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Children and adolescents living with HIV positive parents: Emotional and behavioural problems

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Abstract

This study explores the emotional and behavioural problems in children living with an HIV-positive parent, and identifies specific high-risk and protective factors for their psychological well-being. Data were collected on 718 parents living with HIV and on 1136 HIV-affected children in a European multi-centre study (EUROSUPPORT IV) adopting a cross-sectional and retrospective study design. Sociodemographic characteristics, HIV-related stressors, variables relating to caregiving and outcome variables relating to family functioning and children's symptoms were assessed using a self-reported questionnaire. Results indicated a low level of parental HIV disclosure to children, and an elevated level of behavioural symptoms in HIV-affected children as reported by parents. Children had experienced a high degree of distressing life events. In multivariate analysis, perceived healthy family functioning emerged as protective for a low degree of behavioural symptoms in children and adolescents. The results call for a shift towards family-centred service delivery in HIV care and counselling. Service implications are discussed in the light of increasing numbers of women and couples living with HIV who become parents and need tailored support in facing the challenges of being a caregiver living with HIV.

Keywords: Q7

Introduction

In current HIV-related medical and social science research, the social experiences of families living with HIV receive little attention (De Matteo et al., 2002; Rotheram-Borus et al., 2005). However, the multiple challenges families face, such as responding to the needs of HIV-infected children or handling dilemmas of HIV disclosure are of practical relevance to both families and clinicians. In Europe these issues will become increasingly important in the near future, as the number of heterosexual transmissions and frequency of infected women are rising (Hamers & Downs, 2004).

Compared to a decade ago, people living with HIV (PLWH) who decide to have children have more time to parent (Miller & Murray, 1999). An estimated 80% of all women living with HIV are in their reproductive years (Siegel & Shrimshaw, 2001). The currently

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available treatment options may account for an increase in the desire for having children among women living with HIV (Chen et al., 2001; Gallotta et al., 2005; Kirschenbaum et al., 2004; Sowell et al., 2002), as mother-to-child HIV transmission rates have been reduced substantially (Gottlieb, 2002).

As HIV is turning into a chronic disease, it might be valuable to look at experiences of children of parents suffering from other chronic diseases, such as cancer, kidney disease or diabetes. Reviewing studies of a high methodological standard (Compas et al., 1996; Lewis & Hammond, 1996; Worsham et al., 1997) showed that such children suffered from moderate levels of distress manifested mainly as internalizing problems such as anxiety or depression. Given the highly persistent HIV-related stigma and the socioeconomic burden many families living with HIV have to face (Campo, 2004; Ingram & Hutchinson, 2000; Murphy et al., 2002; Rotherham-Borus et al., 1998), one could speculate that the prognosis for children of parents living with HIV/AIDS would be worse. However, HIV has also been described as being surrounded by silence and shame due to the related stigma and discrimination, which may lead parents to conceal their HIV-status (Armistead et al., 2001; Draimin 1993; Murphy et al., 2001; Wiener et al., 1998). There is a body of empirical evidence that children of ill parents are at risk for mental health problems (Armistead et al., 1997; Roy 1990; Worsham et al., 1997), but it is not clear which role-mediating factors such psychosocial support, parental coping styles or daily caregiving experiences may play.

Aims of the study

This paper describes the results of an analysis carried out within the framework of the EUROSUPPORT IV study. While the objective of the EUROSUPPORT study was to yield insight into the overall psychosocial needs of families living with HIV, the aim of this study was to assess the degree of emotional and behavioural problems in children living with an HIV-positive parent, and to identify specific high-risk and protective factors for the psychological well-being of these children.

Figure 1 provides an overview of the hypothesized relationships between factors believed to influence caregiving in families living with HIV and its outcomes. Three areas related to caregiving were assessed: HIV-related stressors, the practical experience of parents in caregiving and the perceived impact on the family and the children. We hypothesized that socioeconomic and HIV-related stressors influenced caregiving, which in turn impacted family functioning and behavioural outcomes in children.

Methods

Context of the study

EUROSUPPORT is a network of 15 European HIV treatment centres and research organizations from 10 different western European countries. The study design was cross-sectional and retrospective. The Institute of Tropical Medicine (ITM) coordinated the study, and data were collected from all participating study sites.

To assess the variables as indicated in the working model, a structured self-reported questionnaire was used. Self-developed items from previous EUROSUPPORT studies were used and also used from a Flemish pilot study on the same topic (Nöstlinger et al., 2004a, b). The instrument was tested further through face-to-face interviews with selected participants for clarification of items, and subsequently pilot-tested in a small sub-sample.

