Custody Plans Among Parents Living With Human Immunodeficiency Virus Infection

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Objectives: To describe and to examine predictors of making custody plans by parents living with the human immunodeficiency virus (HIV) infection.

Interventions: The custody plans of 296 parents living with HIV for 708 children were examined over 5 years, with at least 85% reassessed annually.

Results: Over time, increasing numbers of parents living with HIV made custody plans for all of their children (23.8%-52.8%), typically with extended family members. However, parents change plans frequently, and 44.8% of parents living with HIV died without custody plans. Custody planning was less likely in families with only adolescent children, when parents had a partner, or when parents were depressed. Parents’ disclosure of HIV status, physical health status, substance use, and ethnicity were unrelated to making custody plans.

Conclusion: Custody planning is a slow and unstable process in families affected by HIV.

Arch Pediatr Adolesc Med. 2004;158:327-332

CUSTODY PLANNING IS ONE of the most difficult decisions faced by parents living with a potentially terminal illness, including the human immunodeficiency virus (HIV) infection. Worldwide, more than 14 million children have lost a parent to HIV, with 125,000 of those children living in the United States. About 360,000 families in the United States are coping with an HIV-affected parent. When parents fail to make adequate custody plans, their children are at higher risk for emotional and behavioral problems than when parents have made a plan. Bereaved children may be left without a primary caretaker if their parent dies. However, similar to terminally ill parents with other disorders, many parents living with HIV (PLH) do not make adequate custody plans. Given the limited prospective information on custody planning, the first goal of this study is to describe patterns of custody planning by PLH over 5 years.

Custody planning over time was expected to vary based on characteristics of parents and their children, including parental sex and ethnicity and the child’s developmental level. Because mothers are typically their children’s primary caretakers, we anticipated that mothers with HIV would be more likely to make custody plans than fathers. The child’s age was also expected to influence custody plans, with younger children more likely to have a designated guardian than adolescents. Because families typically have children at several different ages, we were unsure whether parents would make plans for all children in a family at the same time or plan individually for each child based on the child’s developmental status. Therefore, we describe the longitudinal patterns of legal custody plans for each child based on the child’s age and on patterns of making plans for all children within a family. Furthermore, we examined whether living in a family with younger siblings would influence an adolescent’s probability of having a custody plan over time.

Family members, often grandparents, typically become guardians when parents are ill or die. However, the PLH’s relationships with their parents or extended families may be strained or broken, given that many PLH have histories of substance abuse. Clinicians report that caretaking by the extended family is often assumed for the children, but the PLH may not actually discuss these expectations with the future caretaker. Therefore, we examined the persons indicated as future caretakers.
participants for their children and whether parents had discussed their plans with the designated guardian.

After determining longitudinal patterns of parental custody planning, we assessed potential parental predictors of making legal custody plans for their children. These included parent’s disease progression, HIV serostatus disclosure, relationship status, substance use, emotional distress, and coping style. It is crucial to determine patterns and predictors of custody planning in families affected by parental HIV to develop effective interventions for PLH and improve adaptation in their children.

METHODS

PARTICIPANTS

The New York City, Human Resources Administration, Division of AIDS Services provides comprehensive case management services to 95% of the individuals with AIDS who qualify for public assistance. Parents living with HIV were selected between August 1993 and March 1995 from a consecutive series of clients registered with the Division of AIDS Services. Parents living with HIV were approached by their Division of AIDS Services case managers to allow referrals to the research project. Parents living with HIV were eligible for recruitment if (a) they were between the ages of 25 and 70 years, (b) they had at least 1 adolescent child between the ages of 11 and 18 years who was not institutionalized, and (c) the case manager did not evaluate that the project would be detrimental to the PLH. There were 35 potential participants who were ineligible based on the case manager’s evaluation and 155 potential participants who died before recruitment. Of the 429 eligible PLH, 65 (15.2%) were untraceable, 46 (10.7%) refused participation, and 11 (2.6%) were severely ill or incarcerated and were not recruited. Thus, 71.6% (307/429) of the PLH were recruited, reflecting 84.3% (307/364) of the traceable PLH. Because the children of 2 of the 307 PLH were in temporary out-of-home placements, these families were not included in this analysis (n=305). Among the 305 PLH, there were 852 children. Children were excluded based on 3 criteria: (1) those 18 years or older at baseline, (2) those for whom parents did not report any custody plan information on any assessment, and (3) those born after recruitment. Therefore, 708 children of 296 PLH were included in the analysis.

