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## Parental HIV disclosure in Burkina Faso: Experiences and challenges in the era of HAART

Georges Tiendrebeogo, Fabienne Hejoaka, Edwige Mireille Belem, Pascal Louis Germain Compaoré, Liezel Wolmarans, André Soubeiga, Nathalie Ouangraoua

### Abstract

Increasingly parents living with HIV will have to confront the dilemmas of concealing their lifelong treatment or disclosing to their children exposed to their daily treatment practices. However, limited data are available regarding parental HIV disclosure to children in Burkina Faso. Do parents on antiretroviral therapy disclose their HIV status to their children? What drives them? How do they proceed and how do children respond? We conducted in-depth interviews with 63 parents of children aged seven and above where the parents had been in treatment for more than 3 years in two major cities of Burkina Faso. Interviews addressed parental disclosure and the children's role in their parents' treatment. The rate of parental HIV status disclosure is as high as that of non-disclosure. Factors associated with parental disclosure include female sex, parent's older age, parent's marital history and number of children. After adjustment, it appears that the only factor remaining associated with parental disclosure was the female gender of the parent. In most of the cases, children suspected, and among non-disclosers many believed their children already knew without formal disclosure. Age of the children and history of divorce or widowhood were associated with parental disclosure. Most parents believed children do not have the necessary emotional skills to understand or that they cannot keep a secret. However, parents who disclosed to their children did not experience blame nor was their secret revealed. Rather, children became treatment supporters. Challenges to parental HIV disclosure to children are neither essential nor specific since disclosure to adults is already difficult because of perceived risk of public disclosure and subsequent stigma. However, whether aware or not of their parents' HIV-positive status, children contribute positively to the care of parents living with HIV. Perceptions about children's vulnerability and will to protect them against stigma lead parents to delay disclosure and not to overwhelm them with their experience of living with HIV. Finally, without institutional counselling support, disclosure to children remains a challenge for both parents and children, which suggests a need for rethinking of current counselling practices.

**Keywords:** : HIV, parental disclosure, children, care and support, counselling, Burkina Faso

### Résumé

Les parents vivant avec le VIH sont de plus en plus confrontés au dilemme de savoir s'ils doivent cacher ou au contraire dévoiler leur maladie à leurs enfants qui sont les témoins quotidiens de leurs prises de médicaments. Il existe toutefois peu de données concernant la question de l'annonce de l'infection à VIH des parents aux enfants au Burkina Faso. Les parents sous traitement antirétroviral dévoilent-ils leur statut à leurs enfants? Quelles sont leurs motivations? Comment procèdent-ils et quelles sont les réactions des

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enfants? Nous avons conduit des entretiens approfondis avec soixante-trois parents d'enfants âgés de plus de sept ans, qui étaient sous traitement depuis plus de trois ans. L'étude a été menée dans les deux principales villes du Burkina Faso. Les entretiens abordaient notamment la question de l'annonce de la maladie des parents aux enfants et le rôle de ces derniers dans le traitement parental. Le pourcentage de parents ayant révélé leur statut est semblable à celui des parents n'ayant pas informé leurs enfants. Les facteurs associés à l'annonce parentale sont le fait d'être de sexe féminin, l'âge plus avancé des parents, l'histoire conjugale et le nombre d'enfants. Après ajustement, le seul facteur positivement associé à l'annonce et le fait d'être une femme. Dans la plupart des cas, les enfants soupçonnaient la maladie du parent, sachant que parmi les parents n'ayant pas informés leurs enfants, nombreux pensent que ceux-ci suspectent leur maladie bien que n'ayant pas été formellement informés. L'âge des enfants ainsi que les situations de divorce ou veuvage sont associées à la révélation parentale. La plupart des parents considéraient que les enfants n'avaient pas les compétences émotionnelles nécessaires pour comprendre ou qu'ils ne pouvaient pas garder un secret. Cependant, les parents ayant informé leurs enfants n'ont pas été blâmés et n'ont pas vu leur secret dévoilé. Les enfants sont au contraire devenus un soutien dans le traitement des parents. Le défi inhérent à la révélation de la maladie des parents aux enfants n'est pas spécifique et ne doit pas être essentialisé, l'annonce entre adultes étant également difficile en raison de la crainte d'une révélation publique et de la stigmatisation. Pourtant, qu'ils soient ou non informés de la maladie de la séropositivité de leurs parents, les enfants contribuent aux soins de leurs parents vivant avec le VIH. Leurs perceptions de la 'vulnérabilité' des enfants et leur volonté de les protéger de la stigmatisation amènent les parents à ajourner l'annonce afin de ne pas imposer aux enfants l'expérience difficile de la maladie. Au final, en l'absence de soutien institutionnel en matière de conseil, l'annonce aux enfants demeure une épreuve pour les parents autant que les enfants, nécessitant de repenser les pratiques actuelles de conseil.

