

# Separation between HIV-Positive Women and Their Children: The French Prospective Study, 1986 through 1993

## ABSTRACT

**Objectives.** We studied the risk and circumstances of separation (due to either maternal death or drug use) between women infected by human immunodeficiency virus (HIV) type 1 and their children.

**Methods.** This analysis was based on the French Prospective Study of Infants Born to HIV-Seropositive Women (1986 through 1993). Data recorded at each follow-up visit included the mother's effective presence with the child and the child's care after separation.

**Results.** A child's cumulative risk of long-term or permanent separation from his or her mother was 37% at 60 months. Maternal drug use was associated with an added risk during the child's first years (adjusted relative risk [RR] = 3.4, 95% confidence interval [CI] = 2.3, 5.0). The risk among drug users was even higher when the mother used injection drugs during pregnancy (adjusted RR = 2.9, 95% CI = 1.9, 4.3). Risk of early separation related to drug use tended to diminish since survey initiation. After separation, 57% of the children were placed through child welfare services and 43% were cared for by relatives.

**Conclusions.** In the French Prospective Study, 2% to 3% of HIV-infected children were separated each year from their mothers as a result of the mother's death from acquired immunodeficiency syndrome (AIDS). Separations related to drug use have decreased over the years, and the family is becoming the most frequent carer after separation. (*Am J Public Health*. 1996;86:376-381)

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### Introduction

Many comments and estimates have been published on the impact of losing one or both parents at an early age through acquired immunodeficiency syndrome (AIDS).<sup>1-5</sup> The World Health Organization estimates that several hundred thousand children have already lost their mothers in Africa,<sup>1</sup> and it has been predicted that by 1995, nearly 25 000 American children will be in this situation.<sup>6</sup> Such estimates are based on fertility and mortality rates among women infected with the human immunodeficiency virus (HIV) in the geographic area concerned.<sup>7</sup> In industrialized countries, there is an added risk of separation when the mother is infected through intravenous drug use: the risk of death from AIDS is added to the risk of separation due to the behavioral disorders that sometimes accompany active drug use.<sup>8-10</sup> Better knowledge of the risk and circumstances of separation is essential to organize the necessary social support structures. In addition, knowledge of how the different care options are used is crucial for establishing strategies adapted to these children's social and familial settings. The French Prospective Study of Infants Born to HIV-Seropositive Women, which was set up in 1986, provides an opportunity for a longitudinal analysis of this problem in an industrialized country among nearly 1500 mother-child pairs over a period of 8 years.

### Methods

#### *The French Prospective Study*

Full details of the cohort have been published elsewhere.<sup>11</sup> Briefly, children

are monitored from birth to the age of 36 months if they are not infected by HIV and for as long as possible if they are infected. Information on the children is collected by means of questionnaires addressed to the participating centers at regular intervals (9, 18, and 24 months, and then every 6 months). Sixty-two pediatric and obstetric units throughout France enroll all HIV-infected mothers and their newborns, with the parents' informed consent. With 350 to 400 inclusions a year since 1990, this survey covers 75% to 80% of the estimated total of such births in mainland France.<sup>12</sup>

Although no data are collected in this pediatric cohort study on the progression of maternal HIV infection after the child's birth, the mother's presence or

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absence is routinely recorded at each visit. The notion of separation in this study includes death of the mother from AIDS but also includes all other situations in which the mother does not live with the child and does not effectively participate in his or her upbringing. This analysis takes into account only long-term separations (more than 9 months) and permanent separations. When children are separated from their mother, it is noted whether they are cared for by their own family (including the father) or through child welfare services (foster family, institutions, or adoption). Separations due to hospitalization of the child are not considered in this analysis.

