

Parents living with HIV in a high-income country: do patients need specific support?

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Summary

Questions under study: The number of HIV-infected persons with children and caregiving duties is likely to increase. From this statement, the present study was designed to establish how HIV-infected caregivers organise their parenting routines and to determine their support needs. A further aim was to ascertain caregivers' perception of conspicuous behaviours displayed by their children. Finally, it sought to determine the extent to which the caregivers' assessment of their parenting activity is influenced by the required support and their children's perceived conspicuous behaviours.

Methods: The study design was observational and cross-sectional. Sampling was based on the 7 HIV Outpatient Clinics associated with the national population-based Swiss HIV Cohort Study. It focused on persons living with HIV who are responsible for raising children below the age of 18. A total of 520 caregivers were approached and 261 participated. An anonymous, standardised, self-administered questionnaire was used for data collection. The data were analysed using descriptive statistical procedures and backward elimination multiple regression analysis.

Results: The 261 respondents cared for 406 children and adolescents under 18 years of age; the median age was 10 years. The caregivers' material resources were low. 70% had a net family income in a range below the median of Swiss net family income and 30% were dependent on welfare assistance. 73% were undergoing treatment

with 86% reporting no physical impairments. The proportion of single caregivers was 34%. 92% of the children were living with their HIV-infected caregivers. 80% of the children attended an institution such as a school or kindergarten during the day. 89% of the caregivers had access to social networks providing support. Nevertheless, caregivers required additional support in performing their parenting duties and indicated a need for assistance on the material level, in connection with legal problems and with participation in the labour market. 46% of the caregivers had observed one or more conspicuous behaviours displayed by their children, which indicates a challenging situation. However, most of these caregivers assessed their parenting activity very favourably. Backward elimination multiple regression analysis indicated that a smaller number of support needs, younger age of the eldest child and fewer physical impairments on the part of the caregiver enhance the caregivers' assessment of their parenting activity.

Conclusion: Physicians should speak to caregivers living with HIV about their parenting responsibilities and provide the necessary scope for this subject in their consultation sessions. Physicians are in a position to draw their patients' attention to the services available to them.

Key words: HIV/AIDS; parenting; parents; caregivers; support

Grants

This article refers to an investigation that was substantially supported by the Swiss National Science Foundation (Project No. 3146C0-103044) and the Swiss HIV Cohort Study. It was conducted in conjunction with the Eurosupport Study Group.

Conflict of interest

There was no conflict of interest as the granting institution is an independent foundation. As this observational study did not evaluate substances or procedures of interest to the participating centres or any branch of industry, there were also no conflicting loyalties.

Introduction

General practitioners, consultants and physicians working at HIV centres are important figures in the network of service providers for persons living with HIV. Their role is not restricted to diagnosis, the provision of illness-related information, decisions on the conduct of therapy and supervision of the patients' general state of health. In fact, physicians providing treatment also play a

significant role in prevention [1] and are consulted by patients regarding the various problems they encounter in coping with diagnosis, adherence, mastering of daily routines and maintaining partner relationships under changed circumstances.

In this context, physicians are also repeatedly confronted with new developments, a foreseeable one being the growing number of HIV-positive

individuals with one or more children. This development raises issues not yet much encountered in the care of persons living with HIV.

Various convergent trends are responsible for this development. Firstly, in Switzerland as in Europe as a whole there has been an increase in the proportion of infections through heterosexual transmission and accordingly an increase in the proportion of HIV-infected women [2–4]. In addition, the success of antiretroviral therapies has substantially prolonged the life expectancy of people with HIV. This has led to a significant change in their life prospects, with concomitant effects on their desire (and the realistic nature of that desire) for parenting despite HIV infection [5]. Furthermore, antiretroviral therapy has reduced the danger of mother-to-child HIV transmission to below 2% [6–8].

Given the likelihood of an increase in the numbers of parents with HIV raising children, various urgent questions are arising with increasing frequency. How do such parents organise and cope with their routine parenting activities? What resources do they draw upon for this purpose? What kind of support do they feel a need for? These questions are also relevant for HIV-infected persons who, although not parents themselves, are confronted with a situation where they have to accept responsibility for raising children in a two-generation system, either as step-parents, foster parents, partners of people with children or as surviving dependents of a parent. Alongside biological parents, these people are referred to in the following as “caregivers”.

