) Exposure/risk group	10
DU(n - 140)	21
MSM(n = 58)	12
Heterosexual $(n = 259)$	45
Other $(n = 72)$	11
Year of diagnosis	
Before or during 1989 ($n = 120$)	22
1990-1993 (n = 225)	41
1994 - 1996 (n = 193)	36
Lowest CD4 counts ^c	
\geq 500/ μ L (n = 60)	13
$200-499/\mu$ L (n = 232)	33
$50-199/\mu$ L ($n = 154$)	34
$0-49/\mu L (n = 92)$	20
Any hospital stays in last 6 mo ($n = 100$)	18
Used HAART ($n = 365$)	68
Household composition	
Lived with spouse/partner ($n = 241$)	4/
Lived with other adult(s) ($n = 216$)	38
Lived alone $(n = 81)$	16
Used drugs in past 12 mo $(n = 231)^{\circ}$	40
Lowest decile of perceived social support ($n = 59$)	10
Geographic region	2
Northeast $(n = 194)$	30
Midwest $(n = 64)$	12
South $(n = 194)$	38
West $(n = 86)$	11
MSA, in millions	
Rural to 1.5 ($n = 158$)	35
1.5-2.5 (n = 75)	10
2.5-4.5(n = 99)	15
>4.5 (n = 206)	40
Child characteristics ($N = 1017$) ^a	
Age, y ^b	
0-4 (n = 173)	15
5-9 (n = 324)	32
10-14 (n = 355)	33
$\geq 15 (n = 165)$	20
Child HIV-positive ($n = 48$)	5

^a Numbers differ for parent and child characteristics, because each parent could give separate responses for \leq 5 children.

^b Mean parent age with SD (range) = 35.7 ± 8.5 years (18–60 years); mean child age with SD (range) = 9.6 ± 2.1 years (0–17 years). Continuous age was used in multivariate models.

^c These categories were defined as hierarchical and mutually exclusive, such that a parent who fits in >1 category was placed in the first applicable category listed here.

^d Drug categories included sedatives, amphetamines, analgesics, marijuana/hashish, cocaine, inhalants, lysergic acid diethylamide/hallucinogens, or heroin.

Variable	In Custody at Both Survey Waves (N = 531), %	Not in Custody at Either Survey Wave (N = 383), %	Did Not Maintain Custody Between Survey Waves (N = 44), %	Gained Custody Between Survey Waves ($N = 59$), %
	47	42	4	7
Parent characteristics	.,		·	,
Gender			а	
Mother	71	22	4	4
Father	23	63	5	9
Parent age, v			a	-
18–29	65	26	5	4
30-39	46	46	3	6
40-49	41	42	7	9
≥50	12	69	5	15
Household composition			a	
Lived with spouse/partner	51	40	5	5
Lived with other adult(s)	60	27	4	8
Lived without other adult(s)	5	83	4	8
Exposure/risk group ^b	5	05	a	0
IDU	36	54	3	7
MSM	13	64	10	13
Heterosexual	60	30	10	6
Othor	62	31		3
Lowest CD4 counts, par vil	02	10	C T	J
\sim 500	20	44	12	11
200 400	52	44 21	15	0
200-499	57	51	4	0
50-199	40	44 E 0	5	/
0-49	20	20	4	C
Any nospital stays in past 6 mo	50	20	4	7
0	50	39	4	/
	35	53	Ь	5
HAARI	50	12		2
Yes	50	43	4	3
NO 12	46	41	5	8
Used drugs in past 12 mo	22		d	
Yes	32	54	6	8
No	57	34	4	6
Perceived social support				
Not socially isolated	49	41	4	6
Socially isolated	31	52	6	11
Geographic region			a	_
Northeast	47	45	1	7
Midwest	67	29	1	3
South	43	40	10	7
West	41	49	3	8
Child characteristics				
Child age, y			a	
0-4	70	21	5	4
5–9	58	35	3	4
10–14	37	47	6	10
15–17	30	59	4	7
Child HIV status			d	
HIV-positive	75	20	4	1
HIV-negative	46	43	4	7

TABLE 2Bivariate Analysis of Custody Profile (N = 1017)

For these analyses, 538 parents provided responses regarding 1017 children.