### *The French Child Welfare System*

Aide Sociale à l'Enfance, a state structure now decentralized to county level, forms the backbone of child welfare services in France. If a child's mental or physical health is threatened, he or she can be separated from the mother through a court order, once a judge has determined the degree of danger. The judge recommends either that the child be maintained within the family with psychosocial support (an option not included in our definition of separation) or that the child be separated from her or his parents. The judge hands the child over either to other family members or to the welfare services (i.e., Aide Sociale à l'Enfance). If either parent dies, a judge names a guardian and family advisor. In most cases, a family member plays the role of legal guardian; however, if that is not possible, an administrative guardianship is organized. A mother can also decide freely to place a child in care, either temporarily or permanently. In terms of care modalities after separation, we distinguished care within the extended family from institutional care. The mode of care is also under direct responsibility of Aide Sociale à l'Enfance. The term "institutional care" covers several options, including permanent adoption, instances in which the child is a charge of the state, care within a foster family with financial support, or a nursery with or without medical care. Family-type care is always favored, even though the nature of the underlying illness can make it difficult to find a caregiver. Some counties pay a supplement to families that take in a sick child. Whether privately run or charitable, all child care organizations are state

approved and under strict control of Aide Sociale à l'Enfance. Relatives who agree to care for the child can receive financial support from the state.

### *Statistical Analysis*

Quantitative variables are expressed as means and standard deviations. The Cochran test was used for comparisons of means, and the chi-square test was used for comparisons of percentages. To determine the independent effect of the mothers' and children's characteristics on the risk of mother-child separation, three multivariate Cox models were applied to all mother-child pairs and then to two subgroups defined according to the way in which the mother was infected. Multiple logistic regression analysis was used in examining the relationships between the mothers' and children's characteristics and the mode of care after separation. The independent variables significantly related to dependent variables were selected according to the ascending and descending step-by-step methods of the Cox and logistic models. However, the adjusted relative risks (RRs) and odds ratios (ORs) and their 95% confidence intervals (CIs) were estimated by using saturated models. Some analyses were univariate because of the small number of cases involved or specific calculations concerning a limited period of time. In these cases, the 95% confidence intervals for relative risks were estimated according to the Mantel-Haenszel method for prospective cohort studies. All *P* values are two-tailed, and the threshold of significance was set at .05. The different curves were established according to the life table technique. Univariate analyses were performed with SAS software (SAS Institute, Cary, NC). The Cox models and the logistic regression were performed with BMDP statistical software.

## **Results**

### *Demographic Characteristics of Mothers*

Between January 1, 1986, and December 31, 1993, 1758 mother-child pairs were enrolled in the French Prospective Study of Infants Born to HIV-Seropositive Women. The analysis described here involved the 1470 mother-child pairs for whom at least the first follow-up questionnaire (at 9 months) was available. Children born to mothers infected by HIV type 2 (HIV-2) were not included in this