**Mots clés:** VIH, annonce parentale, enfants, soins et soutien, conseil, Burkina Faso

## Introduction

Nowadays, you may see a very young child who already understands what HIV is. You may also have [children] who do not understand. However, for disclosing to children you need strategies! As far as I am concerned, I used the opportunity of being a member of an association and having to carry out some awareness raising activities ... so, every time I bring home flyers, posters or condoms ... Gradually, we discussed AIDS at home. One day the question came like this: What, if one of us had AIDS? (...) And we discussed what that would mean to all of us. Yes, if one of us had AIDS it would be difficult, however now that treatment is available ... I told them: well! Mamma is HIV positive ... (39-year widow with two sons and one daughter aged 21, 17 and 16)

In Burkina Faso, as in many other African countries, parental HIV-positive status disclosure to children is a predicament as is illustrated by the quotation. In the early years of the HIV epidemic characterized by stigma, lack of active therapy and the lethal character of AIDS, disclosure to affected children was not parents' primary concern though some parents may have shared their secret with their children when at an advanced stage of AIDS or faced with enacted stigma (Hejoaka 2004).

However, over the last decade the development of highly active antiretroviral therapy (HAART) has transformed AIDS – for those who have access to these drugs – into a manageable chronic infection. The HIV prevalence in the general population in Burkina Faso was estimated at 1.0% in 2010, and the main mode of HIV transmission is heterosexual. The country is home to approximately 110,000 people living with HIV (PLHIV) among whom 34,472 adults and 1776 children were receiving ART by December 2011. Alongside public and private

institutions, an active network of civil society organizations contributes to prevention, care and support activities and to the fight against the enduring stigma and negative attitude towards PLHIV (UNAIDS 2012).

As the epidemic evolves, new opportunities to satisfy the needs of people living with HAART such as resuming life trajectory, social life, creating families or raising children are revealed. However, the inscription of HAART into a long-term management of a chronic condition presents new kinds of challenges such as disclosure to their close social environment, including their children. Increasingly PLHIV – parents or parents to be – will have to confront the dilemmas of concealing their lifelong treatment or disclosing to their affected children exposed to their daily treatment practices. These present new perspectives for social sciences.

Since the beginning of the AIDS epidemics, HIV disclosure to children has received quite some attention within scientific literature. Most of the knowledge on parental disclosure derives from studies conducted in northern countries where health professionals have gained experience in the routine management of chronic illnesses (Steele, Nelson & Cole 2007; Wiener, Mellins, Marhefka & Battles 2007). These studies addressed issues of parents' HIV status disclosure to children (Hawk 2007; Murphy 2008) and eventually disclosure of their own HIV status to HIV-positive children (Gerson, Joyner, Fosarelli, Butz, Wissow, Lee, *et al.* 2001) and report on rates and determinants of parental disclosure. Common features of parental HIV disclosure in these studies suggest low levels of disclosure ranging from 40% to 75% but similar to disclosure by parents with other illnesses (Armistead, Tannenbaum, Forehand, Morse & Morse 2001; Nostlinger, Jonckheer, de Belder, van Wijngaerden, Wylock, Pelgrom, *et al.* 2004; Rotheram-Borus, Lee, Gwadz & Draimin 2001) and that mothers were more likely to disclose earlier than fathers (Lee & Rotheram-Borus 2002). Non-disclosure

is motivated by fear of the emotional impact of disclosure on children, and fear that children may not be able to keep the family secret (Kmita & Baranska 2004). Another reason is that parents do not know how best to carry out disclosure to their children (Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy, *et al.* 2010; Murphy 2008). Surveys also revealed that disclosure is more common with older children and is associated with parental poor health and perceived severity of physical symptoms (Lee & Rotheram-Borus 2002), stressful life events and high level of social support (Murphy, Stritto & Steers 2001). With improved health, it is anticipated that parents may not consider disclosure as a priority or even desirable (Lee & Rotheram-Borus 2002).