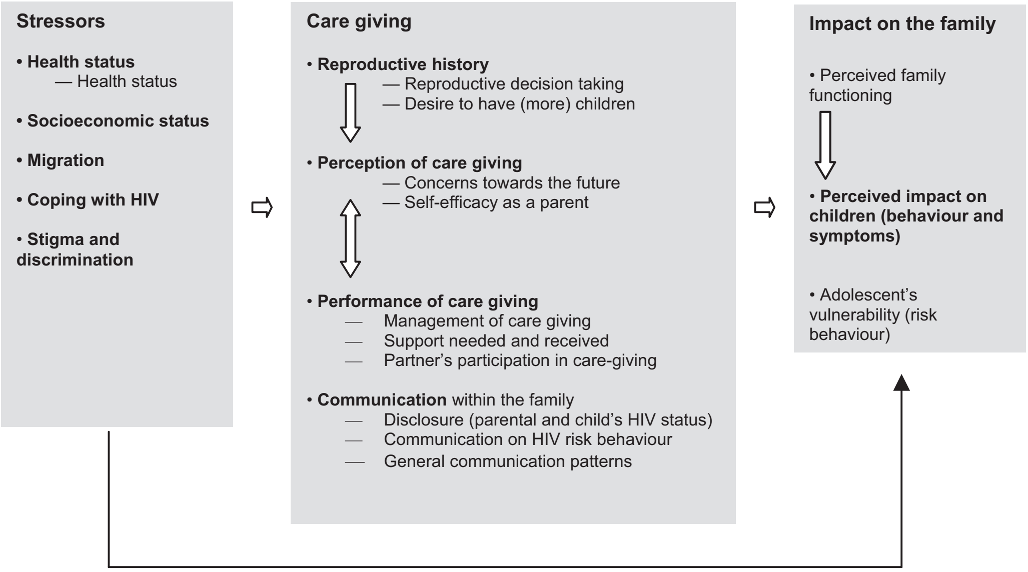

Figure 1. EUROSUPPORT IV working model.

Variable measurement

To measure the outcome variable family functioning a validated standardized scale was used (General Family Functioning scale of the McMaster Family Assessment Device FAD; Epstein et al., 1983). This instrument has good psychometric properties and relevance for the study population. Parents rated dimensions of general family functioning on a four-point scale ('strongly agree'/'agree'/'disagree'/'strongly disagree'). Items included statements referring to support, communication, openness and problem-solving capacities, as well as trust and acceptance within the family. A score was computed according to the instructions of the FAD ranging between 1 and 4 ('healthy family functioning' to 'unhealthy family functioning').

Children's psychological well-being was operationalized as emotional and behavioural problems perceived by the parents. An adapted version of the symptom checklist of the Child Behaviour Checklist was used (ages 4–18 years; Achenbach, 1995; Achenbach & Edelbrock, 1983). Selected symptoms of this scale were given as 'yes/no' items. A behavioural symptom score was computed by summing all 'yes' answers (divided by the number of valid answers and multiplied by factor 10 yielding a score from 1 to 10).

Children's behavioural and emotional problems were measured indirectly through parents' reports and were assessed for each eldest child younger than 18, and living together with the respondent. While this approach may be biased, the framework of a cross-national study in 10 countries did not allow for interviewing affected children directly. However, parents' report on behavioural and psychological problems of the children may serve as a sound proxy for their level of adjustment (Ford et al., 2005; Romer et al., 2002). Q9

To assess caregivers' self-efficacy statements describing caregiving competence and efficacy, they were rated on a four-point scale ('strongly agree'/'agree'/'disagree'/'strongly disagree'). Also for caregivers' perceived self-efficacy, a score was computed using the same procedures as for the family functioning score. This resulted in a score ranging from 1 to 4 (low to high perceived self-efficacy as a caregiver). For all scales internal reliability was assessed by computing Cronbach's alpha coefficients, which are given in the Results section.

Procedures

HIV-infected caregivers were identified by means of a short screening questionnaire consecutively distributed and filled in by health-care personnel. According to this pre-study, 27% (1000/3723) of all patients living with HIV were parents. Caregivers were eligible for the self-reported questionnaire study if they lived together with at least one child under the age of 18; caregiving was defined in a broad sense, including biological parents, adoptive parents and foster parents. Participation was voluntary and anonymous. Upon obtaining the patient's informed consent, the questionnaire was distributed with a pre-paid return envelope.