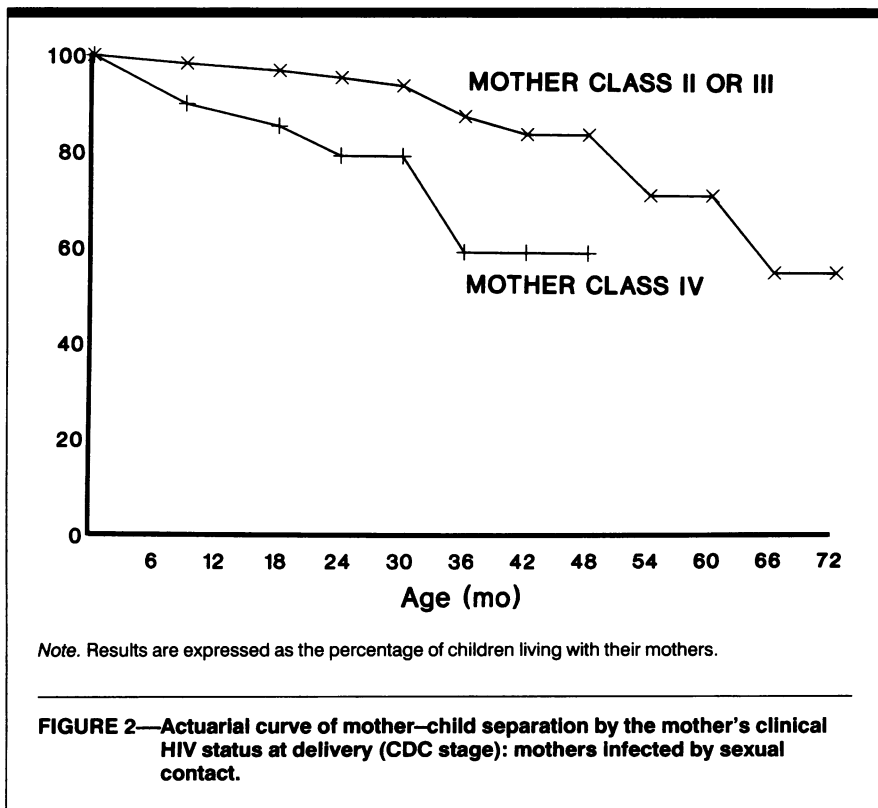
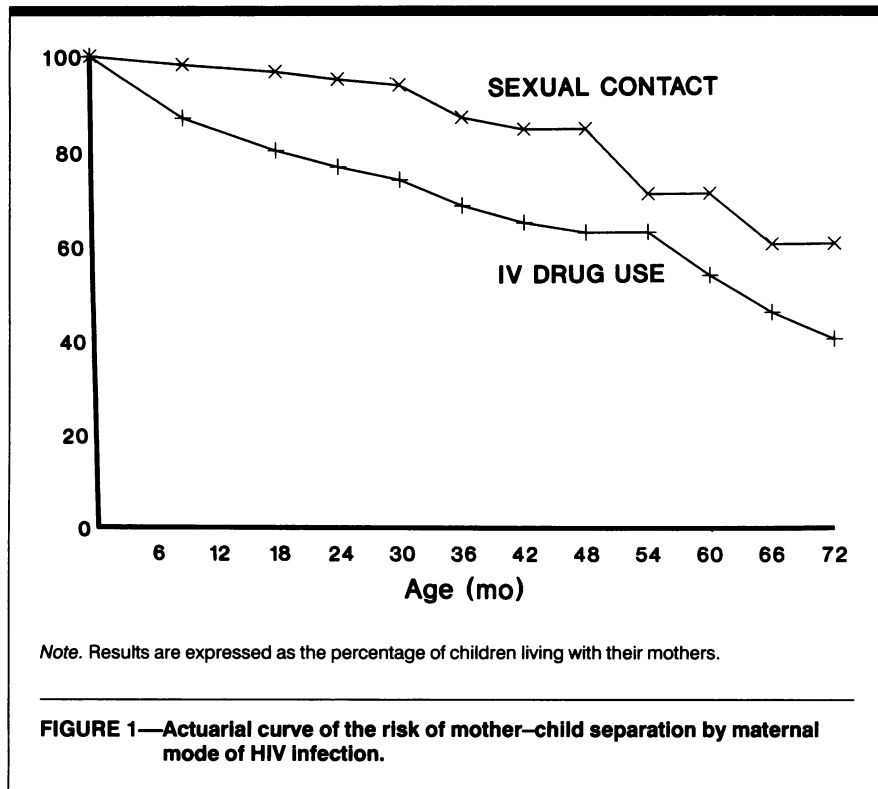
analysis. The mode of infection was known for 1443 women, and the breakdown was as follows: intravenous drug abuse, 43% (*n* = 614); transfusion, 3% (*n* = 49); and probable heterosexual contact, 54% (*n* = 780). There were not enough mothers infected by transfusion (*n* = 49) to be included in this analysis. The distribution of the modes of infection changed during the study: the proportion of women infected through intravenous drug abuse fell from 69% in 1986 to 26% in 1992, while the proportion of women infected through sexual contact increased from 28% in 1986 to 69% in 1992.