As compared to northern countries, little attention has been given to parental HIV disclosure to children in resource-limited countries. While the literature examining disclosure to HIV-positive children of their HIV status is growing, little is known about parental HIV status disclosure to their affected children in developing countries, with the exception of rare studies (see, for example, De Baets, Sifovo, Parsons & Pazvakavambwa 2008; Wood, Chase & Aggleton 2006). On the one hand, in most of the situations parents may form the intention to share the news with their children but do not feel well prepared to discuss sensitive issues (sexuality, disease, death, grief, need for a child to take the HIV test, etc.) or to face their children's reactions following disclosure of their parents' HIV status. On the other hand, health-care providers were ill prepared to provide the necessary counselling support to parents in need of such support as documented in northern countries (De Baets *et al.* 2008; Wood *et al.* 2006), China (Xu, Yan, Rou, Wang, Ye, Duan, *et al.* 2007), Botswana (Nam, Fielding, Avalos, Gaolathe, Dickinson & Geissler 2009), Uganda (Rwemisisi, Wolff, Coutinho, Grosskurth & Whitworth 2008) and in South Africa (Palin, Armistead, Clayton, Ketchen, Lindner, Kokot-Louw, *et al.* 2009).

Disclosure is promoted during counselling sessions, which have become easier for health-care providers and HIV counsellors alike since the advent of ARVs. Yet, at the same time counselling has lost its core values, principles and approaches, and currently focuses on disclosure 'to at least one person'. In this area, we see special emphasis placed on disclosure to sexual partners, medical injunctions (treatment literacy and adherence) and child desire. Indeed, as described by Lugalla, Madihi, Sigalla, Mrutu and Yoder (2008), HIV post-test counsellors spend time explaining how to live with the virus, where to go for help or support, whom to see for medical care, ways to maintain good health, and they urge their clients to tell someone else about their test results. In Burkina Faso, progress has been made to prevent mother-to-child HIV transmission and to enrol children living with HIV on ART. However, while counsellors may invite a partner to help a client disclose, parents are left alone without institutional support to disclose to their children. As described by Hejoaka (2012), this context of 'double standard' – whereby standard procedures for disclosure exist for adults and not for children – is a contributing factor to poor overall parent-to-child disclosure results. Indeed, she shows in her study among children living with HIV in Bobo-Dioulasso (Burkina Faso) that many of these children were seldom informed of their own HIV-positive status.

Drawing on the findings of research conducted in Burkina Faso, this article documents the complex experience of parental HIV status disclosure to affected children. Whereas this research departs from a summary of quantitative findings, its very qualitative nature allows for exploring in details the patterns and meanings beyond the statistics, and provides a basis for grounded understanding of parental disclosure. The approach is centred on the analysis of *emic* understandings, i.e. the way people that we interviewed draw meanings into medically recommended practices that fit with their cultural and symbolic context within local patterns of social relationships.

The data and narratives presented in this article derive from a wider qualitative study exploring long-term adherence to HAART, which justified a focused enquiry into the dynamics of parent to child HIV disclosure. Why do parents with a long history of HAART do (not) disclose to their children? When and how do they involve their children in their illness and treatment experience? How do children respond to parental disclosure? With increasing parents having children free of HIV thanks to the up scaling of programmes for prevention of mother-to-child HIV transmission, many people on HAART will face the challenge of parental disclosure to affected children.

However, whether disclosure is desirable or not, many parents are still in a difficult position regarding disclosure to their children insofar as parents and/or children may need specific and sustained counselling support to meet the challenges of parent to child disclosure.

## Methods and participants

Participants to this focused study were parents living with HIV on HAART for more than 3 years that were concomitantly participating in a larger 4-year qualitative study into long-term adherence in the two major urban agglomerations of Burkina Faso where ART were first made available: Ouagadougou and Bobo-Dioulasso. In these two cities, various public institutions, community-based and non-governmental organizations (NGO) provide treatment and adherence support services. We selected five centres based on the volume of people on HAART for more than 3 years that they serve, and in a way that reflects on the diversity of actors. The main selection criteria were participants' experience with HAART for more than 3 years and willingness to participate. Sampling was opportunistic and purposive, and in each site, the group of all people meeting the criteria were identified from the database and made eligible to the study. In each site, eight women and eight men were recruited with maximum variation – e.g. year of ART initiation, ethnic group, marital status – to capture the evolving needs of people on HAART.