Statistical methods

Statistical analyses were performed with SPSS PC for Windows (version 12.0) and Stata 8.0 (College Station, TX USA). Univariate analyses were carried out using t-tests and Pearson's χ^2 tests for continuous and categorical variables, respectively (Fisher's exact test was applied if the expected cell count was less than 5). Bivariate analysis was carried out by means of *t*-tests and analysis of variance (ANOVA), and logistic regressions were performed. The dependent variable in all models was children's emotional and behavioural problems perceived by the parents, expressed as a score and recoded as a binary variable (lowest quartile vs. other quartiles). Significance was tested by *t*-tests (using the log-transformed variable because it of not normal distribution) or ANOVA, depending on the class of variables. Logistic regression was applied to compute the odds ratio for children with some behavioural problems vs. no behavioural problems.

Finally, all the variables significantly associated were inserted into a multivariate model. A stepwise backward procedure was then applied. Removal of variables was set at $\alpha > 0.05$ for the likelihood ratio test.

Results

Descriptive analysis

Sociodemographic and medical sample characteristics. A total of 788 questionnaires were returned. Information from non-respondents was not available. After validating the answers according to selection criteria, the final sample included 718 caregivers, or 91% of all questionnaires received. Table I shows the sample's sociodemographic characteristics.

In our sample, mothers had more unfavourable conditions than fathers with respect to overall socioeconomic conditions. Gender-specific differences were also found with respect to caregivers' mode of HIV transmission: 52% (368/706) of all caregivers contracted HIV through unprotected heterosexual intercourse: 60.5% of mothers (293/475) vs. 32.5% of fathers (75/234; χ^2 test $p < 0.000$). At the time of data assessment, 74% of all caregivers (526/710) received antiretroviral treatment, and 78% (542/694) reported no current physical complaints; 64.5% (374/580) had undetectable viral loads and 88.5% (456/515) reported a level of CD4 counts higher than 200 cells/mm^3 blood. Median time since first HIV diagnosis was 9 years.

Table I. Sociodemographic characteristics.

	Female	%	Male	%	Total	%	Sign.
Age	484	67	234	33	718	100	
Median age (years)	37	—	41	—	38	—	
Mean age (years)	37.2	—	41.10	—	38.8	—	
Standard deviation	5.8		6.11		6.3		0.00*
Family status							
Living with family	267	57	174	77	441	63	
Single parent	202	43	54	24	256	37	0.00**
Origin							
Country of residence	304	64	167	74	471	67.5	
Migrant	168	36	59	27	227	32.5	0.01**
Education and work situation							
Low education (none, primary combined)	230	48.5	116	50	346	49	0.04**
Low income (< € 1.500–)	215	46	90	39	305	45	0.002**
Being employed	204	51	140	72	344	58	0.000**

* *t*-test; ** χ^2 test.

Family situation and children's characteristics. Many respondents were single parents (see Table I). Mothers were significantly more likely to be single parents than fathers. Caregivers reported a total of 1136 children under the age of 18 (mean number of children living at home was 1.5 with a range from 1 to 5; SD = 0.8; median number = 1); 52% (590/1136) of these children were girls and 48% (545/1136) were boys. A total of 82% (906/1107) were living with the primary caregiver, 12% (131/1107) were living with other relatives, 3% (31/1107) were living with relatives in the home country, 2% (18/1107) in an institution or foster family, and for 21 children (2%) the parents referred to other living arrangements. Table II shows the children's age distribution.

At the time of data collection, 62% (678/1094) of all children went to school, 14% (152/1094) went to day care (applying only for those children younger than 6 years of age), 3% (31/1094) to a special institution for learning disabled, 2% (22/1094) followed vocational training or worked and 18% (206/1094) were not enrolled in any educational facility and thus were cared for fully at home. In many families both parents were reported as living with HIV (412/1014, 41% of all children). The majority of children were not HIV infected (916/1095, 83.5%), 8.5% were HIV-positive (93/1095), and for 86 children (8%) their HIV-status was reported as unknown.

Disclosure of HIV to the children. Fifty-one of the children living with HIV (55%) were informed about their own HIV-diagnosis, whereas 21% (226/1094) of all children knew about the parental HIV-status. Children's age and disclosure of parental HIV-status were significantly associated, as shown in Table III.

Table II. Children's age.

	n	%
< 1 year	33	3
1–5 years	201	18
5–10 years	313	27.5
10–15 years	380	33
15–18 years	209	18.5
Total	1136	100

Table III. Disclosure of parental HIV to children by age group.