PROCEDURES

Staff using laptop computers, typically in participants’ homes, conducted face-to-face interviews, typically as 2 interviewers making a home visit. Interviewers received a minimum of 18 hours of training in conducting standardized interviews, ethics, confidentiality, HIV/AIDS, and handling emergency situations. Approximately 60% of interviewers were African American or Latino, and 30% were bilingual in Spanish. Parents living with HIV received $25 for each 1- to 2-hour interview. Interviewers were audiotaped for quality assurance (10% were randomly selected for monitoring). Follow-up interviews were conducted every 3 months for the first 2 years of the study and every 6 months until 5 years. The follow-up rates for PLH were lowest during the first year (68.5%), increased with training during the second year (85.0%), and were 88.3% for years 3 to 5. Parents living with HIV were assessed at least once annually at the following rates per year: 100%, 87.1%, 92.6%, 91.2%, and 88.5%.

ASSESSMENTS

As part of the baseline interview, information was collected on background characteristics, including sex, age, living situation, socioeconomic status, and the age and sex of each child. Parental death was documented based on review of New York State death records and report of children or relatives. A broad set of measures was collected over time; however, the following measures were used in this analysis.

Custody Plans

Parents living with HIV were asked to report their custody plans for each child, and these were rated as follows: (1) having a legal custody plan or a standby arrangement or (2) having no formal custody plan. Custody plans were also coded as to whether the parents had discussed the plan for each child with the named custodial guardian (1) or not (0) or with the child (1) or not (0), and according to the number of changes in custody plans across time per child. We then scored whether custody plans were made for all children, some children, or no children in the family. We also scored the number of changes in plans; changes were defined based on making and then unwinding plans across assessment periods.

HIV Diagnosis and Health Status

Parents’ self-reported their date of diagnosis with HIV, whether they had AIDS, and whether they were symptomatic or asymptomatic for HIV. In addition, a sum was calculated of the PLH’s self-report of the presence (1) or absence (0) of 23 physical health symptoms.

Brief Symptom Inventory

The Brief Symptom Inventory22 is a 53-item inventory assessing symptoms of emotional distress. The Brief Symptom Inventory yields a global severity index (α=.97) and subscales for anxiety (α=.85) and depression (α=.84). Participants rate the level of severity for each symptom during the previous week on a scale from 0 (not at all) to 4 (extremely).

Substance Use

The presence (1) or absence (0) of alcohol and other drug use was summed over each assessment period.

HIV Disclosure

The date of parents’ perceptions of disclosure of HIV status to each child was calculated from the date of diagnosis.

DATA ANALYSIS

Patterns in custody planning were examined based on characteristics of individual children and the family unit. Also assessed were the time from recruitment and the time from parental HIV diagnosis until the time a legal plan was made for each child. Observations were censored at the time of parental death or the last interview, whichever came first.

We examined custody plans made at 2 different time periods: recruitment and from recruitment to 5 years. To examine factors associated with having made custody plans by recruitment and over time, separate univariate analyses examined the relationship between each factor associated with legal custody arrangements. In each of these analyses, the time since recruitment and the age and sex of the parent and child were controlled. After univariate models were examined, mixed mod-
els for dichotomous outcomes were conducted for the custody plans at recruitment. Parents’ educational level, emotional distress, substance use, illness status, death, ethnicity, and time from diagnosis to baseline were examined as factors associated with custody in the univariate and mixed models.

For those children without a custody plan at recruitment, Kaplan-Meier curves were plotted to examine time to legal custody plan from date of recruitment based on parental sex, family type, and children’s age at baseline. By using computer software (SUDAAN), Cox proportional hazards regression models were conducted for the predictors previously listed, controlling for family membership (because there was >1 child per family). Hazard ratios (HRs) and their 95% confidence intervals are reported to indicate the relative risk of making custody plans.

Half of the parents and youth were randomized to an intervention. There were no significant intervention effects in any analysis on custody plans or disclosure. Therefore, we do not include intervention effects in any analysis.

RESULTS

Most PLH were mothers (80.4%) and of Latino (45.3%) or African American (34.1%) heritage, 11.1% were white, and 9.5% were of other ethnicities. Parents living with HIV were a mean age of 38.0 years (SD, 5.6 years). About half (54.0%) had graduated from high school. Only 10.1% of families included both biological parents, 26.4% of PLH had another adult partner in the household, and 7.4% of households included other relatives. Only 40.3% of PLH had AIDS, 42.1% were HIV symptomatic, and 17.6% were HIV asymptomatic; the mean CD4 cell count was 180.8/µL (SD, 173.5/µL; median, 138.5/µL). Parents living with HIV were typically recruited 3 to 4 years following their HIV diagnosis.