All participants were contacted by the institutions' counsellors and were informed of the purpose and the methodology of the research, and written informed consent was obtained for interviews. Trained sociologists and the principal investigator – physician and medical anthropologist – interviewed all participants during the period from November 2006 to April 2007. Four face-to-face in-depth individual interviews *per* participant were scheduled and the researchers met with interviewees every 2–3

weeks in the five sites. However, after three rounds of interviews, all themes were fully covered and the information provided by interviewees during the repeated sessions was consistent. Among other themes related to adherence that were essential to the larger 4-year ethnographic study into long-term adherence, the topic guide used for this study included open questions and discussion points on disclosure to children and the role of children in adherence support.

Descriptive statistics were computed for sociodemographic variables and cross-tabulations were performed to analyse univariate associations between disclosure and parents' characteristics (gender, age group, marital status, number of children, children's age group, education level, religion, profession, number of years since tested for HIV and duration on HAART). Significance level was based on Pearson's chi-square test, set at 5% or a *p*-value <0.05 indicating statistical significance. This was followed by a multivariate binary logistic regression to analyse the associations of disclosure and gender, age group, marital status, number of children, children's age group, religion, profession and duration on HAART with dependent disclosure. The *Hosmer and Lemeshow goodness-of-fit test* was used. All variables for the logistic regression was categorized by creating dummy binary variables. SPSS 20.0 for Windows was used for this quantitative analysis.

Overall, data from 63 participant parents of at least one child aged 7 years (school age) or above were selected for this focused study into parental disclosure to children (see participants' characteristics in Table 1). As a reminder, our working definition of children refers to a biological son or daughter of any age of a participant.

Respondents include 37 women (59%) and 26 men (41%) among whom 29 participants were single parents (25 women and 4 men) and 34 participants were living in a heterosexual union (13 women and 22 men). Amongst those living together with a partner, 18 were married, 11 widowed and remarried and 5 were divorced and remarried.

All participants had at least one child with the number of children ranging from one to seven. The age of the children ranges from 7 to 30 years of age. Thirty parents (15 women and 15 men) had only children below the age of 18. Thirty-three participants (22 women and 11 men) were parents with both adult and young children and were classified as parents with children above 18. Five women had children tested HIV positive (two widowed, two widowed and remarried and one married).

Twenty-seven participants were in the age brackets [20–40 years] and 36 were between 41 and 63 years old. Forty-six participants had a paid labour and men were likely to have a paid labour as compared to women. Eleven (nine women and two men) out of the 46 participants with a paid labour were HIV counsellors.

The onset of HIV among the participants could not be ascertained. However, the majority of the participants (62%) stated they tested positive 3–5 years before the study while 38% tested 6–10 years before the study. All had 3 or more years of experience with HAART with 47 participants on treatment for 3–4 years and

**Table 1. Participants' characteristics, parental disclosure, Burkina Faso, 2006.**

Participants' characteristics	Number	%	Disclosure (%)	<i>p</i> -value*
Parental disclosure	63	100	47.6	
<i>Gender</i>				0.006
Female	37	59	62.2	
Male	26	41	26.9	
<i>Age group</i>				0.013
[20–40 years]	27	43	29.6	
[41–63 years]	36	57	61.1	
<i>Marital history</i>				0.046
Widowed, divorced and single parent	45	71	55.6	
None of above	18	29	27.8	
<i>Education level</i>				0.893
Illiterate	14	22	50	
Primary school	16	25	56.2	
Secondary school	25	40	40	
University or higher education	4	6	50	
Autodidact or Coranic school	4	6	50	
<i>Religion</i>				0.498
Christian	35	56	51.4	
Muslim	28	44	42.9	
<i>Years since HIV test</i>				0.767
[3–5 years]	39	62	46.2	
[6–10 years]	24	38	50	
<i>Duration on HAART</i>				0.720
[3–4 years]	47	75	48.9	
[5–6 years]	16	25	43.8	
<i>Profession category</i>				0.099
Non paid labour	17	27	64.7	
Paid labour	46	73	41.3	
<i>Number of children</i>				0.009
1 or 2	34	54	32.4	
3 and more	29	46	65.5	
<i>Parents with children</i>				0.008
Aged 18 and above	33	52	63.6	
Aged below 18	30	48	30	

\*Pearson's chi-square test at 5% level of significance.