	Yes *n* (%)	No *n* (%)	Total *n* (%)
<1 year	–	27 (100)	27 (100)
–5 years	7 (4)	180 (96)	187 (100)
5–10 years	29 (10)	268 (90)	297 (100)
10–15 years	87 (24.5)	268 (75.5)	355 (100)
>15 years	92 (46.5)	105 (53.5)	197 (100)
Total	215 (20)	848 (80)	1063 (100)

$p < 0.000$ (χ^2 test).

Communication about HIV in the family. The total number of eldest children, for whom more detailed information on disclosure and HIV-related coping information was provided, was 702. Of those children, 100 (15% of the valid data) were HIV positive, with a median CD4 count of 618 cells/mm^3 blood (mean = 588 cells/mm^3; SD = 415 cells/mm^3). Thirty-five children knew about their HIV diagnosis (35%), whereas 65 (65%) did not know. Median age of disclosure of children's HIV-status was 10 years (mean = 10.9 years; SD 3.5). With respect to the parents' HIV status, 25% (166/662) of all eldest children knew about it, whereas it had not been disclosed to 75% (496/662) of them. The median age of disclosure of parental HIV to the eldest child was 11 years (mean = 10.7 years; SD = 4.8 years). Of all children who knew that the parent was living with a disease, 78% (130/166) were informed explicitly about HIV, whereas 22% (36/166) were told that the parent was living with a (chronic) disease without mentioning HIV. In most cases, the information was conveyed by the respondent (105/166 or 62%). However, in 11% of all cases (19/166), the respondent was supported actively by a professional health-care provider. The remaining people to disclose were partners, relatives and other people. Reactions to parental disclosure varied (see Table IV).

Most of the parents reported that the observed reaction lasted for a limited period of time [23% (30/130) less than a month, 14% (19/130) between a month and half a year, 11% (15/130) between half a year and a year], and 12% (16/130) described a reaction lasting longer than a year. However, in 39% of all cases (51/130 respondents) parents reported that they still were observing the specific reaction at the time of data assessment. The majority of parents observed an improved adjustment, i.e., they felt that the child was coping better (51/80, 64%). Only some parents felt that the child was coping worse (8/80, 10%), and the remaining 26% (21/80) noticed no change.

Perceived family functioning. Answers to the general family functioning scale were combined to a score indicating the degree of perceived family functioning, as described above. The

Table IV. Child's perceived reaction to disclosure of parental HIV.

	n	%
Depressive reaction	65	39
Mature reaction	45	27
Anxiousness	18	11
Other reactions	12	7
No particular reaction	26	16

$n = 166$.

scale reliability coefficient was good, with a Cronbach alpha of 0.906. The mean score for all valid answers (688/718) was 2.02 (SD = 0.6; median = 2; range 1.0–4.0).

While parents positioned their families in the middle range between healthy and unhealthy family functioning, high numbers of distressing life events were also reported (see Table V). Although the biographical context of these events was not assessed, some of them may potentially be related to HIV.

While loss or separation of a loved person was reported most often for all children (41.5% and 36%, respectively), HIV-positive, HIV-negative children and children with unknown status differed with respect to some of the other reported distressing life events: Parents reported a significant higher level of discrimination and hospitalization for HIV-positive children, whereas migration was highest for children with unknown status. Suicidal attempts were lowest for HIV-negative children.

Parents were also asked to report on the children's emotional and behavioural problems. Table VI provides an overview of all symptoms reported above the 5% level. HIV-positive and HIV-negative children differed with respect to some of the symptoms reported, i.e., physical problems, contact problems and eating problems. The mean overall score of behavioural symptoms was 1.03 (median: 0.52; SD = 1.39; range 0–8.94).