However, to date there has been very little in the way of well-established research findings on the situation of caregivers living with HIV. Only sporadic studies exist, eg on single mothers with late-stage AIDS and on HIV-positive mothers or parents in the United States [9–13] and in some individual western European countries [14–20].

A central issue in these studies is whether HIV-positive parents and other HIV-infected caregivers disclose their serostatus to the children they are looking after. The resources available to caregivers living with HIV received only marginal attention in these studies. They merely establish that caregivers of this kind have few resources at their disposal, that some of them are highly dependent on state aid and that their social resources are largely inadequate, ie their social networks are small-scale and deficient [11, 14, 19]. Rotheram-Borus et al. recorded significantly higher depression scores and anxiety levels for HIV-positive parents than for those in control groups [11], while Silver et al. also detected high levels of psychological distress in single mothers with late stage HIV/AIDS correlated with restrictions in the mother’s ability to perform ordinary daily activities and childcare duties [21].

Further, our knowledge about caregivers living with HIV is not only limited in itself. Most of the studies we may refer to are based on data col-

lected at a time when antiretroviral combination therapies were in their infancy and their success in enhancing the quality of life for the people involved was anything but firmly established. Accordingly, these studies reflect the situation pertaining to a different set of parameters and this affects their relevance to the present-day situation in a high-income country such as Switzerland, where the welfare state provides all those affected with unrestricted access to antiretroviral treatment. Furthermore, to date no studies have addressed how well these caregivers feel they cope with their parenting routines, what problems they confront and how they themselves assess their parenting activity.

Also, little attention has been paid to the extent to which HIV-positive caregivers are confronted with psychosocial problems [9, 22] and conspicuous behaviours displayed by their children, what problems they perceive and whether this means that they have special support needs.

If these patients with care-giving responsibilities are to be given the assistance they require, we urgently require a broader knowledge base regarding their life situations, the challenges they face and the support they need. Hence the purpose of this study is to shed light on the psychosocial problems and support needs of HIV-infected caregivers. It is designed to enhance the service-provider’s knowledge of their patients’ needs and thereby lay the foundation for the further development and improvement of services offered to them. From this perspective a comparison of the pressures and the support needs of HIV-infected caregivers on the one hand, and caregivers living without HIV on the other, is not essential and is therefore not intended.

Against this background, the present study addresses the following five questions:

1. How do persons living with HIV in Switzerland organise their parenting routines?
2. In what areas do caregivers living with HIV need additional support and who should provide it?
3. Do the caregivers perceive conspicuous behaviours on their children’s part and, if so, what are they?
4. How do caregivers assess their parenting activity?
5. What impact do the support needs and the children’s perceived conspicuous behaviours have on the caregivers’ assessment of their parenting activity?

The last of these questions is linked to the **hypothesis** that assessment of parenting activity is inversely proportional to the intensity of their support needs and the number of conspicuous behaviours displayed by the children. In other words, the lower their support needs and the smaller the number of conspicuous behaviours perceived, the more favourably will the caregivers assess their parenting activity, irrespective of their age and gender, the age

and gender of their children, the caregivers' social status and their experience of physical impairments.

The study was conducted in close conjunction with Eurosupport Study Group IV, a network of centres and institutes from nine countries of the

European Union headed by the Institute of Tropical Medicine of the University of Antwerp (Belgium). During the same period, this study group also worked on a similar issue for the Public Health Directorate of the European Union [17].

Methods

Study design

The study design was observational and cross-sectional. The data collection was carried out in one phase, lasting from October 2003 until August 2004. For data collection an anonymous, standardised, self-administered questionnaire was used. This instrument was developed in conjunction with the Eurosupport Study Group, on the basis of instruments that had been developed and used in former studies and on the grounds of current items phrasing [18].

The instrument was tested by face-to-face interviews with selected participants for the clarification of items and subsequently pilot-tested in a small sub-sample [17]. Then the questions and response items of the sociodemographic variables were adapted to the Swiss context, eg by introducing the terms used by the Swiss Federal Statistical Office.

After a process of translation and back-translation it was made available in the national languages of Switzerland (German, French, Italian) and in English and Spanish.