Among the women infected by sexual contact, 45% were from Africa, 9% were from the Caribbean, and 46% were from Europe. The steady partners of European women infected by sexual contact were infected through intravenous drug abuse in 72% of cases. On average, the women infected through intravenous drug abuse and sexual contact were, respectively, 26.6 years of age (*SD* = 3.9) and 27.0 years of age (*SD* = 4.7) at the time of delivery. Maternal HIV clinical status at the time of delivery was known in 1300 cases: 1053 women (81%) were asymptomatic (Centers for Disease Control and Prevention [CDC] stage II), 137 (11%) had polyadenopathies (CDC stage III), and 94 (7%) had AIDS or an AIDS-related complex (CDC stage IV). Sixteen women seroconverted during the pregnancy (CDC stage I). This distribution has remained stable throughout the study.

As of January 1, 1994, the mean follow-up of the 1470 mother-child pairs (the minimum in this analysis was 9 months) was 52.0 months (*SD* = 22.8); 67% of the children had been followed for more than 18 months. The HIV transmission rate, as determined by serological testing at the age of 18 months or death from AIDS before this age, was 19.8% (211/1063). Children with a follow-up of less than 18 months were considered infected in this analysis if, on two occasions, they were positive in at least one of the three classical tests: p24 antigenemia, lymphocyte coculture, or viral DNA detection by means of polymerase chain reaction.

### *Mother-Child Separation*

*All mother-child pairs.* The family situation was stated on 92% of the 5039 available follow-up questionnaires. Six percent of the children were separated from their mothers 9 months after birth. The incidence increased to 21% at 36



months and 37% at 60 months. A multivariate Cox model was performed to take into account the effect of potential confounding factors on separation. The studied variables were mode of maternal HIV

infection (sexual route vs intravenous drug use), mother's clinical CDC stage at delivery (stage II/III vs stage IV), mother's age at delivery (<30 years vs ≥30 years), child's year of birth (prior to 1989,

1989/90, 1991 or later), and child's HIV status (uninfected vs infected). Only two variables selected by the model were independently associated with separation. The risk of separation was higher for the children whose mothers were infected through intravenous drug use than for the children of mothers infected by the sexual route (adjusted RR = 3.4, 95% CI = 2.3, 5.0;  $P < 10^{-4}$ ). The risk was also higher for children whose mothers were at CDC stage IV at delivery than for those whose mothers were at stage II/III (adjusted RR = 2.52, 95% CI = 1.5, 4.1;  $P < .001$ ).

*Children born to mothers infected sexually.* The incidence of early separation (before the age of 9 months) was 2%; this rate increased to 13% at 36 months and 30% at 60 months (Figure 1). A multivariate Cox model was applied to this subgroup; the same variables as for the whole group, along with mother's ethnic origin (African/Haitian vs European), were used. In this case, the only variable identified by the Cox model was maternal CDC stage at delivery (adjusted RR = 4.3, 95% CI = 1.8, 10.1;  $P < .005$ ). There were few separations (4%) before the age of 2 years when the mother was at CDC stage II/III; the separation rate was 21% when the mother was at CDC stage IV. The corresponding figures at the age of 36 months were, respectively, 12% and 40% (Figure 2).

*Children born to mothers infected through intravenous drug use.* The risk of separation in this subgroup was higher than in the subgroup of mothers infected by the sexual route; at the earliest time point (9 months of age), 13% of these children were separated from their mothers, in comparison with 2% of those whose mothers were infected by the sexual route. All of the mothers in this subgroup were of European origin. We added to the Cox model the absence or presence of a neonatal withdrawal syndrome, which reflects active intravenous drug use during pregnancy. This variable was strongly associated with separation (adjusted RR = 2.9, 95% CI = 1.9, 4.3;  $P < 10^{-4}$ ), and again maternal CDC stage was linked to risk of separation (adjusted RR = 1.9, 95% CI = 1.0, 3.5;  $P < .05$ ). At 9 months of age, 31% of the children who had a withdrawal syndrome at birth were no longer living with their mothers, in comparison with 8% of the other children born to mothers infected through intravenous drug use (Figure 3).

