

Families affected by HIV: parents' and children's characteristics and disclosure to the children

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Abstract *The reduced risk of mother-to-child transmission due to improved HIV treatment has resulted in an increasing number of healthy children born to mothers living with HIV. The study's objective was to identify the number of parents or caregivers in a sample of persons living with HIV in Flanders, the number of HIV-affected children as well as specific family-related characteristics. Using a structured survey quantitative data were assessed on a total of 628 patients at three Flemish Aids reference centres. Qualitative data were collected in a small sub-sample of African caregivers living in Flanders. Twenty-seven per cent of the overall sample had children younger than 18 years, totalling 165 HIV-affected families with 279 children. Parents from developing countries had significantly more children than European parents. One hundred and eighty-two (68%) of all children were HIV-negative, while the HIV status of 75 (28%) was unknown. Disclosure rate was low: 26 (10%) children were aware of the parental HIV disease. The study shows that HIV-affected families have to deal with complex psychosocial issues such as migration, family illness, family secrecy around HIV and disclosure. Service implications are discussed.*

Introduction

The recent improvements in HIV therapy have resulted in a substantial decrease in mother-to-child transmission (EuroHIV, 2002; Gottlieb, 2002). Provided that mother and child receive prophylactic state-of-the-art treatment, vertical transmission has been brought down to less than 2% (Shapiro *et al.*, 2002). The desire of women living with HIV to have children has increased (Berer, 2002), and subsequently more children have been born to HIV-positive mothers. With a changing perception of HIV as a medically manageable and chronic disease, this trend is likely to persist in the future.

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Parents or caregivers living with HIV may have to face various challenges during their parenthood. While they may have more time to parent, they have to cope with their HIV diagnosis, disease progression and complex adherence issues, as well as with psychological problems such as feelings of guilt or concerns towards the future of their children. Various studies in the USA (Dutra *et al.*, 2000; Lee *et al.*, 2002; Rotheram-Borus *et al.*, 2003) looked at the impact of parental HIV on (adolescent) children, whereas European research on this topic is scarce. In families living with HIV in studies in the USA, adolescents typically were aware of the parental disease and were called upon to assist in the daily household. Highly active antiretroviral therapy (HAART), widely available since 1996 in Western European countries, might have influenced the coping with HIV within affected families: as caregivers remain healthy for a longer time thanks to effective medical treatment, disclosure rates appear to be lower (Thorne *et al.*, 2000).

The present study had two objectives. The primary objective was assessing the scope of the problem, i.e. the number of parents or caregivers living with HIV (CLWH), and the number of children affected by parental HIV. Up to now, data on the patients' family background have not been available on a systematic basis, but are considered important for targeted service planning and delivery. The study's secondary objective was identifying specific characteristics of CLWH and their children, such as disclosure of parental HIV status to the children.

Methods

A structured survey form was developed to assess the number of CLWH, the number of HIV-affected children and demographic, medical and family-related characteristics. This survey was given to every consecutive patient consulting three Flemish Aids reference centres (ARCs) between June and December 2002. A physician or study nurse interviewed the patient and filled in the form. The definition of 'caregivers' used in this study refers to people with children under the age of 18. Caregivers include biological parents, as well as adoptive and foster parents.

In addition, a small-scale qualitative study took place in a sub-sample of 13 African caregivers assessing the psychosocial problems of CLWH in detail (in the present paper we only refer to the qualitative results relating to parental disclosure).

Descriptive analysis was carried out using SPSS to describe patients' and children's characteristics; CLWH and people living with HIV (PLWH) without children were compared computing *t*-tests, median tests or chi-squares according to the class of variables.

Results

A total of 628 consecutive patients consulting three ARCs (Institute of Tropical Medicine (ITM), Antwerp, University Hospital Leuven (UZL) and the Academic Hospital of the Free University, Brussels (VUB)) were assessed (493 or 78% consulted the ITM; 100 or 16% the UZL, and the remaining 35 or 6% the VUB). A total of 168 patients (27%) reported having children under the age of 18.