Variables and measures

The questionnaire comprised 85 questions. They enabled data collection for variables relating to performance of caregiving duties (living situation of children, day-care, after-day care, support received) and health-related variables (period of time since HIV diagnosis, medical treatment [HAART] and physical impairments) as well as sociodemographic variables (gender, age, marital status, vocational training, region of origin, net family income per month, work situation) and characteristics of the children (number of children, gender, age, serostatus). Support needs were assessed using a list of 21 items describing responsibilities and daily tasks with answering options yes/no. The variable "support needs" was computed by summing up the "yes" answers, yielding a score ranging from 0 to 21. The children's conspicuous behaviours perceived by the caregivers were assessed using the Child Behaviour Checklist (CBCL) for ages 4 to 18 years [23, 24]. It records the behavioural problems and competences of children as reported by their parents or others who know the child well, and has a test-retest reliability of 0.84 to 0.97. The checklist used consisted of 19 items with answering options yes/no. The variable "children's conspicuous behaviours" was computed by summing up all the observed symptoms, yielding a score ranging from 0 to 19. The assessment of parenting activity was achieved using a list of 10 items describing care-giving competence and self-efficacy as a caregiver. The respondents had to rate their parenting competences and self-efficacy using a self-rating four-point scale (strongly agree/agree/disagree/strongly disagree). The dependent variable "assessment of parenting activity" equals the average of the scores attained on the 10 items, yielding a score ranging

from 1 (minimal level) to 4 (maximal level). The variable "social status" was computed by summing up the scores of the variables "net family income" and "vocational training", yielding a score ranging from 2 to 12.

Sampling

The study focused on caregivers living with HIV and responsible for raising children, ie taking care of children and young people below the age of majority (18 years) living in the same household. Sampling was based on the Swiss HIV Cohort Study, involving 5,577 HIV-infected persons living in Switzerland in 2003 [25, 26]. Among its participants, the Swiss HIV Cohort Study identified 635 persons living in a household with minors (children and adolescents below the age of 18).

For reasons of anonymity, these target persons could not be contacted directly and provided with the questionnaire. Accordingly, the questionnaires were distributed by the physicians associated with the seven centres involved in the Swiss HIV Cohort Study (SHCS). At their subsequent consultations, the relevant patients were informed about the study by their medical examiners (panel physicians), encouraged to participate and given a questionnaire. The target persons were sent a reminder by the centres involved two weeks after the return date for the questionnaire. This was addressed to all participants, irrespective of whether they had returned the questionnaire or not. The letter thanked the target persons for their cooperation and asked those of them who had not returned the questionnaire to complete and return it. The reminder was passed on to the target persons by the relevant centres.

In order to achieve a representative sample we aimed for a sample size of at least 235 respondents. During the 10-month period of data collection, 520 patients were contacted by the physicians and given the questionnaire. This corresponds to a coverage rate of 82%, which is lower than expected and is presumably due to the fact that some SHCS participants do not regularly attend their centre every 6 months. Nevertheless, as shown in the results section, the minimum sample size was exceeded.

Analytic strategy

In the first stage the data were analysed via descriptive statistical procedures using SPSS software. In the second stage we used a backward elimination multiple regression analysis [27, 28] to determine which of the independent variables "support needs" and "children's perceived conspicuous behaviours" represented predictors for the dependent variable "assessment of parenting activity". The model was controlled for the variables gender and age of caregivers, gender and age of the eldest child, social status and caregivers' experience of physical complaints.

Table 1

Demographic characteristics of the caregivers living with HIV.

Characteristics	SHCS (%)*	Sample (%)**
Gender (N = 261)		
female	65	67
male	35	33
Age (N = 257)		
20–29 years	6	7
30–39 years	44	46
40–49 years	43	43
over 50 years	7	4
Marital status (N = 259)		
Married		52
In a relationship		20
Separated		17
Widowed		6
Single		5
Vocational training (N = 259)		
None	40	20
Apprenticeship	46	53
Teacher training college	4	4
Vocational high school/technical college/engineering	5	14
University, college, specialised college	5	9
Region of origin (N = 258)		
Switzerland	53	51
Other EU country		18
Africa		19
Central or South America		4
Asia		7
Other		1
Net family income per month (N = 254) in Swiss francs***		
0–1,500		5
1,500–3,000		17
3,000–4,500		20
4,500–6,000		26
6,000–9,000		16
9,000–12,000		9
Over 12,000		4
Don't know		3
Work situation (N = 257)		
Regular full-time employment		28
Regular part-time employment		35
Unemployed		9
Unable to work and on disability benefit		16
Housewife/househusband; student		12
Number of children (N = 259)		
1		49
2		34
3		10
4		4
5 or more		3

* Caregivers in the SHCS (as far as assessed); ** caregivers in the sample; *** 1 Euro was equivalent to 1.55 Swiss francs

Results

Respondents

Of the 520 caregivers contacted, 261 took part in the study, representing a response rate of 50%. On average, the respondents required 41 minutes to complete the questionnaire.