^a Percentages differ across the subgroups at a *P* value of <.001 within the bivariate multinomial logistic regressions.

^b The categories were defined as hierarchical and mutually exclusive, such that a parent who fits in >1 category was placed in the first applicable category listed here.

^c Percentages differ across the subgroups at a P value of <.01 within the bivariate multinomial logistic regressions.

^d Percentages differ across the subgroups at a P value of <.05 within the bivariate multinomial logistic regressions.

household income between \$10 001 and \$25 000 (compared with \$5000 or less); children were less likely to be placed with them if the parent was a college graduate (compared with parents not finishing high school); had an annual income greater than \$25 000 (compared with \$5000 or less); reported their exposure/risk group to be MSM (compared with heterosexual); or completed the interview in Spanish (Table 4).

TABLE 3	Multivariate Multinomial Logistic Regression Predicting Custody Profile ($N = 1017$)

Variable	Not in Custody at Either Survey Wave, OR (95% CI)	Did Not Maintain Custody Between Survey Waves, OR (95% Cl)	Gained Custody Between Survey Waves, OR (95% Cl)
Parent characteristics			
Parent age, decadesª	0.94 (0.89–0.98) ^b	0.98 (0.89-1.08)	1.02 (0.95-1.09)
Mother	0.09 (0.05-0.17) ^d	0.26 (0.06-1.25)	0.13 (0.05–0.36) ^d
Household composition ^c			
With spouse/partner	1.00	1.00	1.00
With other adult(s)	1.15 (0.65-2.03)	0.97 (0.30-3.13)	2.48 (0.96-6.39)
Without other adult(s)	29.43 (9.96-86.93) ^d	18.02 (2.95–109.98) ^e	16.37 (3.99–67.14) ^d
Exposure/risk group ^f			
MSM	2.44 (0.80-7.44)	6.62 (1.00-44.06)	3.46 (0.71-16.96)
Heterosexual	1.00	1.00	1.00
Other	0.53 (0.22-1.28)	0.75 (0.16-3.44)	0.40 (0.06-2.70)
IDU	1.22 (0.61-2.45)	0.83 (0.26-2.59)	0.82 (0.27-2.52)
Lowest CD4 counts, per μ Lª			
≥500	1.88 (0.83-4.29)	4.52 (0.74–27.70) ^b	1.58 (0.46-5.43)
200–499	1.00	1.00	1.00
50-199	1.06 (0.54-2.11)	0.53 (0.16-1.77)	0.84 (0.32-2.26)
0–49	1.48 (0.70-3.10)	0.74 (0.18-3.00)	0.13 (0.03–0.62) ^b
≥1 hospital stay in last 6 moª	2.11 (1.07–4.16) ^b	4.62 (1.66–12.86) ^e	1.76 (0.67-4.64)
Used HAART	0.79 (0.41-1.50)	0.65 (0.23-1.79)	0.31 (0.12–0.85) ^b
Used drugs in past 12 mo ^c	3.23 (1.87–5.58) ^d	3.29 (1.20–9.00) ^b	3.07 (1.34–7.01) ^e
Lowest decile of perceived social support	1.47 (0.60–3.65)	2.32 (0.56–9.54)	1.51 (0.38–6.05)
Geographic region ^c			
Northeast	1.00	1.00	1.00
Midwest	0.30 (0.11–0.80) ^b	0.45 (0.05-4.28)	0.32 (0.05-1.93)
South	1.31 (0.72-2.40)	18.55 (5.03–68.50) ^d	1.29 (0.48-3.47)
West	0.87 (0.38-2.01)	2.36 (0.37-14.90)	0.77 (0.21-2.75)
Child characteristics			
Child age, y ^c	1.15 (1.08–1.22) ^d	1.05 (0.94–1.17)	1.07 (0.99–1.16)
Child HIV-positive	0.58 (0.17-2.01)	1.58 (0.25–9.97)	0.15 (0.02-1.38)

The reference outcome was maintaining custody for both survey waves. For these analyses, 538 parents provided responses regarding 1017 children.

