Predictors of Child Custody Plans for Children Whose Parents Are Living with AIDS in New York City

Marguerita Lightfoot and Mary Jane Rotheram-Borus

Custody planning among parents living with HIV or AIDS (PLHAs) can buffer the negative impact of parental death. The formal and informal custody plans for 594 children by 253 PLHAs and the relationships among custody plans, parental health, and psychosocial status were examined. About one-half of the parents had no formal custody plan. Parents were more likely to make plans for younger children. In addition, formal custody planning was more likely to occur among parents who reported using positive action, withdrawal-depressive, passive problem solving, social support, or spiritual coping styles and who reported higher parental self-esteem. Parent's substance use and emotional distress were not significantly related to custody plans. These data suggest the need for interventions to encourage formal custody planning.

Key words: custody; HIV/AIDS; parents; people living with HIV/AIDS

Worldwide, at least 10 million children have lost either a mother or both parents to AIDS (World Health Organization, 1999). About 125,000 children have been orphaned by AIDS in the United States (Corey, 1999). Consequently, attention is being directed to how parents living with HIV or AIDS (PLHAs) influence the long-term welfare of their children. In the aftermath of losing a parent, children may receive inadequate mental health and medical care, as well as inadequate educational services and planning. One of the most difficult tasks faced by PLHAs is to decide who will care for their children if or when the parent dies. However, insufficient empirical investigation of the custody planning behavior of PLHAs has been done. This article attempts to fill this gap in knowledge by reporting findings from an original empirical investigation and describing PLHA custody planning and factors that predict parental custody planning.

Importance of Custody Planning
Few systems of care exist to help parents with the complex issues involved in custody planning. It is estimated that more than one-half of PLHAs die without a formal plan for the long-term care of their children (Draim, 1993; Rotheram-Borus, Murphy, & Draim, 1997). Although this lack of planning is found among parents living with other chronic diseases (Wills, Peck, Sells, & Rodabaugh, 2001), PLHAs face unique issues. For example, realistic fears of prejudice and discrimination that result from the social stigma of AIDS lead some parents to hide their illness (Rotheram-Borus, Draim, & Reid, 1997). Although it has been suggested that denial of a terminal illness may prolong life (Weisman & Worden, 1975), a consequence of denial may be failure to prepare legal custody plans (Rotheram-Borus, Draim, et al.).

Parental failure to make custody plans may place children at higher risk of long-term negative...
outcomes (Levine, 1994). For example, without a formal custody plan, the state may decide where children are placed. This decision may be inconsistent with a parent’s wishes, and desired guardians may have to fight for custody. Children bereaved by sudden, unexpected parental loss demonstrate more negative outcomes than children who are prepared for such a loss (West, Sandler, Pillow, Baca, & Gersten, 1991). In addition, the legal complications are greater (Levine, 1994).

Factors Predicted to Influence Custody Planning

Prior research suggests that physical and mental health, lifestyle, coping mechanisms, and social supports influence the adjustment of PLHAs (Rotheram-Borus, Murphy, et al., 1997). Consequently, these factors were evaluated as predictors of custody planning. First, we hypothesized that the parent’s health status influenced custody plans. As parental HIV disease progresses, parents are confronted with their own mortality and the decisions surrounding death, including the care of their children. Therefore, we expected that parents who reported more HIV symptoms and lower T-cell counts (a marker for disease progression) were more likely to have custody plans for their children.

Second, we explored the relationship between parent’s mental health and custody planning by measuring the degree of current emotional distress and self-esteem. The PLHAs often report feeling isolated and anxious regarding their health and the health of their children (Levine, 1996). Parents also report high levels of stress and emotional distress, particularly about disclosure of serostatus (Goldie, 1994; Mellins & Ehrhardt, 1994; Rotheram-Borus, Lightfoot, & Shen, 1999). Distress can interfere with PLHAs’ decision making and custody planning. Furthermore, when PLHAs are unable to disclose their illness because of emotional distress, their ability to adequately engage in custody planning is threatened. We expected that parents with high self-esteem would feel more confident making custody decisions for their children and therefore be more likely to have engaged in custody planning.

Illness coping styles of parents was the third predictor of custody planning we examined. PLHAs are likely to have more difficulty coping with their illness than parents with other chronic or terminal illnesses (Zayas & Romano, 1994). If parents had difficulty coping with their illness, we expected that they would also have difficulty planning for custody of their children.