Table 1 shows the demographic characteristics of the caregivers participating in the present study and the total caregivers identified in the SHCS to the extent permitted by SHCS data (cf. table 1).

The financial resources of the respondent caregivers show a median net family income per month in the range between CHF 4,500 and 6,000, which is markedly lower than the median income of a family household with two children in the Swiss population (CHF 7,607 [29]).

The 261 respondent caregivers living with HIV care for a total of 406 children and adolescents under 18 years of age, the median number of children being 2. The children's median age is 10 years (cf. table 2).

91% of 253 respondent caregivers are biological parents, 5% step-parents, 2% adoptive parents and 2% foster-parents. The proportion of single caregivers is 34%, of these 81% are women and 19% are men. 4% of the respondent caregivers live in a same-sex relationship, all of them men.

HIV infection and health status

At the time of the study, half of the respondents had known about their infection for over 10 years. The median year of HIV diagnosis is 1994. However, 13% (of 259 respondent) caregivers had only been informed of their infection in the two years prior to the study.

Among the 252 respondent caregivers, 86% had no physical complaints. 14% indicated that they have physical impairments. According to the information received from the respondents, at the last medical examination 68% of the caregivers had a viral load of less than 50 copies/mm³. The

Table 2

Children's characteristics.

Characteristic	%
Gender (N = 406)	
Male	47
Female	53
Age (N = 402)	
0–6 years	33
7–12 years	37
13–18 years	30
Serostatus (N = 394)	
HIV-positive	5
HIV-negative	91
Unknown	4

median number of CD4 helper cells reported was 500, ranging from cases with 24 to cases with 1,900. 29% gave no information on the number of CD4 helper cells and 30% left the question on the virus count unanswered.

At the time of the study 73% of the caregivers were undergoing antiretroviral treatment, 16% had interrupted or terminated the treatment and 11% had never received antiretroviral therapy.

Parenting, organisation, problems and support needs

Organisation of parenting duties

A large proportion of the children (92%) lived with the respondent caregivers. In the day-time, however, the majority of the children spent most of their time in an institution of one kind or another (cf. table 3).

In the periods the children spent outside one of these institutions, the respondent was usually responsible for looking after these children. 69% of the (386) children were looked after by the respondents themselves after returning home from the institution in question, while 17% were looked after by the respondent's partner, an arrangement only referred to by male respondents. Viewing responsibility for care in terms of the respondents' gender, we find that 88% of the female respondents indicated that they looked

after their children themselves when the children came home from the institution in question (crèche, daycare, school, etc.). None of the women said that their partners were responsible for caregiving. This corresponds to the information given regarding responsibility for care of the children (cf. table 4).

Caregiving support

89% of the respondents received support with caregiving. 55% of the 232 respondent caregivers received caregiving assistance from their partners (cf. table 5). A large proportion (85%) were mainly satisfied with this support. Here, however, men were less likely than women to benefit from assistance from their parents or other relatives.

Here the respondents had recourse to different social networks depending on their situation. Partners were the most important source of assistance, taking over child care for anything from a few hours to a whole week. In the case of longer periods of absence, close relatives were generally the ones approached with a request for assistance (respondent's parents or partner's parents). Friends and neighbours were usually only called in for a few hours, as were child minders and other volunteer helpers.

Table 3

Current day-care, school or other institution attended by the children.

Response	Children (N = 387) %
None	19
Daycare, kindergarten	15
Childminder, day fostercare	1
School	52
All-day school	6
School for learning disabilities	2
Vocational training/work	5

Table 4

Who is the main person responsible for caring for and looking after your child/children?

Response	Male caregiver (N = 85) %	Female caregiver (N = 172) %	Total (N = 257) %
I myself	44	97	79
My partner	42	1	15
The children's biological father/mother	14	1	5
Other person	0	1	1

Table 5

Is any other person supporting you on a regular basis in caring for your children?