The subsequent risk of separation increased at a lower rate, similar to the risk observed for women infected by sexual contact.

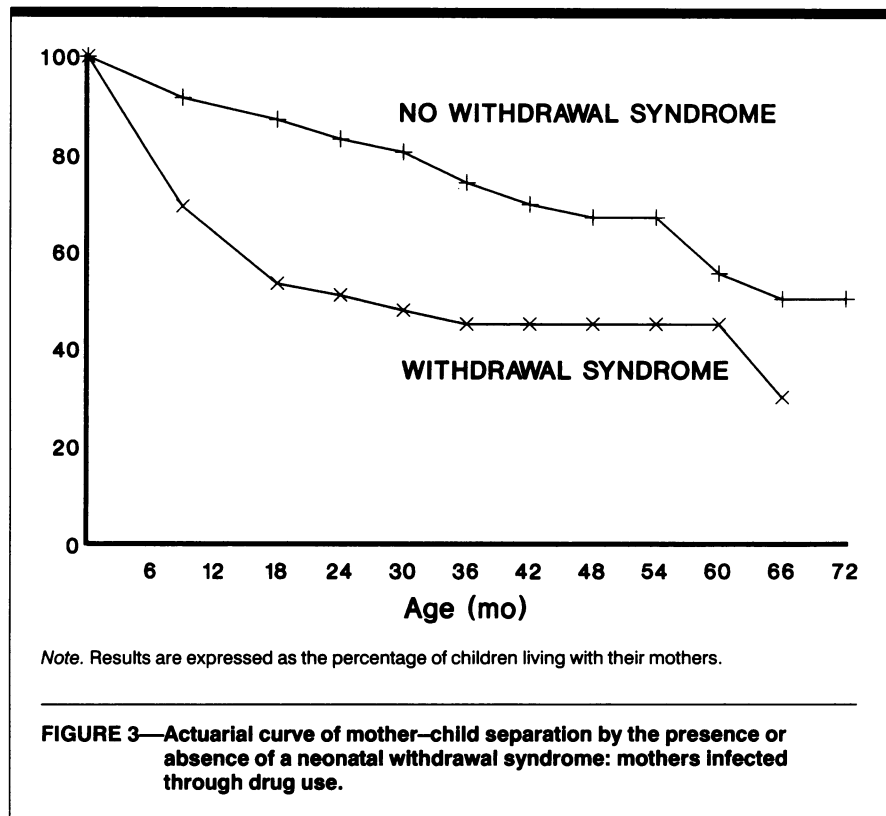
Early separation (before 9 months of age) from mothers infected through intravenous drug use became less frequent during the course of the cohort study, the incidence falling from 19% (n = 262) in 1986 through 1988 to 10% (n = 153) in 1989/90 and 8% (n = 123) in 1991 through 1993 (P < .003). These calculations could not be included in the multivariate analysis because they were limited to separations occurring before the age of 9 months.

*Care Setting after Separation*

Overall, 43% of the children were cared for by their biological or extended families after separation, and 57% were placed by child welfare services. To determine the independent influence of mode of maternal HIV infection, mother's CDC stage and age at delivery, child's age at separation (<24 months or ≥24 months), child's year of birth, and child's HIV status on the risk of institutional care, we performed a multiple logistic regression analysis (Table 1). Both ascending and descending step-by-step processes involved the selection of only one variable: child's age at separation (adjusted OR = 7.7, 95% CI = 2.7, 22.4; P < 10<sup>-4</sup>). When this parameter was studied by using smaller age groups, the family's role increased gradually: 25% of children who were separated from their mothers before 9 months of age were cared for by their families, in comparison with 50% when separation occurred between 9 and 24 months and 73% when separation occurred between 24 and 36 months (Figure 4). None of the children separated from their mothers after the age of 42 months were placed by child welfare services.