The fourth factor examined was the relationship between custody planning and parents’ substance use. Most parents become infected through high-risk behaviors such as heterosexual sex with an injection drug user or their own injection drug use (Centers for Disease Control and Prevention [CDC], 1998). Therefore, the PLHA lifestyle often includes a history of involvement in a substance abuse subculture. Substance abuse results in higher rates of emotional abuse and neglect, financial problems, physical abuse, and reduced attention to health care, including adherence to medication regimens and medical appointments (Lightfoot et al., 2000; Wright & Devine, 1995). Often, PLHAs are blamed for their serostatus because of their involvement with drugs, which may discourage disclosure (Herek & Capitano, 1993).

The fifth factor examined was the association between custody planning and the size and type of a parent’s support network. Earlier research suggests that a large social support network and diversity in network members facilitate custody planning (Thoits, 1995). For example, having a professional (that is, a teacher or therapist) in one’s social network may increase the likelihood that discussions regarding custody planning occur.

Method

Participants

From August 1993 to March 1995, the Division of AIDS Services in New York City received notification of all people diagnosed with AIDS or advanced HIV who had financial needs. A list of 429 eligible PLHAs was constructed for recruitment into a study that evaluated an intervention to improve behavioral and mental health outcomes among adolescents and their parents with AIDS (Rotheram-Borus et al., 2001). For a family to be eligible for recruitment, the parent had to have been alive during the recruitment period (155 died before recruitment was possible). In addition, the parent had to have at least one child between ages 11 and 18 and permission from a clinical social worker to participate (There were 32 denials.). Of the 429 parents, 65 (15 percent) were untraceable and 46 (11 percent) refused to participate. Extreme illness and institutionalization (that
is, jail) resulted in 11 parents (3 percent) not being recruited. Thus, 84 percent (307 of 364) of the traceable parents, or 72 percent of the total eligible parents (307 of 429), were recruited. Only PLHAs with children living at home at the time of the interview and who reported on the custody plans for their children were included in our analysis. This resulted in a sample size of 253 PLHAs who reported the custody plans for their 594 children at the baseline assessment.

**Procedure**

The PLHAs were assessed at home in individual two-hour interviews; each received $25 for the interview. Interviewers were predominantly African American or Latino (62 percent); five of 15 were bilingual in Spanish and English. Interviewers were certified after being trained in ethics, confidentiality (particularly of PLHAs’ status), child abuse, crisis protocols, HIV/AIDS, and conducting in-home assessments on laptop computers. Quality assurance was maintained by routinely monitoring randomly selected audiotapes; an estimated 10 percent were monitored.

**Assessment**

Baseline assessment completed by the PLHAs included the following areas: custody plans, sociodemographic characteristics, physical health, mental health, coping style, substance use, and social support.

**Custody Plans.** Based on focus groups and pilot interviews with PLHAs and clinical social workers at the Division of AIDS Services, participants were asked to report for each of their children on the following: a potential guardian; relationship of the potential guardian to the child; whether discussions about custody plans had taken place with the potential guardian; if contact was made with a social services agency regarding the custody of the child; whether a will, either prepared by a lawyer or at home, was made to specify the parents’ desires in writing; and if there was a “standby agreement” (that is, a legal document in New York State that outlines the custody plan). These categories were not mutually exclusive. For instance, PLHAs could have indicated that they had a will and made contact with a social services agency about their children’s custody arrangements.

To categorize the concreteness of parents’ custody plans, participants were coded as having made either a formal (that is, arrangements with a social services agency, a will, or a standby agreement) or an informal (that is, discussions with potential guardians) custody agreement for each child.

**Sociodemographic Characteristics.** The PLHAs reported their age, gender, ethnicity, education level, financial condition (that is, very poor, poor, having the necessities, comfortable), and number of children in the household. They also reported the gender and age of each of their children.

**Physical Health.** The PLHAs reported a count of the presence (coded as 1) or absence (coded as 0) of 23 physical health symptoms (for example, fever, night sweats, nausea, and vomiting) and the associated level of distress (ranging from 1 = none to 5 = extreme) for each symptom over the preceding three months. Two indices were calculated—number of physical health symptoms and mean level of distress across all physical health symptoms (Rotheram-Borus et al., 2002).

**Mental Health.** The Brief Symptom Inventory (BSI) (Derogatis, 1992) was administered to assess overall emotional distress. This 53-item scale covers nine primary symptom domains: somatization, obsessive–compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Participants reported the degree of distress for each symptom during the preceding week on a scale from 0 = not at all to 4 = extreme (α range = .67–.89).