Response	Male caregiver (N = 74) %	Female caregiver (N = 158) %	Total (N = 232) %
My partner	55	54	55
My parents	12	27	22
My partner's parents	16	17	16
The child(ren)'s biological father/mother	18	15	16
Other relatives	8	19	16
Older siblings	7	11	10
Friend or neighbour	14	23	20
Professional helper	12	16	15
Volunteers	4	1	2
Other	4	3	3

Note. Multiple responses

Table 6

Currently or during the last six months, has your child experienced any of the following problems or displayed any of the following behaviours?

Response	Total caregivers (N = 119) %
Being too anxious or fearful for his/her age	25
Feeling very unhappy, sad or depressed	23
Trouble sleeping or other sleeping problems (eg nightmares)	39
Feeling nervous, tense, restless	39
Aggressive behaviour (eg towards other children)	31
Suffering from constant headaches or tummy-aches	23
Learning problems, poor performance at school	26

Note. Multiple responses
Only items >20%

Table 7

Caregiver's support needs.

Response	Male caregivers (N = 61) %	Female caregivers (N = 146) %	Total (N = 207) %
I need support in ...			
Household tasks	18	26	24
* Parenting (looking after children, adequate child care facilities, support in helping my children with schoolwork, organising social activities for my children)	39	60	54
Resolving family conflicts and problems	20	20	20
Talking about HIV to my children	20	25	24
My children's emotional or behavioural problems	20	25	23
Coping with my own HIV infection	31	33	32
Leading a healthy life	38	25	29
Sexual health counselling (safer sex, family planning)	26	19	21
Sexual relationships (eg finding a partner)	21	20	20
Legal problems	56	34	41
Access to the social welfare system and benefits	38	39	39
Access to work	36	30	32
Financial problems	44	51	49
Improving my housing situation	26	21	22

Note. Multiple responses
Only items >20%, * p <.05

Table 8

Support requirements from people or organisations.

Response	Male caregivers (N = 33) %	Female caregivers (N = 103) %	Total (N = 136) %
I need more support from ...			
My partner	33	36	35
My family	18	22	21
Other persons living with HIV	36	22	26
Self-help group	30	22	24
The HIV physician treating me	21	19	20
Psychologist	36	23	27
HIV service organisation	33	28	29
Other service organisation (eg family planning, drug service organisation)	24	18	20
* Public welfare organisation (social assistance)	24	34	32

Note. Multiple responses
Only items >20%, * p <.05

However, there is a group of respondents who had no one to turn to for assistance. 12% had no potential helpers they could approach to look after their children for a week, eg if they had to go into hospital. 17% did not know who they could rely on to take over if they needed to be away from home for a few hours (eg for a visit to the doctor). 19% had no one to turn to if they needed

someone to look after the children for a whole day.

Conspicuous behaviours by the child perceived by the caregivers

46% of (119 respondent) caregivers were aware of conspicuous behaviours on the part of their eldest child. They related these behaviours

Table 9

Backward elimination multiple regression analysis summary for variables predicting caregivers' assessment of their parenting activity.

Variable	B	SEB	β
Support needs	-.04	.01	-.30***
Age of child	-.02	.01	-.19**
Physical impairments	-.16	.07	-.16*

Note. $R^2 = .16$, $N = 205$, $p < .001$

* $p < .05$; ** $p < .01$; *** $p < .001$

to the special situation they are in. 88 of the respondents identified several conspicuous behaviours in their eldest child, those most frequently referred to being nervousness, sleeping problems and aggressiveness (cf. table 6). The only gender-related difference indicated was the significantly higher frequency with which women reported a child suffering from constant headaches or tummy-aches compared to men.

Caregiver's support needs

Of the 119 caregivers who indicated that their children displayed conspicuous behaviour(s), 57% sought professional assistance but 43% did not. The reason given by 61% of those not seeking assistance was that the problem was not serious enough to warrant professional help. 26% said that they were able to solve the problem themselves. Other reasons given by a small number of

caregivers were that the problems would go away on their own, that they themselves had enough problems or that they had no information as to how to obtain access to professional help.