16 participants on treatment for at least 5 and up to 6 years at the beginning of the study.

A preliminary analysis of the first round of interviews done by the research team used an inductive content analysis technique that allowed to organize emerging patterns, themes and categories of analysis and provided the rationale for further inquiries during the subsequent interviews. All interviews were tape-recorded. At



the end of the fieldwork, all interviews were translated when the language skills of the interviewees necessitated such, transcribed, coded by the principal investigator and analysed using the Atlas-ti software for qualitative data analysis (version 6.2). The approach to the data analysis draws on the Grounded Theory approach to allow conceptualization and theorization.

The research was conducted in accordance with the research protocol approved by the Ministry of Health's Research Ethics Committee in Burkina Faso (DCO/OC-134/05: Development of ART adherence-enhancing interventions in Burkina Faso. Deliberation No. 2006-20). The principal investigator secured all materials. Although interviewees were asked not to start the recording during the introductory dialogues, in a few circumstances interviewees provided their names and telephone contacts; these were systematically cleaned during the transcription and data entering.

## Results

### To tell or not to tell: parental disclosure in a nutshell

We report that women were significantly more likely than men to disclose to their children ( $p$ -value = 0.006). Parents with children aged above 18 were significantly more likely to disclose as compared to parents with only children aged below 18 ( $p$ -value = 0.008). This corroborates the hypothesis that women, participants over 40 years old and parents with three or more children – groups that happen to be the ones with older children – were significantly more likely to disclose their HIV status to their children than parents between 20 and 40 years ( $p$ -value = 0.013) and parents with one or two children ( $p$ -value = 0.009). Participants with history of widowhood, divorce or single parenthood were more likely to disclose than parents without antecedents of single parenthood, divorce or widowhood were ( $p$ -value = 0.046).

Occupational categories, even when they were in relation with, HIV counselling did not account for disclosure ( $p$ -value = 0.099). Religious affiliation did not also associate significantly with disclosure ( $p$ -value = 0.498). Disclosure was associated neither to the duration on HAART ( $p$ -value = 0.720) nor to the number of years since tested HIV positive ( $p$ -value = 0.767). Having a HIV-positive child did not significantly associate with parental disclosure (Fisher's exact test = 0.149). Nevertheless, four (two widows and two remarried widows) out of the five participants with HIV-positive children disclosed to their children – among whom three were aged 6, 8 and 11 years and were on ART, and the fourth was 11 and on Cotrimoxazole<sup>®</sup> – while the fifth and married woman did not disclose to her 8-year HIV-positive child but not on ART.

Finally, after adjustment, it appears that the only factor remaining associated with parental disclosure was the female gender of the parent (Hosmer and Lemeshow goodness-of-fit test sig. = 0.111). Refer to Table 2.

A closer look at the statistics shows that the percentages of disclosure (48%) and non-disclosure (52%) to children are similar.

**Table 2. Binary logistic regression, parental disclosure, Burkina Faso, 2006.**

Variables in the equation	Sig.	Exp(B)	
Gender (Female/Male)	0.041	5.544	
Children above 18 years (Yes/No)	0.491	1.745	
History of divorce, single parenthood or widowhood (No/Yes)	0.964	0.965	
Age group of parent ( $\leq 40$ , $> 40$ )	0.219	0.348	
No of children ( $\leq 2$ , $> 2$ )	0.136	0.347	
Paid labour (No/Yes)	0.549	1.550	
Religion (Christian/Muslim)	0.462	1.623	
Duration on HAART ( $> 5$ , $\leq 5$ years)	0.322	0.476	
Constant	0.940	0.917	
<i>Hosmer and Lemeshow goodness-of-fit test</i>			
Step	Chi-square	df	Sig.
1	13.033	8	0.111

Note: For all independent variables in the logistic model, the reference category is listed first. For example, for gender, females are the reference category meaning that females are 5.5 times more likely than men to disclose. For age group of parent, 20–40 years ( $\leq 40$ ) is the reference category. We see from the analysis above that parents in the age group 20–40 years are 0.35 times less likely to disclose. The latter was not statistically significant though.