In the univariate analysis of the subgroup of children separated from a mother infected by the sexual route (the number of such cases was too small for the multivariate analysis), ethnic origin was significantly linked to the care setting: children of African and Haitian origin separated from their mothers (n = 18) were twice as likely as the other children to be placed in care by the welfare services (RR = 2.1, 95% CI = 1.1, 3.8; P < .02).

The proportion of children cared for by their families tended to increase during the cohort study, regardless of the age at separation: 21% of the children born in



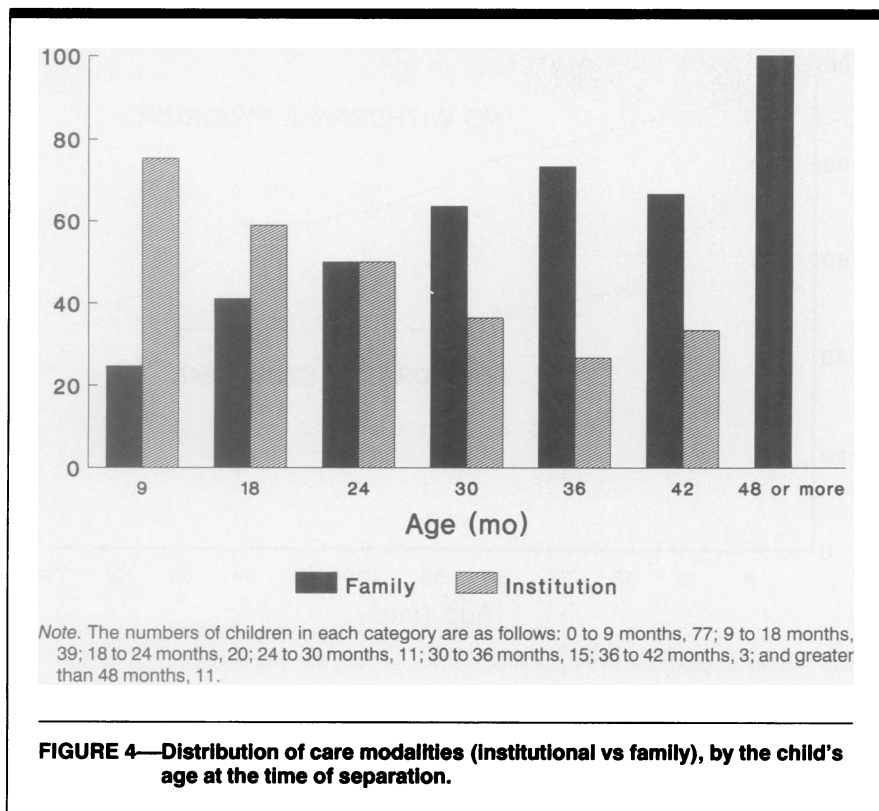
**TABLE 1—Multivariate Logistic Regression: Foster Care Compared with Extended Family Care in 130 Children Separated from HIV-Positive Mothers, the French Prospective Study, 1986 through 1993**

Independent Variable	Crude Odds Ratio	Adjusted Odds Ratio (95% CI)	P
Child's age at separation, mo <24 (n = 96) ≥24 (n = 34)	6.1	7.7 (2.7, 22.4)	<10 <sup>-4</sup>
Mode of maternal HIV infection Sexual route (n = 95) Intravenous drug use (n = 35)	1.3	1.0 (0.4, 2.6)	NS
Mother's age at child's birth, y <30 (n = 100) ≥30 (n = 30)	0.7	0.6 (0.2, 1.7)	NS
Clinical CDC HIV stage of mother Stage II/III (n = 112) Stage IV (n = 18)	1.7	2.0 (0.6, 6.5)	NS
Child's year of birth 1988 or earlier (n = 62) 1989/90 (n = 53) 1991 or later (n = 15)	0.7 1.0	0.9 (0.4, 2.0) 1.7 (0.5, 5.8)	NS NS
Child's HIV status Uninfected (n = 95) Infected (n = 35)	1.7	0.7 (0.3, 2.0)	NS

Note. Adjusted odds ratios and 95% confidence intervals (CIs) were estimated by a saturated multivariate logistic model.