80% of the 261 respondent caregivers would welcome more support in at least one area of their everyday lives. 30% indicated more than 5 areas in which they would welcome assistance. As table 7 indicates, the caregivers would appreciate support primarily in their parenting routines as well as in handling financial or legal problems. For the male respondents, assistance with legal problems was the main focus of interest. Female caregivers most frequently asked for support in their parenting activities. Both genders ranked financial support second.

52% of the 261 respondent caregivers indicated that they would welcome more support from at least one of the following persons or organisations (cf. table 8):

Male caregivers showed more interest than their female counterparts in meeting with other persons living with HIV and receiving support from psychologists. Female caregivers more often asked for additional support from public welfare organisations than men.

Assessment of parenting activity

The respondent caregivers assessed their own parenting competence largely favourably. The mean on the 10 items measuring competence and efficacy of the caregivers was 3.38 (SD = 0.38). Here the maximum score is 4.0. On this index, 80% of 246 respondents achieved a score between 2.5 and 3.7, which reflects a very favourable assessment of their parenting activity. 18% even indicated a very high estimation of their parenting activity, with scores between 3.8 and 4.0. Only 2% of the caregivers had a low assessment of their parenting competences and self-efficacy (score below 2.5).

We used backward elimination multiple regression analysis to test the hypothesis that lower support needs and a smaller number of conspicu-

ous behaviours displayed by the children increase the caregivers' assessment of their parenting activity. As table 9 shows, the hypothesis can only be validated for support needs. The perceived conspicuous behaviour of the children had no effect on self-efficacy. The lower the support needs, the higher the reported assessment of parenting activity. But besides support needs, the age of the eldest child and the experience of physical complaints of the caregiver also play an important role. The younger the eldest child and the fewer physical impairments the caregiver reported, the higher their estimation of parenting activity. The effects are independent of the age and gender of the caregiver, the gender of the eldest child and the caregiver's social status.

Discussion

Methodological considerations

The questionnaire obtained a response rate of 50%. Given a population that is continuously asked to participate in scientific studies and prefers to be inconspicuous, this response rate is comparatively high and therefore acceptable. It is strikingly higher than the rates usually achieved with anonymous self-administered questionnaires [30–32]. Furthermore, the sample is representative in terms of gender, age and region of origin.

However, respondents with lower levels of education are underrepresented (cf. table 1). This may affect the results, since we probably learn less about the support needs of caregivers living in low-resource settings. As a result, the reported support needs could be an underestimate.

Caregivers and their parenting activities

The present study has a number of points in common with the findings of previous investiga-

tions [14, 19]. In accordance with existing studies on the situation in other countries, the investigation in Switzerland indicates that caregivers living with HIV are highly dependent on welfare assistance such as unemployment benefits, invalidity pensions or support from public assistance schemes.

However, in contrast to other studies on HIV-positive parents, this investigation arrives at a favourable conclusion as far as social resources are concerned [11, 14, 19]. The HIV-positive caregivers participating in this investigation have access to intact social networks providing support required in connection with parenting.

Despite this fact, a large number of the caregivers appear to need additional support in coping with their parenting duties. Also, they indicate a need for material assistance, support in legal problems and in participation in the labour market.

For most of these caregivers, parenting is a constructive experience. They have a high assessment of their parenting activity and capacity to see their children through the growing-up process. They assess themselves as well able to cope with their responsibilities and they retain this assessment despite the fact that over half of the respondents have observed one or more conspicuous behaviours on the part of their children, which would normally indicate a challenging situation. Only half of the respondents have recourse to professional assistance in coming to terms with this situation.

The conspicuously high scores in the assessment of parenting activity require critical reflection on the findings of the study, since the assessment may be subject to a *social desirability* effect. The question is whether caregivers with HIV or AIDS can afford, as it were, to envisage the eventuality that they might not be completely able to look after the children entrusted to their care in an appropriate way. General fears of failure, the specific concern of avoiding the attention of child-protection institutions and remaining as inconspicuous as possible, with a view to avoiding possible corrective measures, may militate against a more critical assessment of their own abilities. One factor supporting this hypothesis is the relative disinclination on the part of the HIV-positive caregivers to seek professional help, although they are quite frequently aware of the problems their children face. Future research should focus on this point in greater depth and shed more light on the connections involved. Further investigation would need to focus on subgroups of caregivers living with HIV, eg on the specific situation of HIV-infected migrants, on caregivers in low-resource settings and caregivers who have been through a career of injection drug use.