Characteristics of study participants

Table 1 shows the differences between CLWH and PLWH without children. One hundred and ninety-two (31%) of the total sample were women. However, among the caregivers, more

Table 1. Characteristics of study participants

	CLWH		PLWH		<i>p</i>
	<i>n</i>	(%)	<i>n</i>	(%)	
Female gender	98	58	94	20	<0.0005 (chi square)
Median age	38.7	—	41.4	—	>0.000 (median test)
Migrants (origin from developing countries)	104	63	64	17	<0.0005 (chi square)
Belgian citizenship	76	48	291	82	<0.0005 (chi square)
Heterosexual HIV transmission	132	80	127	35	<0.0005 (chi square)
ARV medication	138	85	300	81	NS
CD4 counts (median)*	421.0	—	474.5	—	NS
VL (median)*	50.0	—	50.0	—	NS
Median time since HIV diagnosis	5.7	—	6.6	—	NS

* for PLWH on ARV only.

than half (58%) were women. The gender difference between CLWH and PLWH without children was significant. The median age in the total sample was 40.3 years, with an age range between 19–76 years. Caregivers were significantly younger than PLWH without children.

In the total sample, Belgium was predominantly the country of origin. The number of migrants stemming from developing countries was significantly higher among CLWH than among PLWH without children. A lower percentage of CLWH had Belgian citizenship than of PLWH without children. Forty caregivers (25%) reported a legal residence permit, 29 (18%) reported an asylum-seeking status and five caregivers (3%) reported an illegal status (the statutory situation of eight caregivers or 5% was unknown to themselves; there were ten missing cases).

Unprotected heterosexual transmission was the predominant source of HIV infection in the overall sample (259 or 49%). While homo- or bisexual contacts were the primary route of HIV transmission for PLWH without children (223 or 61%), heterosexual HIV transmission was the predominant source of infection for CLWH (132 or 80%). This difference was statistically significant (see Table 1).

There were no differences between CLWH and PLWH without children with respect to the medical parameters assessed (see Table 1). Most patients took antiretroviral medication at the time of data assessment (438 or 82% in the total sample), with a slightly higher percentage among the caregivers. Relatively high CD4 counts were reported (the most recent CD4 count was lower than 200 cells per mm³ blood only for 22 or 13% of the caregivers and for 38 or 10% of PLWH without children, respectively). Likewise, the majority in both groups had undetectable viral loads. Both groups had learned about their HIV infection some years ago (median time = 5.7–6.6 years). A relatively small percentage in both groups had learned about their HIV infection more recently, i.e. during the previous year (15 or 9% of the caregivers versus 20 or 6% of the PLWH without children).

Family characteristics

Caregivers reported a total of 279 children under the age of 18, living in 165 families. Most caregivers had one child (78 or 48%), followed by families with two children (54 or 33%). The median number of children was two (mean = 1.8; SD = 1.1; range = 1–8 children). Caregivers from developing countries had significantly more children (median = 2; range = 1–8) than caregivers from European countries (median = 1; range = 1–4; median test; $p < 0.006$).

Of the caregivers, 23% were single parents (the majority being women, i.e. 26 mothers and nine fathers, equalling 74% versus 26% of all caregivers who were living only with their children and no other adult in the same household). The vast majority of all caregivers (75 or 50%) lived with partner and children in one household, and the remaining 41 parents (27%) did not live together with the children. Twenty-three or 15% lived alone, and 12 (4%) were currently living with a new partner and their children lived elsewhere (the remaining six or 4% being coded as 'other').

Looking in-depth into the characteristics of parents currently not living with their children, we found that migration contributed significantly to family separation: a substantial number of these parents were migrants (mainly from sub-Saharan Africa) and their children lived with relatives in their respective country of origin.

Children's characteristics

Data were reported on a total of 279 children under the age of 18. The majority of these children were pre-adolescents and adolescents (median age = 11 years; range = 2 months–17.11 years). Children between seven and 12 years of age constituted the largest group (110 or 40%), followed by the age group above 12 years (102 or 37%). Thirty-two or 12% were pre-school children (aged between four and six years) and 26 (9.5%) were toddlers (aged between one and three years). Five babies (2%) had not yet reached their first birthday.

Children's gender was equally distributed (137 or 51% girls and 130 or 49% boys; information was missing for 12 children). Most of the children were biological children (259 or 95%), the remaining were stepchildren or adopted children (information was missing for seven children).