Table V. Distressing life events (multiple answers).

	n (%)	Median age	HIV+ (%)	HIV– (%)	Unknown (%)	*p**
Loss of a loved person	229 (41.5)	6.0	19 (41)	198 (41)	14 (48)	0.74
Separation of a loved person	198 (36)	5.0	22 (48)	167 (36)	9 (31)	0.21
Frightening experience	103 (20)	5.0	10 (24)	88 (19)	5 (5)	0.69
Stress in school	99 (18.5)	11.6	7 (16)	84 (18)	8 (29)	0.33
Loss of friends	84 (16)	9.0	10 (23)	69 (15)	5 (18)	0.37
Migration	81 (15)	6.6	8 (18)	64 (14)	9 (30)	0.05
Discrimination	63 (12)	8.0	12 (28)	48 (10)	3 (11)	0.003
Bullying	54 (10)	9.0	3 (7)	46 (10)	5 (19)	0.24
Hospitalization	58 (11)	3.0	21 (46)	35 (8)	2 (7)	0.00
Physical violence	36 (7)	5.0	1 (2)	34 (7)	1 (4)	.36
Living in an institution	33 (6)	4.0	4 (8)	27 (6)	2 (2)	0.74
Sexual abuse	23 (4)	5.0	3 (7)	19 (4)	1 (4)	0.72
Suicidal attempt	10 (2)	14.0	3 (7)	5 (1)	2 (7)	0.03

$n = 702$, %: ages refer to valid answers. * p (χ^2 test).

Table VI. Perceived behavioural symptoms (current or during the last 6 months).

	n (%)	HIV+ (%)	HIV– (%)	Unknown (%)	*p**
Nervousness, restlessness	128 (19.5)	11 (9)	108 (84)	9 (7)	0.94
Sleeping problems	113 (17)	11 (8)	95 (84)	7 (6)	0.87
Learning problems	103 (16)	14 (14)	82 (88)	7 (7)	0.12
Depressiveness	95 (14.5)	6 (6)	80 (84)	9 (9)	0.32
Physical problems (headaches, nausea)	92 (14)	14 (15)	76 (83)	2 (2)	0.01
Aggressiveness	89 (13.5)	6 (7)	74 (83)	9 (10)	0.26
Anxiousness	88 (13)	7 (8)	75 (85)	6 (7)	0.96
Eating problems	77 (12)	12 (16)	61 (79)	4 (5)	0.05
Contact problems	61 (9)	9 (15)	45 (74)	7 (11.5)	0.03
Hyperactive behaviour	34 (5)	2 (6)	30 (88)	2 (6)	0.83
Feeling too guilty	52 (8)	4 (8)	46 (88.5)	2 (4)	0.70

$n = 702$, %: ages refer to valid answers; multiple answers. * p (χ^2 test).

Table VII. Adolescent vulnerability (current or during the last 6 months). Q1

	Total	%
Alcohol use	158	47
Illegal drug use	174	52
Sexual risk behaviour	162	48
Absence from school/work	147	44
Aggressiveness	169	50
Self-aggressiveness	158	47

n = 439, %: ages refer to valid answers; multiple answers.

Adolescent children may be of particular concern to parents because of the many developmental tasks related to psychological adjustment in this period. For pre-adolescent and adolescent children (12 years and above) parents were asked to rate adolescent vulnerability as measured by the items listed in Table VII. There were no significant differences between HIV+ and HIV- adolescents with respect to this variable.

Bivariate and multivariate analysis

Factors influencing children and adolescents' behavioural and emotional problems. We investigated factors significantly associated with children's behavioural outcome. As indicated initially in the EUROSUPPORT working model, we looked at socioeconomic factors, health-related variables, parental caregiving characteristics, parental support needs, HIV-related communication, HIV-related discrimination and perceived family functioning as influencing stressors (Table VIII).

In the bivariate analysis a number of factors were significantly associated with a low degree of perceived behavioural problems in children. Among sociodemographic characteristics living with a partner, higher occupational qualifications, employment and having migrated more than 5 years ago to the country of current residence were significantly associated with a lower degree of behavioural symptoms in children. Among health-related variables only consumption of substances such as sleeping antidepressants, tablets and recreational drugs turned out to be a risk factor for behavioural symptoms. Among factors related to the actual caregiving performance, parent's perceived self-efficacy and concerns related to the future well-being of the child significantly determined the degree of behavioural symptoms. Parents who felt sufficiently supported either by the partner or by psychosocial professionals also reported significantly fewer behavioural problems in their children than those who needed more support from these resources. In addition, perceived experience of discrimination seemed to have an effect: parents who reported to have suffered from HIV-related discrimination reported a higher degree of behavioural symptoms than those who had not. This was also true for children's experience with the same phenomenon. Finally, unhealthy general family functioning was an additional risk factor for a higher degree of behavioural symptoms in children.

When entering these factors into a multivariate model, the main factor associated with favourable outcomes in the degree of children's emotional and behavioural problems was a high degree of perceived general family functioning (OR .32, 95% CI 0.13–0.78; $p = 0.013$; data not shown in Table VIII). Having good problem-solving skills, good communication skills between the family members and being able to create an atmosphere of openness and trust in the family, in which feelings can be shown mutually, turned out to have a protective effect on the children.