 $^{a}P < .05$ and $^{c}P < .001$: the *P* values come from an adjusted Wald test measuring the overall association between the independent variable (eg, household composition) and custody status. Individual tests of coefficients were performed only when this overall test was significant at a *P* value of < .05.

 $^{b}P < .05$; $^{e}P < .01$; and $^{d}P < .001$: the *P* values come from an adjusted Wald test comparing a "difference of differences," the odds of the indicated outcome (relative to the reference outcome) when comparing the indicated level of an independent variable to its reference level. For example, 27.47 is the OR of no custody at either survey wave compared with maintained custody at either survey wave when contrasting those who lived without other adults with those who lived with a spouse/partner.

^fThese categories were defined as hierarchical and mutually exclusive, such that a parent who fits in >1 category was placed in the first applicable category listed here.

Children were more likely to be in their grandparents' custody if the parent was their mother, had an annual income between \$10 001 and \$25 000 (compared with \$5000 or less), or had any hospital stays in the previous 6 months. Children of older parents or whose parents completed the interview in Spanish were less likely to be in their grandparents' custody. Children were more likely to be in the custody of another relative, friend, or spouse/partner who is not the biological parent if their HIV-infected parent was their mother or reported "other" as their exposure/risk group.

Reasons for Losing Custody

The most frequently reported reasons for having ever lost custody of a child were drug use (62%), financial inability to care for the child (27%), HIV status and asso-

ciated illness (10%), and mental illness (10%). Forty-three percent also cited other unspecified reasons.

Parents with HIV-Positive Children

Five percent of children were HIV-positive. They were more likely than HIV-negative children to be in the custody of their parents (Table 2). Seventy-seven percent were in the custody of the HIV-infected parent. Among the rest, a grandparent (54%), other biological parent (16%), other (14%), unrelated foster/adoptive parent (9%), or another relative (7%) had custody of children not in the parent's custody (data not shown in a table).

DISCUSSION

For many HIV-infected parents, maintaining custody of their children while coping with the physical and emo-

Variable	State, Foster, or Adoptive Parent, OR (95% Cl)	Grandparent, OR (95% Cl)	Relative, Friend, or Other OR (95% CI)
Parent characteristics			
Parent age, decadesª	0.92 (0.83-1.03)	0.91 (0.82-1.00)	1.07 (0.99-1.17)
Mother ^b	15.98 (4.51–56.48) ^c	9.12 (3.19–26.07) ^c	14.32 (4.12–49.77) ^c
Education ^b			
Some high school	1.00	1.00	1.00
High school graduate	0.98 (0.24-3.97)	1.25 (0.35–4.50)	1.29 (0.40-4.12)
Some college	0.12 (0.01-1.57)	1.91 (0.53–6.88)	0.55 (0.12-2.53)
College graduate	<0.01°	5.21 (0.55–49.66)	1.14 (0.16-8.33)
Annual household income, \$ (1996) ^b	1		
0-5000	1.00	1.00	1.00
5001-10 000	1.35 (0.39-4.63)	0.68 (0.19-2.40)	1.56 (0.48-5.06)
10 001-25 000	7.17 (1.55–33.25) ^d	5.36 (1.55–18.58) ^e	1.86 (0.33-10.48)
≥25 001	<0.01°	1.00 (0.26-3.81)	4.02 (0.80-20.32)
Exposure/risk group ^{b,f}			
IDU	1.88 (0.57–6.26)	0.60 (0.21-1.70)	0.76 (0.21-2.77)
MSM	<0.01°	0.05 (0.004–0.56) ^d	0.29 (0.04-2.03)
Heterosexual	1.00	1.00	1.00
Other	9.94 (0.64–154.47)	3.64 (0.61–21.67)	8.02 (1.55–41.37) ^d
Lowest CD4 counts, per μ L			
≥500	0.56 (0.11-2.92)	0.67 (0.19–2.37)	0.23 (0.04-1.34)
200–499	1.00	1.00	1.00
50–199	2.62 (0.66-10.44)	1.72 (0.50–5.91)	0.80 (0.24-2.65)
0–49	0.43 (0.07-2.74)	0.20 (0.04-1.03)	0.25 (0.06-1.08)
≥1 hospital stay in last 6 mo	0.89 (0.24-3.38)	3.47 (1.09–11.03)	2.25 (0.69-7.32)
Year of diagnosis			
≤1989	1.00	1.00	1.00
1990–1993	0.49 (0.15-1.66)	0.87 (0.22-3.35)	0.80 (0.21-3.05)
1994–1996	0.38 (0.10-1.48)	0.72 (0.19–2.78)	0.42 (0.13-1.33)
Used HAART	0.61 (0.12-3.27)	0.95 (0.23–3.99)	0.29 (0.06-1.30)
Interviewed in Spanish ^b	<0.01°	< 0.01°	0.97 (0.15-6.25)
MSA, in millions			
Rural to 1.5	0.30 (0.6–1.59)	0.80 (0.21-3.12)	1.62 (0.44-5.97)
1.5–2.5	1.72 (0.34-8.75)	1.93 (0.48–7.80)	0.96 (0.19-4.71)
2.5-4.5	2.75 (0.49–15.43)	0.48 (0.09-2.48)	1.09 (0.24-4.90)
>4.5	1.00	1.00	1.00
Child characteristics			
Child age, y	0.95 (0.82-1.12)	1.04 (0.93–1.17)	1.00 (0.90-1.13)
Child HIV-positive	4.60 (0.08-281.77)	36.16 (1.11–1178.65)	35.55 (0.62–2042.86)