Table 2 shows the characteristics of the affected children. The majority of them were not HIV infected. However, there was a relatively large group of children whose HIV status was reported as unknown. In many cases, this concerned parents who currently did not live with the child (43 children or 63% of all cases with unknown status). Parents of 59 children (23%) were both living with HIV. Again, in 74 cases (29%) the interviewed parent did not know the other (biological) parent's HIV status. The other parent of 21 children (8%) had already died. However, we could not systematically assess whether this was due to AIDS.

The vast majority of the children did not know about the parental HIV status. Relatively small percentages of children were either aware of it (10%) or the interviewed parent did not know whether HIV had been disclosed to the child (9%). Table 3 indicates the relationship between age distribution and parental disclosure of HIV towards the children.

Overall, disclosure occurred in a total of 19 families (totalling 26 children or 10% of all children being informed). Also, in the adolescent age group disclosure occurred rarely. The median age of children to whom the parental disease had been disclosed was 16 years, whereas the median age of the children not aware was ten years. Median age and disclosure were significantly associated (median test; $p < 0.000$). Also, caregivers' ethnicity was significantly

Table 2. *Characteristics of children affected by HIV*

	Yes		No		Unknown		Total	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>N</i>	(%)
Child is HIV-positive	12	4.5	182	68	75	28	269	100
Other parent is HIV-positive	59	23	125	48	74	29	258	100
Disclosure of parental HIV	26	10	216	81	25	9	267	100

Table 3. *Disclosure and children's age distribution*

Age group	Aware		Not aware		Unknown		Total	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>N</i>	(%)
4–6 years	1	3	27	87	3	10	31	100
7–12 years	5	5	86	81	15	14	106	100
13–18 years	20	21	69	72	7	7	96	100
Total	26	11	182	78	25	11	233	100
Mean age	14	—	9.7	—	11.0	—	—	—
Standard deviation	3.3	—	4.9	—	3.8	—	—	—
Median age	16.0	—	10.0	—	11.0	—	—	—

associated with parental disclosure. Whereas 17 children (20.5%) from European families were aware of the parental HIV status, this rate was significantly lower (nine children or 5%) among families originating from developing countries (chi-square test; $p < 0.0005$).

The qualitative data (assessed through in-depth interviews in a sub-sample of 13 African CLWH with 28 children) revealed some important reasons for not disclosing. Generally, there was strong resentment towards disclosing, and many interviewed caregivers reported multiple reasons not to do so (see Table 4). However, in most cases, caregivers were not convinced they had taken the right decision. A commonly expressed fear was that children would learn about parental HIV from other sources, in turn leading to a situation which they felt should absolutely be avoided. Hence, nine caregivers (of 13) expressed their need for adequate professional support to be better prepared for the process of disclosure within the family.

Discussion

In this study, 27% of the PLWH had caregiving responsibilities. The study participants, however, cannot be considered representative of the general population of PLWH in Belgium. Comparing the results with national HIV surveillance figures showed that women, heterosexuals and migrants were under-represented in our sample. Therefore one might assume that in the general population of PLWH in Belgium the rate of CLWH could probably be higher. The Belgian situation is particular within a European perspective in that a relative high percentage of AIDS patients (35%) originates from a migrant background (College van Aids Referentielaboratoria, 2002). We do not have any further biographical information on the study participants belonging to migrant populations (32% of the overall sample), but the number of persons with an uncertain statutory status provides some indication about the possible magnitude of existing social and legal problems. It is therefore likely that CLWH may

Table 4. *Obstacles to disclosure*

Qualitative data assessment* (in-depth interviews)	<i>n</i>	(%)
Emotionally too disturbing for the child	18	67
Anticipated negative consequences related to stigma	16	59
Child considered too young	11	41
Caregiver's perceived incapability to disclose	4	15
No perceived benefits for the child	1	4

* Data provided on 27 children; multiple answers.

be confronted with complex issues of social exclusion and poverty, in addition to their health problems.