The Rosenberg Self-Esteem Scale (Rosenberg, 1965) is a 13-item self-report measure of self-esteem. Participants rated endorsement of 13 items (for example, “You feel you have a number of good qualities”) on a four-point Likert scale ranging from 1 = strongly agree to 4 = strongly disagree.

**Coping.** The Dealing with Illness Scale (Namir, Wolcott, Fawzy, & Alumbaugh, 1987) is a 76-item measure that assesses the degree to which respondents use a particular coping strategy. The participants rated the degree to which a particular coping strategy was used in the preceding three months on a five-point rating scale. Coping items were rated on a scale of 0 = never to 5 = always (α range = .63–.88). Seven coping styles emerged from a factor analysis: positive action (that is, “Began solving problems you had avoided before”); withdrawal–depressive (that is, “Felt depressed and didn’t want to move”); self-destructive–escape (that is, “Used drugs more to forget”);
social support (that is, “Went to a support group”); spiritual hope (that is, “Started going to your place of worship more often”); nondisclosure (that is, “Figured out ways to hide your serostatus from others”); and passive problem solving (that is, “Thought about how you could have done things differently”) (Rotheram-Borus, Murphy, Reid, & Coleman, 1996).

Substance Use. Drug use was reported by specific probes for use of marijuana, crack, cocaine, injecting drug use, heroin, barbiturates, inhalants, hallucinogens, and methamphetamines over the past three months. Four indices were calculated: any alcohol use (coded as 1) or not (coded as 0); any drug use (coded as 1) or not (coded as 0); the number of substances used; and whether or not the parent used hard drugs (for example, crack, cocaine, heroin, barbiturates, inhalants, hallucinogens, or methamphetamines).

Social Support. Based on pilot testing with interviews, and focus groups and the work of Barrera and Ainlay (1983), we developed a social network instrument (Rotheram-Borus, Draidin et al., 1997). Participants were asked to list important people in their lives. Names were listed on a grid and probes about the length, frequency, and nature of the relationship were generated from information about network members. From these items two summary measures were computed: percentage of network members in each of five categories (that is, family member, partner, friend, acquaintance, or professional); and mean level of support across all network members (ranging from 1 = very supportive to 5 = unsupportive).

Results

Predictors

Sociodemographic Characteristics. The 253 PLHAs ranged in age from 25 years to 70 years ($M = 38.1, SD = 5.7, Mdn = 37.0$). Eighty-one percent were mothers. The participants were predominately Latino (45 percent), mostly of Puerto Rican or Dominican descent; 34 percent were African American; 11 percent were white; and 6 percent reported other ethnic backgrounds. Most participants could read English (91 percent). About one-half of the PLHAs had graduated from high school (53 percent). Most households included children (94 percent) and may have included an adult partner (27 percent), the PLHA (11 percent) or grandparent (2 percent), other relatives (8 percent), friends (2 percent), or others (2 percent).

The PLHAs reported the custody plans for all of their children currently living at home. There were a total of 594 children for 253 parents. The PLHAs had a mean of 2.98 children ($SD = 1.69$), who ranged in age from a few months to over 18 years ($M = 12.3, SD = 4.67$). Children were evenly distributed by gender (51 percent were male); 11 percent were age five or younger; 21 percent ranged in age from six to 10 years; 32 percent were between ages 11 and 14; 31 percent were between ages 15 and 18; and 5 percent were over age 18.

Custody Plans. All PLHAs had thought about the custody of their children and had a rough idea of a custody plan. Most had identified the preferred guardian of their children (90 percent). Most of those who had identified a guardian had initiated a discussion with the potential guardian (95 percent). According to the parents, almost all guardians who were asked to be guardians agreed to care for the child (99 percent). The PLHAs reported that their preferred guardians were predominately family members: the child’s aunt or uncle (26 percent), the child’s grandparents (25 percent), the other biological parent (26 percent), or the child’s sibling (11 percent). About one-half of the PLHAs only had an informal custody plan (51 percent) for their children.

About a quarter of the participants had a will or legal document (26 percent) or standby custody agreement (24 percent) delineating the custody plans for their children. In addition, about one in four PLHAs had made custody arrangements through a social services agency (27 percent). These choices were not mutually exclusive, and there was some overlap among choices. Overall, almost one-half of the PLHAs (49 percent) indicated a formal custody plan for their children.