Table VIII. Factors associated with children's behavioural symptoms (current or during the last 6 months as perceived by the parents).

Q1

		n	Behavioural symptoms mean score (SE)	*p**	Crude odds ratio	95% conf. interval	*p***
Sociodemographic characteristics							
Gender	Female	379	1.11 (0.07)				
	Male	185	0.86 (0.9)	0.09	0.82	(0.59–1.13)	0.23
Living situation	Not with partner	227	1.19 (0.1)				
	With partner/nuclear family	322	0.88 (0.07)	.028	0.66	(0.48–0.91)	0.013
Education	No or primary school completed	280	0.9 (0.07)				
	Secondary school or university degree completed	272	1.06 (0.08)	0.8	0.91	(0.66–1.24)	0.57
Occupational qualification	No or vocational training combined	272	1.1(.09)				
	Higher educational qualification combined	278	0.9 (0.07)	0.10	1.30	(0.95–1.78)	0.09
Current work situation	Currently working	273	0.85 (0.07)				
	Currently unemployed	193	1.2 (0.11)	0.009	1.42	(1.00–2.01)	0.04
Partner's current work situation	Currently working	273	0.85 (0.08)				
	Currently unemployed	88	1.1 (0.13)	0.05	1.61	(1.02–2.54)	0.04
Income	Monthly income less than €500	48	1.5 (0.24)				
	Monthly income more than €500	489	0.98 (0.06)	0.03	1.95	(1.08–3.54)	0.02
Origin (first- or second-generation migration)	First- or second-generation migration to country of residence	158	1.13 (0.11)				
	No first- or second-generation migration	395	1.01 (0.06)	0.8	1.22	(0.86–1.71)	0.25
Years of migration	Less than 5 years on country of residence	18	1.92 (0.75)				
	More than 5 years in country of residence	133	1.02 (0.12)	0.005	6.02	(1.77–20.46)	0.004
Health status							
HIV-related health complaints	No physical HIV-related complaints	426	0.96 (0.06)				
	Physical HIV-related complaints	126	1.22 (0.13)	0.13	1.12	(0.76–1.64)	0.54
Years living with HIV diagnosis (parent)	Less than 5 years since HIV diagnosis	107	1.09 (0.14)				
	More than 5 years since HIV diagnosis	448	1.01 (0.06)	0.66	1.09	(0.74–1.59)	0.65
Use of alcohol	Never	151	0.94 (0.12)				
	Some consumption (1 time/week or more)	385	1.01 (0.06)	0.25	1.07	(0.75–1.51)	0.69
Use of antidepressants	Never	441	0.89 (0.63)				
	Some consumption (1 time/week or more)	68	1.63 (0.19)	0.00	2.08	(1.22–3.53)	0.007
Use of sleeping tablets	Never	424	0.85 (1.28)				
	Some consumption (1 time/week or more)	75	1.69 (0.19)	0.00	2.90	(1.66–5.05)	0.00
Use of recreational drugs	Never	409	0.87 (0.06)				
	Some consumption (1 time/week or more)	105	1.49 (0.06)	0.00	2.49	(1.56– 3.98)	0.00
Caregiving characteristics							

(Continued)

Table VIII. (Continued).