TABLE 4	Multivariate Multinomial Logistic Regression Predicting Custodian for Children Not in Custody
	of the Parent ($N = 442$)

The reference outcome was other biological parent. For these analyses, 270 parents provided responses regarding 442 children.

^a P < .05; ^b P < .001: the P values come from an adjusted Wald test measuring the overall association between the independent variable (eg, risk group) and who received custody. Individual tests of coefficients were performed only when this overall test was significant at a P value of < .05. ^c P < .001; ^d P < .05; ^e P < .01: the P values come from an adjusted Wald test comparing a "difference of differences," the odds of the indicated outcome (relative to the reference outcome) when comparing the indicated level of an independent variable with its reference level. For example, the OR of state, foster parent, or adoptive parent custody compared with the custody of the other biological parent when contrasting MSM with those in the heterosexual risk group was < .01.

 $^{\rm f}$ These categories were defined as hierarchical and mutually exclusive, such that a parent who fits in >1 category was placed in the first applicable category listed here.

tional strains of the disease can be very difficult. In our study, 47% of children were in the parent's custody at the time of both follow-up surveys. Children of HIV-infected parents often experience emotional distress, clinical levels of internalizing and externalizing problems, negative life events, and contacts with the criminal justice system.^{28,29} Many of these issues are exacerbated during adolescence, when parents and other adults can play a key role in supporting these children. In our study, adolescent children were even less likely to be in the custody of their HIV-infected parents than younger

children. By better understanding the challenges that HIV-infected parents face when losing or relinquishing custody of their children, pediatricians and other clinicians may be able to offer support for parents to either maintain custody or to provide suitable support for their children when they lose custody. They may be able to help ensure that parents can cope with a challenging situation and provide them with as much stability as possible.

The advent of HAART after the mid-1990s slowed the progression of the disease and enabled HIV-infected par-

ents to spend more time with their families.^{30,31} HAART has helped change the nature of HIV from an often rapidly progressing, terminal illness to a chronic condition. Although HIV-infected adults now have fewer hospital admissions, they still may have to deal with adverse effects from treatment, comorbidities (eg, depression), and the social impact of the disease (eg, stigma).^{32,33} The combination of these factors may also put the parent at risk for losing custody. At the time of our study, HAART had recently become available, and fewer HIV-infected adults were taking HAART than today. HAART may have been so new that its use had not yet improved parents' ability to maintain custody. On the other hand, some are concerned that high-risk behaviors that led to HIV exposure in the first place may reappear among HAART users,³⁴ so the increased use of HAART could indirectly increase other threats to custody, such as losing custody because of drug use.