Of the 708 children recruited, 15.5% were 5 years or younger, 26.3% were aged 6 to 11 years, 27.7% were aged 12 to 14 years, and 30.5% were aged 15 to 17 years. Children were a mean age of 11.2 years (SD, 4.7 years; median, 13 years), and 51.8% were male. More than half the families (58.8%) had adolescent and younger children (mixed-age families), while 41.2% had only adolescent children. None of the adolescents were infected with HIV, and only 9 of the younger children were seropositive.

CUSTODY PLANS AND ASSOCIATIONS WITH PARENT SEX AND ETHNICITY AND CHILD AGE

Parents could use a will, a standby agreement, or both to specify a legal guardian for their children. The types of plans made were consistent over time. Of the 31.0% (n=182) of children for whom PLH had made a custody plan at baseline, 34.6% (63/182) had a legal will designating the plan, 27.5% (50/182) had a standby custody arrangement, and 37.9% (69/182) had both types of legal plans. When plans were made following recruitment, the patterns were similar: 42.7% (112/262) of parents used a will as the sole instrument to indicate their custody plans, 28.6% (75/262) used a standby custody arrangement only, and 28.6% (75/262) used a will and a standby agreement (percentages do not total 100 because of rounding).

Parents were increasingly more likely to make custody plans over time. At recruitment, parents had made custody plans for 31.0% of children; 5 years later, legal plans had been made for 65.9% of children. The pattern of custody plans within a family also shifted over time. At recruitment, 66.5% of parents had not made plans for any of their children, 23.8% had made plans for all of their children, and 9.7% had made plans for some of their children. Five years later, only 30.9% of parents had not made plans for any of their children, 52.8% had made plans for all of their children, and 16.3% had made plans for some of their children. Over 5 years, 48.3% (143/296) of parents died. At death, 42.9% (127/296) of parents had no custody plans for any of their children. In the 6-month period immediately before parental death, PLH were not more likely to make custody plans.

Figure 1 describes the percentage of children within each age group with custody plans at recruitment and at the 1-, 3-, and 5-year follow-up. For children 5 years or younger, the rates were relatively stable over time: 20.9% (23/110) at recruitment, 28.8% (21/73) at year 1, 29.3% (12/41) at year 3, and 20.0% (3/15) at year 5. For children between the ages of 6 and 14 years, parents made legal plans at recruitment for 29.3% (112/382); 3 years later, parents had made plans for 68.2% (167/245); and 5 years later, plans had been made for 65.7% (132/201). For those 15 years and older, 21.8% (47/216) had plans at recruitment, 44.0% (136/309) at 1 year, 59.2% (250/422) at 3 years, and 62.8% (309/492) at 5 years. Parents were significantly more likely to make plans for children aged 6 to 14 years compared with the other groups, even the youngest group (χ²=12.46, P=.002).

In addition to examining custody patterns for each child, plans were contrasted for families with only adolescent children and for those with mixed-age children. The Kaplan-Meier curves in Figure 2 demonstrate a significant difference in the probability of custody plans based on the family type (log-rank statistic=4.34, P=.04), after controlling for the random effect of family membership. Children living within families with mixed-age children were more likely to have custody plans made by their parents.

Changes in custody plans were common. Over time, about half of the parents (54.1%) changed their custody plans. Parents who made changes did so frequently, with a mean of 4.9 changes each. The frequency of changes in custody plans was similar for children of different ages and sexes. Notably, only 14.5% of children had a plan in
place over the entire 5-year period. A quarter (24.7%) of children sometimes had a plan in place but did not at other assessments; at the final assessment, however, there was a legal custody plan for these children. For an additional 23.4% of children, parent reports also varied over 5 years, but at the final assessment, no plan was established. For about a third of children (37.3%), there were no custody plans at any point over 5 years.

Parents typically selected extended family members as guardians for their children (65.5%): the children’s grandparents (28.1%), great aunts/uncles (2.6%), aunts/uncles (32.2%), or cousins (2.6%). Only 12.4% of parents indicated that the child’s other biological parent was to be the guardian. Another 11.6% designated a sibling as the child’s guardian. Few children had plans with either the parent’s friend (2.6%) or stepparent (4.1%) as the designated guardian. Almost all designated guardians had been approached by the PLH about the plan and had agreed (93.3%).