Physical Health. The PLHAs reported experiencing an average of 14 physical health symptoms ($SD = 5.98$). However, parents reported a relatively low level of distress from their physical symptoms ($M = 2.86, SD = 1.02, range = 1.00–5.00$).

Mental Health. Parents reported relatively high levels of emotional distress. The parents’ BSI global index ($M = 2.00, SD = .74$) was significantly higher ($t(1,609) = −12.88, p < .001$) than the normative sample of adult nonpsychiatric patients provided in the BSI manual ($M = 1.35, SD = .37$).
The PLHAs reported a mean score of 3.04 (SD = .47) on the Rosenberg Self-Esteem Scale.

Coping. The PLHAs reported most frequently using positive action coping and passive problem solving in the preceding three months. They also reported at least sometimes using withdrawal-depressive, social support, spiritual hope, and nondisclosure coping techniques in the past three months. The use of self-destructive-escape coping techniques was reported the least often.

Substance Use. Most parents reported abstinence from both alcohol and illicit substance use (77 percent). The mean number of drugs used in the past three months was .39 (SD = .82). Few parents reported using marijuana (14 percent) or other hard drugs (15 percent).

Social Support. The PLHAs reported a mean number of 3.57 members in their support networks. Their social networks consisted of family members (63 percent), partners (14 percent), friends (15 percent), and professionals (3 percent). Also, the participants reported feeling a high level of support (M = 1.36, SD = .75) from their social networks.

Relationship of Predictors to Custody Arrangements

Univariate analyses using logistic regression were used to examine the relationship between each predictor variable and formal custody planning (see Table 1). The child’s age, but not gender, was significantly related to whether a formal or informal custody plan had been made. The PLHAs were more likely to have an informal custody arrangement for older children. Parental age and ethnicity were not associated with making formal custody plans. Several types of the PLHAs’ coping strategies were significantly related to the custody

<table>
<thead>
<tr>
<th>Table 1</th>
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<tr>
<td>Results of Univariate Logistic Regression Analysis Examining the Association of Each Independent Variable on Custody Plans of Parents Living with HIV/AIDS</td>
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<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Odds Ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s age</td>
<td>1.05</td>
<td>1.009–1.088*</td>
</tr>
<tr>
<td>Child’s gender</td>
<td>1.17</td>
<td>0.832–1.635</td>
</tr>
<tr>
<td>Parent’s age</td>
<td>1.03</td>
<td>0.997–1.064</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>0.534–0.726</td>
<td>0.245–1.822</td>
</tr>
<tr>
<td>Support network</td>
<td>1.009</td>
<td>0.941–1.081</td>
</tr>
<tr>
<td>Size of network</td>
<td>1.340</td>
<td>0.812–2.214</td>
</tr>
<tr>
<td>Percent family</td>
<td>0.58</td>
<td>0.389–1.335</td>
</tr>
<tr>
<td>Mean level of support</td>
<td>0.630</td>
<td>0.530–0.750**</td>
</tr>
<tr>
<td>Coping strategy</td>
<td>0.778</td>
<td>0.663–0.913**</td>
</tr>
<tr>
<td>Positive action</td>
<td>0.751</td>
<td>0.615–0.918**</td>
</tr>
<tr>
<td>Passive problem solving</td>
<td>0.692</td>
<td>0.575–0.833 **</td>
</tr>
<tr>
<td>Withdrawal-depressive</td>
<td>0.760</td>
<td>0.635–0.909 **</td>
</tr>
<tr>
<td>Social support</td>
<td>0.852</td>
<td>0.691–1.051</td>
</tr>
<tr>
<td>Spiritual hope</td>
<td>0.755</td>
<td>0.538–1.060</td>
</tr>
<tr>
<td>Nondisclosure</td>
<td>0.520</td>
<td>0.358–0.754**</td>
</tr>
<tr>
<td>Self-destructive-escape</td>
<td>0.989</td>
<td>0.836–1.171</td>
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<tr>
<td>Self-esteem</td>
<td>0.991</td>
<td>0.962–1.020</td>
</tr>
<tr>
<td>Physical health distress</td>
<td>0.856</td>
<td>0.577–1.270</td>
</tr>
<tr>
<td>Physical health symptoms</td>
<td>0.851</td>
<td>0.577–1.270</td>
</tr>
<tr>
<td>Substance use</td>
<td>0.971</td>
<td>0.800–1.178</td>
</tr>
<tr>
<td>Abstinent</td>
<td>0.919</td>
<td>0.584–1.445</td>
</tr>
<tr>
<td>Number of substances</td>
<td>1.001</td>
<td>0.804–1.245</td>
</tr>
</tbody>
</table>

Note: BSI = Brief Symptom Inventory (Derogatis, 1992)

*p < .05. **p < .01.