Although multivariate models did not find an independent effect of the IDU risk group on custody after controlling for such variables as gender, age, and health, 62% of parents who ever lost custody of a child reported drug use as a contributing factor. In addition, parents who reported drug use in the past 12 months were more likely to have not had custody of their children at either survey wave or to have lost custody of their children between survey waves. Physicians treating parents with HAART may want to recommend continued counseling for parents to prevent the reemergence of IDU and other high-risk behaviors.

Parents whose health status is weakened by HIV/ AIDS may find it difficult to continue to care for their children and maybe at risk for losing custody. A parent's HIV status or illness was mentioned by 10% of parents who ever lost custody of a child as a contributing reason. In our study, CD4 counts <50 per cubic millimeter and any hospitalization in the past 6 months were independently associated with less than full custody at both follow-ups. Several courts have stated that HIV-infected parents who fail to adequately manage their own disease, in conjunction with fulfilling other parental responsibilities, may lose custody of their children.35-37 Physicians may want to guide HIV-infected parents to resources that can help them maintain custody or provide suitable caregivers for their children during a time of decreased physical health.

When HIV-infected parents lose custody of their children, extended family members, such as grandparents, often assume the caretaking role.⁸ Although this arrangement is usually preferable to children becoming wards of the state, the added burden on extended family members can take a toll.^{9,38} Relative caregivers must deal with children's potential behavioral and emotional difficulties and assume added financial burdens.^{9,38} Children of HIV-infected mothers or parents with less education or income were more likely to be placed with the state or a foster/adoptive parent than with the other biological parent. Physicians and others treating HIVinfected parents may want to advise them to identify family members or other adults who could help care for their children if something were to happen to them. In addition, relatives and other caregivers may need assistance dealing with children's emotional problems and financial stresses. Pediatricians may want to recommend that parents bring potential custodians (who are often family members) to their children's clinical appointments so that the custodians can become familiar with the children's medical needs. The pediatrician could also continue to see these children when a change in custody has occurred, helping to ensure their physical and mental health issues are properly addressed.

HIV-infected parents caring for HIV-positive children may face added pressures, given the health needs of their children. In our study, 75% of HIV-positive children were in the custody of their parent compared with 46% of HIV-negative children, suggesting that parents may feel a stronger need to retain custody of HIV-infected children, or alternative custodians may be less willing to take them. No parents reported that the state had custody of their children, but 2 children were with an unrelated foster/adoptive parent. The state may have appointed an extended family member or spouse/partner who was not the biological parent as the custodian in some cases not identified by parents as involving state custody. In general, parents and extended families were able to maintain custody of these children.

HIV-infected parents can reduce the effects of temporary or permanent loss of custody of their children by planning for their future care. The American Academy of Pediatrics Committee on Pediatric AIDS recommends, "Pediatricians should ask state and local child welfare agencies to develop flexible policies that permit temporary placement of children during parental illness and return the children if the parent regains sufficient health."³⁹ Some states have adopted legal options, such as standby guardianship, that allow parents to identify a person to care for their children and assume legal guardianship if the parent becomes temporarily incapacitated and unable to care for the children.^{10,40,41} Mothers with HIV have identified several advantages to permanency planning, including relieving pressure on them as a parent, ensuring normal lives for their children, and ensuring a smooth transition to a new living situation.9 Pediatricians may be able to play a role by providing support and referrals to parents and children experiencing a custody dispute. Because parents may not lose custody of all of their children, pediatricians would continue to care for children in the custody of the parent and may be able to offer support to children dealing with the effects of being separated from siblings.

CONCLUSIONS

HIV-infected parents risk losing custody of their children temporarily or permanently because of their disease, their history of injection-drug use, their financial stability, and/or their mental health status. Children without another parent or family member to care for them during such a time may be placed in state or foster care. These children are subject to increased emotional and behavioral problems and would often benefit from receiving care and support from family and friends during periods of time that they are not in their parent's custody. Pediatricians can help parents maintain custody or help them identify someone to care for the children if they lose custody.

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