However, the findings of the present study do provide first indications on the points at which support provision for caregivers living with HIV may be applied to enhance the situation of these adults and their children.

In Switzerland, as in other high-income countries with firmly established public welfare systems, these caregivers can draw upon both general social services and specialist services provided by organisations specialising in support for people with HIV, such as the AIDS services organisations. Some of these also provide assistance for integration into the labour market, one example being the Swiss AIDS Federation, which operates a free employment exchange for people with HIV (www.workpositive.ch). However, the discrepancy between available service offers and the needs of the caregivers as reflected in their responses suggests that existing services are either insufficiently well known or have such a high threshold that HIV-positive caregivers do not feel that the assistance offered by AIDS services organisations is targeted at them as well.

Physicians are in a position to draw their patients' attention to these offers and to institute contacts with the AIDS services organisations. A precondition for this, however, is for physicians and the health-care providers cooperating with them to be more sensitive to the fact that some of their patients living with HIV have children to look after. Accordingly, health-care professionals need to speak to caregivers living with HIV about their children and their parenting responsibilities, and provide the necessary scope for this subject in their consultation sessions. In this way caregivers can discuss the problems they are encountering in this respect and formulate their actual support needs. By openly addressing problems in this way, the patients would be given the opportunity to face up explicitly to the difficulties they encounter. This might be an important first step towards availing themselves in an autonomous way of the assistance and professional caregiving support available to them. Concrete support which helps to compensate for parents' limitations in the performance of everyday parenting routines would definitely contribute to relieving psychological distress [21] and thereby improve the psychological wellbeing of caregivers living with HIV.

We thank the Swiss National Science Foundation for the substantial funding of the investigation this article refers to (Project No. 3146C0-103044) and the Swiss HIV Cohort Study for their important contribution in data collection and co-funding. The members of the Swiss HIV Cohort Study are M. Battegay, E. Bernasconi, J. Böni, H.C. Bucher, Ph. Bürgisser, A. Calmy, S. Cattacin, M. Cavassini, R. Dubs, M. Egger, L. Elzi, P. Erb, M. Fischer, M. Flepp, A. Fontana, P. Francioli (President of the SHCS, Centre Hospitalier Universitaire Vaudois, CH-1011 Lausanne), H. Furrer (Chairman of the Clinical and Laboratory Committee), C. Fux, M. Gorgievski, H. Günthard (Chairman of the Scientific Board), H. Hirsch, B. Hirschel, I. Hösli, Ch. Kahlert, L. Kaiser, U. Karrer, C. Kind, Th. Klimkait, B. Ledergerber, G. Martinetti, B. Martinez, N. Müller, D. Nadal, M. Opravil, F. Paccaud, G. Pantaleo, A. Rauch, S. Regenass, M. Rickenbach (Head of Data Centre), C. Rudin (Chairman of the Mother & Child Substudy), P. Schmid, D. Schultze,

J. Schüpbach, R. Speck, P. Taffé, P. Tarr, A. Telenti, A. Trkola, P. Vernazza, R. Weber, S. Yerly.

We also thank the members of the Eurosupport Study Group IV for the cooperation. The participating centres (and investigators) of the Eurosupport Study Group IV were Otto Wagner Spital, Vienna (Gunvor Koitz), Medical University, Innsbruck (B. Mumelter), Institute of Tropical Medicine, Antwerp (Bob Colebunders, Christiana Nöstlinger), Cliniques Universitaires St-Luc, Brussels (Vernard Vandercam), Deutsche Aids Gesellschaft (Ulrike Sonnenberg-Schwan), Ludwigs-Maximilians-Universität, Munich (F. D. Göbel), Synthesis, Athens (Nikos Dedes), University of Padua, Padua (Carlo Giaquinto, Gloriana Bartoli), Istituto Scientifico Ospedale S. Raffaele, Milan (Caterina Uberti-Foppa), Hospital Santa Maria, Lisbon (Luis Caldeira), Universi-

dad Complutense, Madrid (Victoria Gordillo), Karolinska Institute, Stockholm (Ann-Sofie Asander), Fachhochschule Nordwestschweiz (Daniel Gredig, Sibylle Nideröst), North Manchester Health Care NHS Trust, Manchester (Ed Wilkins), St. Stevens Centre, London (David Asoe).

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