		n	Behavioural symptoms mean score (SE)	*p*★	Crude odds ratio	95% conf. interval	*p*★★
Desire to have more children	Planning to have another child or being undecided	178	1.15 (0.10)				
	Not planning to have another child	377	0.97 (0.07)	0.23	0.92	(0.65– 1.29)	0.64
Caregiver's perceived self-efficacy†	Low self- efficacy as a caregiver (lowest quartile)	104	1.61 (0.15)				
	Higher self efficacy as a caregiver (other quartiles)	434	0.90 (0.06)	0.00	2.28	(1.46–3.56)	0.00
Concerns about the future in relation to child's well-being	Not concerned	180	0.81 (1.25)				
	Very concerned	15	1.15 (1.50)	0.00	2.17	(1.44–3.29)	0.00
Support needs							
Support from partner	Sufficiently supported	307	0.82 (0.05)				
	More support needed	108	1.66 (0.17)	0.00	2.14	(1.38–3.33)	0.00
Support from psychologist/counsellor	Sufficiently supported	416	0.86 (0.06)				
	More support needed	120	1.66 (0.14)	0.00	2.60	(1.68–4.04)	0.00
HIV-related communication							
Disclosure of parental HIV status	Did not disclose HIV	440	0.95 (0.06)				
(to eldest child)	Disclosed HIV	124	1.33 (0.14)	0.00	1.19	(0.80–1.77)	0.37
Planned disclosure of parental HIV to child	Planning on disclosing	226	1.00 (0.08)				
	Not planning on disclosing	53	0.87 (0.16)	0.21	0.75	(0.43–1.29)	0.30
Openness about HIV infection	No disclosure or only to partner	318	1.04 (0.07)				
	Disclosure to wider family and social environment	241	1.03 (0.09)	0.76	1.00	(0.73–1.37)	0.99
Talking to child about HIV risk behaviour	Never talked to child about it	116	1.09 (1.39)				
	Talked often to child about it	143	1.35 (1.60)	0.38	1.23	(0.76–2.01)	0.38
HIV-related discrimination							
Caregiver's HIV-related discrimination	No experience of discrimination	160	0.77 (0.08)				
	Experience of discrimination	232	1.41 (0.10)	0.00	2.07	(1.40–3.06)	0.00
Eldest child's HIV-related discrimination	No experience of discrimination	237	0.94 (0.09)				
	Experience of discrimination	61	1.97 (0.24)	0.00	2.47	(1.32–4.62)	0.005
Perceived general family functioning							
Degree of general family functioning	Most unhealthy (highest quartile)	122	1.75 (0.16)				
	Other quartiles	427	0.83 (0.05)	0.00	2.73	(1.81–4.16)	0.00

★ *p* value (*t*-test or ANOVA); ★★ *p* value sign. < 0.05. † Internal reliability coefficient Crohnbach's alpha = 0.91.

Discussion

Limitation of the study

Our data stem from a selection of specific HIV treatment centres of the EUROSUPPORT network, hence the results of the present study cannot be transferred to the general population of children affected by HIV in Europe. As respondents participated on a voluntary basis there might be a selection bias. Notwithstanding the methodological limitation of a cross-sectional and retrospective study, our study reveals some important insights into the ways in which children are affected by HIV.

Discussion of the findings

A substantial proportion (about 27% in the pre-study) of patients consulting the participating HIV treatment centres had caregiving responsibilities for children younger than 18 years. However, as others have pointed out, the family setting is not usually addressed in service provision (De Matteo et al., 2002; Rotherham-Borus et al., 2005). In most European countries, services tend not to be family-focused but rather concentrate on the individual patient, and their children remain largely invisible and un-assessed for their needs (Cree et al., 2006).

A large group among patients fulfilling caregiving roles in our sample stemmed from ethnic minorities. This may imply that in many these families had to face the double burden of being migrant and living with HIV, which may be experienced as stigmatizing and stressful. Even when basic needs, such as housing, food and health care, are available HIV has been shown to impact these families ‘first and worst’ (Barnett & Whiteside, 2003). HIV has been described as the fastest way ‘forward’ for a family to move from relative wealth to relative poverty. As our data show, economic means available to the families were low, i.e., less than Ä1500, for more than 45% of the responding parents, with mothers and single parents being disproportionally affected by economic hardships.

The results relating to the effects of HIV on the psychological well-being of children need to be interpreted with caution: there is empirical evidence that somatic illness in a parent is a risk factor for mental health illness in children, but this certainly has to be differentiated according to the type and degree of parental illness, as well as to developmental, psychodynamic and family dynamic perspectives (Roy 1990; Worsham et al., 1997). In our study, parents perceived their children as suffering from some internalized psychological symptoms, such as being nervous, depressive and anxious. Sleeping and learning problems were also mentioned frequently, being in line with studies on symptom formation in children of ill parents (Armistead et al., 1997; Rost, 1992).

Symptom rates reported by parents must not be interpreted as clinically relevant scores. However, they provide an idea about the rather high proportion of parents living with HIV who worry about the emotional and behavioural problems of their children. Epidemiological studies have reported that up to 2.5% of children and up to 8.3% of adolescents suffer from depression at any given time in the United States (Birmaher et al., 1996). European studies reported levels around 4% (European Commission, 2000). A German survey using the CBCL Q8 reported levels of 10% of clinical relevant symptoms in the general population (Barkmann & Schulte-Markwort, 2005). Depression in children has been described to be associated with subsequent adjustment problems, school failure and suicide in later life (Hawton et al., 1998).