**FACTORS ASSOCIATED WITH CUSTODY PLANS**

At recruitment, a univariate analysis controlling for family cluster effects showed the following predictors to be associated with having custody plans for the 708 children at the .05 level: being a female parent (P = .005), positive-action parental coping (P = .04), and younger child age (<15 years, P = .03). Custody plans also tended to be related to longer time since parental HIV diagnosis (P = .06). In the multivariate mixed-model analysis, we found that mothers with HIV were more likely to make custody plans (P = .002), as were parents with a positive-action coping style (P = .06). A longer time since the parent’s HIV diagnosis (P = .02) and having younger children (P = .03) were also predictive of having a custody plan in this mixed-model analysis.

For those children (n=526) who had no custody plans at baseline, we used a Cox proportional hazards regression model to evaluate the first custody plan after the baseline assessment. By examining patterns over time for these 526 children, a survival analysis indicated that patterns of making legal custody plans were similar across parents of different sexes (fathers vs mothers: HR, 0.90; P = .66) and ethnicities (Latino vs other: HR, 0.76; P = .51).

It was anticipated that parents would be more likely to make custody plans for younger children, and that having younger children in the family would increase the likelihood of custody planning for all children in the family. **Figure 3** summarizes the Kaplan-Meier curves examining the probability of making legal custody plans for youth 5 years and younger, those aged 6 to 14 years, and those 15 years and older (P = .006). Custody plans are made sooner for children aged 6 to 14 years compared with older children. The multivariate predictors of increased custody planning over time in the Cox proportional hazards regression model were as follows: PLH not having a partner (HR, 0.71; 95% confidence interval [CI], 0.53-0.96; P = .03), lower levels of depression (HR, 0.71; 95% CI, 0.69-0.95; P = .01), and having adolescent and younger children (HR, 0.71; 95% CI, 0.52-0.96; P = .03). Custody plans also tended to increase with time since the parent’s initial HIV diagnosis (HR, 1.05; 95% CI, 0.99-1.10; P = .08). Parent’s disclosure of HIV status, physical health status, substance use, and ethnicity were unrelated to making custody plans for their children either at recruitment or over time.

**COMMENT**

There are many advantages to the design of this study. Custody plans were gathered prospectively over 5 years, with high follow-up rates. One third of parents with HIV in the United States are living in New York City, and New York City’s organization of services allows us to evaluate a representative sample. Caregivers validated the accuracy of parents’ reports of custody plans. Parents were interviewed up to 15 times regarding their plans, and these repeated assessments likely increased the rate of custody planning.

While custody planning increased over time, almost a third of PLH did not make custody plans for their children over 5 years. The youngest children, those most in need of caregivers, were least likely to have plans. Perhaps parents are denying that they may die; there is some...
evidence that denial of one’s health status is associated with increased survival. 20 Alternatively, PLH may intend to make plans, but have higher priorities in coping daily with the range of physical, emotional, and social stressors. Unexpectedly, neither parental substance use nor illness disclosure predicted custody planning.

When made, custody plans were remarkably fluid. Most parents changed custody plans at least once, with parents reporting almost 5 changes for each child. Making multiple changes in custody plans may suggest the importance of these plans for some PLH. Alternatively, the changes may reflect the instability of the parents’ extended families: designated guardians often enter jail or substance abuse treatment programs and new guardians may need to be identified. While plans reflect parents’ concern for their children, frequently changing plans are likely to have a negative impact on children. 12 Children with confidence in custody plans are less likely to be anxious, and a relationship with the caretaker can be developed before the parent’s incapacitation or death.

This study confirms that standby guardianships 27 are being used by parents: 69.1% of PLH who made a legal plan used the standby arrangement. Standby guardianships allow parents to transfer guardianship to a designated caretaker during illness or at death, and enable parents to revoke prior plans should they change their minds about a designated caregiver, an important provision in the setting of unstable social supports. 1,28,29 All states may want to consider adopting this legislative option, not only for PLH but for all parents with a potentially terminal illness.

Parents overwhelmingly depend on their immediate and extended family members (not the children’s other biological parent) to be the caretakers of their children, suggesting the importance of providing increased social, economic, and legal support to the families of PLH. New caretakers need parenting and coping skills to help them provide a strong foundation for children coping with the death of their parent. Of particular concern is the number of older children in the family being asked to assume responsibility for their younger siblings, reflecting potentially inappropriate child parentification. 25

The many children left without a legal custody plan underscores the importance of clinical attention to custody planning for health care providers. These results also suggest potential areas for intervention to improve custody planning for children of PLH. Making custody plans is associated with having a positive-action coping style, suggesting that interventions that build positive coping styles may enhance planning. Depressed parents are less likely to make custody plans, underscoring the importance of mental health services for PLH. Fathers with HIV are more likely to need support in developing custody plans for their children. Furthermore, parents with young children may need increased support to make plans.