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It is encouraging to note that these parents were making custody plans, even if informal. This may be surprising given that this sample of parents was experiencing high levels of emotional distress. The PLHAs reported that emotional distress was significantly higher than the normative sample of adult nonpsychiatric patients. These results are consistent with earlier studies that reported high levels of depression and anxiety for people living with HIV (Cates, Graham, Boeglin, & Tielker, 1990; Kelly, Murphy, Bahr, & Koob, 1993; Rotheram-Borus et al., 1999). The stress of parenting may exacerbate the emotional distress of PLHAs. Although these findings suggest the need for psychotherapeutic treatment for this population, the emotional distress of the parents was not significantly related to custody plans. These findings suggest that PLHAs are contemplating custody plans, and given the importance of custody planning for the welfare of children, engaging in the custody planning process is an appropriate activity even for parents considerably distressed emotionally.

The coping techniques used by parents were significantly related to making a formal custody plan for their children. The parents who used positive action, passive problem solving, withdrawal—depressive, social support, or spiritual coping techniques were less likely to have informal custody arrangements for their children. Proactive coping involves problem solving and planning for the issues involved in living with HIV; therefore, one would expect people who are proactive in coping with HIV to enact formal plans for the long-term care and custody of their children. It is surprising that PLHAs who used passive problem solving and withdrawal—depressive strategies were also more likely to have formal custody plans. It may be that PLHAs using passive problem solving or depressive coping mechanisms acknowledge not only their maladaptive coping behavior, but also the possible consequences of that behavior and, therefore, plan more formally for their children. An alternative explanation may be that passive and withdrawal—depressive behavior has drawn the attention of others (for example, family member, case manager, or medical provider) who then influence PLHAs to formalize custody plans. The multivariate analysis indicates that the most significant predictor of custody planning is positive action coping. This finding suggests that improving
proactive problem-solving skills facilitates parents’ finalizing custody plans. Further investigation of the relationship between coping styles and custody planning is warranted.

We expected that the characteristics of the individuals in the support networks would influence custody planning. For example, because custody planning requires specialized knowledge of legal procedures, we expected that support networks that include people with professional expertise would result in more formal custody plans. However, we found no relationship between the characteristics of people in the support network and custody planning. There was little diversity among social network members, and PLHAs reported feeling supported by their social networks. The lack of a significant relationship between custody planning and social network may be because of the homogeneity of those providing support. The majority of the PLHAs’ social networks and preferred guardians were family members. These findings support other research that suggests African American and Latino women are integrally involved in the care of their family members, including extended family (for example, Burnette, 1999; Fuller-Thomson, Minkler, & Driver, 1997; Rotheram-Borus et al., 2002). These findings also suggest that the involvement of family members should be assessed when assisting PLHAs in custody planning for their children.

Conclusion

An increasing number of children are likely to lose one or both of their parents to HIV disease. However, many parents have not formalized custody plans for their children, which can endanger the child’s future. Interventions are needed to help affected families develop viable custody plans. Although PLHAs are informally planning for the custody of their children, this study suggests that interventions designed to facilitate the formation of a formal custody plan should address PLHAs’ coping skills and the children’s age. Interventions that build positive action coping mechanisms are likely to be beneficial. These interventions would focus on building proactive problem-solving skills. For example, helping parents break a problem into smaller pieces and evaluate its pros and cons would be important.

Also, encouraging PLHAs to confront issues that are difficult, challenging, or complicated may facilitate proactive behavior. In addition, facilitat-

ing other positive nondisclosure-specific life changes, such as increasing exercise regimens, may encourage positive action coping strategies, which can influence custody planning. This study also suggests that families with young children be targeted for interventions to increase custody planning. Although this sample reflects the demographics of parents living with HIV (that is, heterosexual, African American, and Latino mothers), it was drawn from one AIDS epicenter—New York City. Further research is necessary to determine the generalizability of these findings to other cultural and geographical contexts. Future research in this area is important because interventions that increase the incidence of formal custody plans are necessary for building a stable future for the children orphaned by HIV disease.

References


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