The data on participants' statutory status reflected the current situation at the time of data assessment. As people can easily change from belonging to one group to another (e.g. when political asylum has been denied or a residency permit obtained), this can be considered a rather volatile status. In particular, one can assume that caregivers, who are identified either as asylum seekers or as having an illegal or unknown status, may be confronted with a lot of uncertainty and stress regarding their personal future. Given the socio-economic constraints usually related to migration (Haour-Knippé, 2000), services delivered to this particular group should focus not only on the cultural but also on the family context. As services primarily target the individual patient rather than the family system, family-related needs tend to be overlooked (De Matteo *et al.*, 2002).

Based on the evidence from research looking at the family context of HIV (Antle, 2001), the specific stressors of parents living with HIV (Murphy *et al.*, 2002; Rotheram-Borus *et al.*, 1998; Telingator, 2000) and the impact on adolescent children in the USA (Rotheram-Borus *et al.*, 1997, 2003; Wright & Draimin, 2000), as well as from our own results, we conclude that there is an urgent need to learn more about the functioning of CLWH and the impact of parental HIV disease on HIV-affected children.

Caregivers assessed in this study appeared to be relatively healthy. Subsequently, one may assume that their parental functioning will be affected less on the immediate practical level. However, literature on other chronic diseases such as cancer or diabetes has shown that the impact of chronic parental disease on emotional and relational family issues can be significant (Steele *et al.*, 1997).

One of the study's crucial results pertains to intra-familial HIV-related communication—an emotionally burdening challenge with which CLWH are confronted. The assessed overall rate of disclosure (10%; i.e. unrelated to age groups) is lower than disclosure rates found in the USA, which differed according to various studies between 32% (Shaffer *et al.*, 2001), 52% (Mellins *et al.*, 2002), 57% (Kirshenbaum & Nevid, 2002) and 75% for older and 40% for younger children, respectively (Lee & Rotheram-Borus, 2002). Our findings are in line with other European studies reporting disclosure rates to children of 11% (Åsander *et al.*, 2004; Thorne *et al.*, 2000). Another Flemish study found a disclosure rate to children as low as 4% (Van de Velde, 2003).

When interpreting levels of disclosure, it is important to look at the personal and medical context (i.e. caregivers' and children's characteristics such as age, coping style, intra-familial communication style, access to treatment, treatment efficacy, etc.). If parents benefit from effective ARV treatment, the decision not to disclose could become a feasible option and hence disclosure will occur less likely. It has been shown that the stigma associated with HIV and the related fear of discrimination made parents decide not to disclose their own HIV status to their children (Gewirtz & Gossart-Walker, 2000). Various studies have shown that HIV-associated stigma is still highly persistent, particularly in African communities (European Project Aids and Mobility, 1998; Miller & Murray, 1999).

The qualitative data assessed in this study showed that caregivers' decisions not to disclose were partly determined by the wish to protect children from anticipated harmful consequences of disclosure. However, as Pilowsky *et al.* (2000) point out, sharing information openly within the family might facilitate healthy adaptation in children having to cope with parental disease. They reported two major concerns as decisive for parental disclosure: the need for future care arrangements and the concern to do 'the right thing'. While the first reason obviously has become less influential with HAART, the second concern certainly needs

further attention. Our data show that caregivers indeed are struggling with issues of when and how to disclose their HIV status to their children.

Integrating a family perspective into psychosocial support of caregivers living with HIV calls for assisting them in a tailor-made, culturally sensitive manner in issues such as: how to deal with HIV in a child-adequate, age-specific way, what to tell and what not to tell, how to deal with one's own emotions and fears vis-à-vis the children, balancing the advantages and disadvantages of parental disclosure in specific personal and family contexts, etc. Models of good practice that were identified in the area of other chronic diseases, such as cancer for instance, could provide some interesting parallels in this respect (Romer *et al.*, 2002; Worsham *et al.*, 1997). Understanding more about factors that influence disclosure in a family context may allow for developing and adopting a framework to better support parents living with HIV in this process.

While discrimination has been identified as the major obstacle to prevention and care (UNAIDS, 2002), the silence in many HIV-affected families may now extend the stigma into the next generation, emotionally burdening both HIV-infected caregivers and HIV-affected children. Future research should therefore try to further assess the impact of chronic HIV disease on the family system.

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