Reported symptoms such as sleeping or eating problems may be understood as signs of children’s unresolved distress or as an equivalent of child depression in younger children (Christ et al., 1993). Studies on children of parents with AIDS found latent aggression, accelerated psychic maturation and increased levels of depression and fears in HIV-affected children (Armistead et al., 1997; Steele et al., 1997). However, as HIV turns into a chronic disease, disease-related symptoms may be less visible to the children. In our study many children did not know consciously about the parental HIV disease; when HIV is hidden as a family secret, children's coping may be different.

Parents reported a particular high level of vulnerability in their pre-adolescent and adolescent children, which is confirmed by other studies with adolescent samples (Compas et al., 1994; Hilton & Elfert, 1996). As adolescents normally struggle with developmental issues of separation and individuation, inevitably many are vulnerable to high-risk behaviour. However, for adolescents living with an HIV-infected parent this struggle might be complicated further by the parental illness. Potentially existing feelings of guilt and anticipated loss may be acted out in various ways, corresponding to a general emotion-focused coping in this developmental stage (Compas et al., 1996).

Research on resilience of children living with somatically ill parents found that one of the single most important factors enabling children to cope is the relationship with the healthy caregiver, and his/her ability to support the child fully in the coping process (Telingator, 2000). In our sample more than 40% of all children had two parents living with HIV. When both parents are living with HIV, their ability to substitute fully the other parent may be mutually reduced.

One of the challenges for children and adolescents assessed in this study was to deal with multiple losses. In their attempt to cope with such distressing events, children need ongoing support from caregivers and other social networks. However, shame and persistent stigmatization related to HIV are likely to reduce the ability of families to reach out for support, particular in cases where HIV is a family secret.

In our sample, 20% of the children knew about the parent's health condition. This is a lower rate of parental disclosure compared to studies carried out in the US-reported disclosure rates of 40% and higher (Lee & Rotheram-Borus, 2002; Pilowsky et al., 2000; Schuster et al., 2000). Our results are more in line with recent European findings (Åsander et al., 2003; Thorne et al., 2000; Vallerand et al., 2005), and may be interpreted as an effect of the high rate of PLWH being treated with antiretrovirals. Receiving effective treatment may constitute a chance to conceal the HIV diagnosis for longer periods of time (Ostrom et al., 2006). Our data on parental HIV disclosure to children supports the notion today that parents still view non-disclosure as protective. Concerns about children's vulnerability may not be totally misplaced, at least as a short-term reaction. However, children's uncertainty about an illness in the family may also exert influence on children's well-being (Draimin 1994). For instance, pre-school children tend to construct a meaning of their own or feel magically responsible for what happens to the parents (Hetherington & Stanley-Hagan, 1999; Telingator et al., 2000). Many authors have argued that children cannot be protected from the disease-related family stressors, hence children's experiences should be discussed with them according to their developmental level (Lewandowski, 1992). Others have argued that healthy adaptation will occur more probably when information is shared openly within the family (Wiener et al., 1998).

Finally, with respect to influencing factors on children's emotional and behavioural symptoms, in the multivariate model healthy general family functioning emerged as the best predictor of children's behavioural and emotional problems. While we must acknowledge that there might be influences between family functioning and children's perceived behavioural symptoms, and vice-versa, a strong family cohesion might facilitate children's coping and resiliency. Cohesion of the family system has been extracted previously as one of the typical traits of families with an ill parent (Rost, 1992). Family cohesion may be further strengthened in cases of HIV-affected families in their efforts to safeguard HIV as the hidden family secret.

Conclusions

From these data we conclude that there is a substantial need to integrate a family-centred perspective into psychosocial support for families living with HIV. Parents living with HIV need support to fulfil their caregiving role effectively, taking into consideration the emotional, social, and practical issues of living with a chronic disease and coping with continued stress. Children and adolescents need age-appropriate support in dealing with the parental disease, for instance by encouraging them to ask questions, reassuring them that ambivalent feelings are normal and giving them a model of coping with reality by communication and social skills.

Future research

Future research should try to deepen the understanding of the protective mechanisms children and adolescents are able to adopt in spite of difficult family situations. While this study focused on parent's characteristics as influencing factors on behavioural outcomes in children, there is a need to incorporate developmental concepts and children's and adolescents' views into the investigation; i.e., their subjective reactions, feelings and fantasies in relation to the coping process. Longitudinal study designs, preferably prospective, should be adopted to cover children's developmental transitions as well as the course of the parental disease, as both are clearly affecting the outcome of the coping process.

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