As HIV services are increasingly shifted to medical settings, health care providers will have an opportunity to encourage parents’ custody planning. Without a reliable and competent adult to provide for children after parental death, children are at higher risk for emotional and behavioral distress and unstable living situations (including foster care). Clinicians caring for PLH should be aware of the importance of assessing the presence of legal custody plans during the parent’s treatment. Health care settings should provide access to legal and social services to assist families in developing custody plans for all children.

Accepted for publication September 8, 2003.

This study was supported by grants IROI MH49958-04, K-23 MH02050-03, and P30 MH58107 from the National Institute of Mental Health, Rockville, Md.

We thank the parents, caregivers, and adolescents who participated in this study; and the investigators, managers, interviewers, and group leaders who made this study possible.

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REFERENCES

Error in Table. In the article by Jelliffe-Pawlowski et al titled “Risk of Mental Retardation Among Children Born With Birth Defects,” published in the June issue of the ARCHIVES (2003;157:345-350), Table 4 data for severe mental retardation (MR) combined (isolated severe MR and severe MR co-occurring with another disability) were included in the “Severe MR and Other Disability” column, and data for severe MR plus other disability were included in the “Isolated Severe MR” column. Table 4 is reprinted correctly here.

Table 4. Prevalence of Severe Mental Retardation (MR) Among Children With Specific Nonchromosomal Birth Defects vs Prevalence of Severe MR Among Children Without Any Birth Defect*

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Isolated Severe MR</th>
<th>Severe MR and Other Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. per 1000</td>
<td>Ratio (95% CI)</td>
</tr>
<tr>
<td>No birth defect (n = 117 219)</td>
<td>0.3</td>
<td>Referent</td>
</tr>
<tr>
<td>Spina bifida (n = 29)</td>
<td></td>
<td></td>
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<tr>
<td>Other nervous system defect (n = 232)</td>
<td>30.2</td>
<td>88.4 (39.6-197.4)</td>
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<tr>
<td>Other structural defects†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye (n = 204)</td>
<td>24.5</td>
<td>71.8 (28.3-182.0)</td>
</tr>
<tr>
<td>Ear, face, and neck (n = 170)</td>
<td>5.9</td>
<td>17.2 (2.4-125.4)</td>
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<tr>
<td>Bulbus cordis or cardiac septal closure (n = 163)</td>
<td>6.1</td>
<td>18.0 (2.5-130.8)</td>
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<tr>
<td>Other cardiac (n = 56)</td>
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<tr>
<td>Circulatory system (n = 29)</td>
<td>34.5</td>
<td>101.1 (13.9-735.0)</td>
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<tr>
<td>Respiratory system (n = 45)</td>
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<td></td>
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<tr>
<td>Cleft palate and cleft lip (n = 105)</td>
<td>9.5</td>
<td>27.9 (3.8-203.0)</td>
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<tr>
<td>Other upper alimentary tract (n = 203)</td>
<td>9.9</td>
<td>28.9 (7.0-119.5)</td>
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<tr>
<td>Other digestive system (n = 98)</td>
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<tr>
<td>Genital organs (n = 244)</td>
<td>4.1</td>
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<td>Urinary system (n = 112)</td>
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<tr>
<td>Musculoskeletal (n = 85)</td>
<td>23.5</td>
<td>69.0 (16.7-285.3)</td>
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<tr>
<td>Limbs (n = 153)</td>
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<td>38.3 (9.3-158.5)</td>
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<tr>
<td>Other musculoskeletal (n = 90)</td>
<td>11.1</td>
<td>32.6 (4.5-236.8)</td>
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<tr>
<td>Integument (n = 87)</td>
<td>11.5</td>
<td>33.7 (4.6-245.0)</td>
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<tr>
<td>Other and unspecified anomalies (n = 13)</td>
<td>76.9</td>
<td>225.4 (31.0-1639.7)</td>
</tr>
</tbody>
</table>

Abbreviation: CI, confidence interval.

*Children with specific nonchromosomal birth defects excludes all children with Down syndrome or other identified chromosomal defects. Number per 1000 is by birth defect group (survivors to 1 year, nonmilitary births). Ratio is the prevalence of severe MR among individuals with specific birth defect divided by the prevalence of severe MR among individuals without a major birth defect.

†Excludes children with nervous system defects, not mutually exclusive of other structural birth defects.