1986 through 1988 and separated at 9 months of age were cared for by their families, in comparison with 38% of those

born in 1991 through 1993. These differences were not, however, statistically significant.



**FIGURE 4—Distribution of care modalities (Institutional vs family), by the child's age at the time of separation.**

## Discussion

This study involved a large number of mother-child pairs followed over an 8-year period. The main weakness was the lack of precise information on the mother's situation at the time of separation. By separately analyzing the mothers infected through intravenous drug use and those infected by the sexual route, we postulated that the latter were separated from their children exclusively through maternal HIV disease or death. This was confirmed by the analysis of the cumulative incidence of separation according to CDC stage at delivery. About 2% of children lost their mothers through AIDS each year in this study, in keeping with current data on the mortality rate among HIV-1-infected mothers in industrialized countries.

As in the United States,<sup>8</sup> there was an added risk of separation when the mother's HIV exposure mode was intravenous drug use. Behavioral disorders, social exclusion, and incarceration, which are sometimes related to intravenous drug use, can lead to early separation, often before the age of 9 months. In our study, this was particularly the case when the child had a withdrawal syndrome at birth, which is an indirect marker of continued drug use during pregnancy. It is difficult to compare experiences in different coun-

tries because the factors that lead to a child being separated from his or her drug-using mother are hard to quantify. They depend, among other things, on the type of drug use, the mother's social and familial setting, her history, and the regulations adhered to by the relevant welfare services. We would like to focus here on the changing nature of this problem: it is interesting to note that the risk of early separation from mothers who were or had been intravenous drug users tended to diminish between 1986 and 1993. The stable proportion of neonates who had a withdrawal syndrome during the study period (results not shown) strongly suggests that pre-pregnancy counseling of women at high risk of abandoning their infants did not account for this trend. In contrast, the trend may reflect the impact of better medical and social support during and after pregnancy. In other words, certain situations that led to separation in the mid-1980s are now better dealt with.

The main value of this study is that it shows the important and growing involvement of the family in caring for children separated from their mothers through AIDS and maternal drug abuse. Contrary to Caldwell,<sup>8</sup> we did not find that intravenous drug use significantly influenced the care setting after separation, but clearly,

international comparisons are impossible: there can be large differences within a given country,<sup>8</sup> and our analysis may have been biased by a lack of statistical power resulting from the low number of events. There is indeed a discrepancy in the fact that early separation is associated with both drug and institutional care, but drug care does not seem to be associated with institutional care. The dynamics of the situation in each country are interesting. In France, the role of the family increased gradually with children's age at the time of separation, becoming largely predominant when separation occurred after 36 months. This may suggest that attachment is stronger among relatives when they have seen the child growing up. By helping the family to prepare for the consequences of the mother's death for the child, it may be possible to promote care in the family rather than in an institutional setting. Indeed, planning for the child's future should be an integral part of comprehensive medicopsychosocial case management of families affected by HIV/AIDS. Most of the children were taken in by their grandparents, who are also entitled to adequate support and empowerment in this context. It is clearly more difficult to plan for the child's future when the mother is an immigrant (African or Haitian in this cohort), given the profound family disruption occurring at the time, and it is not surprising that a significantly higher proportion of these children had to be placed by foster care agencies.

Cross-generational solidarity within families is certainly the best solution to the potential social catastrophe generated by AIDS, but this will necessitate targeted and timely support alternatives. The goal is to avoid placing children in institutions, where they face a further risk of stigmatization and exclusion. □

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