This leaves the researcher in a knowledge situation tantamount to a half-full or half-empty glass. Beyond these statistics, as we fully enter the era of HAART, the situation reveals a variety of situations and scenarios that need to be more closely studied in the Burkina Faso context where disclosure to third parties is still quite limited.

### Parental non-disclosure to children: fear of unintentional disclosure and stigma

Reasons for delay or non-disclosure to children included fear that children may not be able to keep the secret or emotionally bear the news, and parents feeling not ready or not knowing how to disclose.

The most common barrier to parental disclosure is parents' perceptions of children's inability to maintain secrecy or to 'keep their mouth shut' if they were informed. A 55-year-old widowed mother of five children – among whom some are studying at the university and two married daughters – explains that only her oldest son was informed and that she had no intention to disclose to her other children.

Since a child cannot keep secrets if you tell them, hum! Their father passed away . . . that is their main worry and they will only be thinking of that . . . Where the child will go to seek support . . . and what can happen when they do – you can only blame yourself if you disclose. (55-year widowed mother of five adult children)

Many parents did not want to disclose to their children since they assumed children do not understand the HIV infection. Parents

underestimated children's knowledge and understanding of HIV/AIDS and associated childhood and adolescence with psychological immaturity.

Children should be grown up before they can be informed about what is going on in the family. When they are young, say 10, or 12, well, they are not conscious of the situation and the range of problems it can bring to the family. That is what led us not to inform them . . . (48-year father of three children aged 16 and above)

Fear of losing their children's respect or that own children may form the same negative judgements or attitudes towards them as would others (strangers) outside the family may explain parental non-disclosure as a 53-year widowed with five children recalls:

They do all to discover and even to blame me. I am telling myself that they will be informed only if God himself lets me down and that I am transported home seriously ill and lying in bed . . . As I told you, one of my children is terrible; he shouts at me, discourages me and makes me spend sleepless nights despite my doing everything to take care of them since their father passed away ( . . . ) If I tell them, they will speak loudly and the neighbours will hear . . . Even when I have an appointment and tell them, they don't care and bother me. They shout at me in the courtyard. They are not caring. That is why I don't want to tell them. (53-year-old widowed, five children above 18)

In the same way, parents are reluctant to disclose to adults because of perceived stigma, they also expressed fear of being stigmatized or discriminated against by their own children as this 55-year-old widow explained:

Will they accept to stay with me? You see? This is the problem. [Where would they go?] . . . I don't know. They are children. Well, they are quite grown up . . . according to them . . . (55-year widowed, three children aged 11–21)

## Concealing one's HIV status to protect children

Children and particularly the youngest ones are seen as dependents and it is culturally expected from parents to preserve them from stress. Some parents explained that they keep the silence to prevent potential emotional suffering that disclosure may bring to their children.

My child is 12. If I tell him, it will be disturbing to him. You know, last December I had a sinusitis and had to stay in bed . . . When the kid saw me, he refused to go to school. I asked him to go but at 12:00, he was already back though he used to stay over lunch. He came straight into my room, threw my blanket away, touched me and enquired if I have eaten or drank water, if I was doing well. Because with the death of their father they have been shocked . . . because of that, he

got bad grades at school though he used to regularly get 7 out of 10 on test scores, . . . It is true, it is me who is sick, but the children are also sick because they suffer with me. (43-year widow with four children aged 12 and above)

Parents' willingness to protect their children also applies to adult children as illustrates the case of a 42-year-old widowed mother of two children aged 20 and 16. She has not disclosed though she agrees the children are almost adults and question her about her pill taking.

Well, they suspect, but I always deny. The children are quite old but if I tell them . . . Their father passed away, I'm left alone, I am the father, I am the mother . . . they have nobody but me. If I tell them, they will not be happy. (42-year widowed, two children aged 16 and 20)

Elsewhere, some parents were overwhelmed by their own worries and felt they will not be able to handle the impact of disclosure to their children.

They [children] are already afraid of the disease. If you tell the child and he falls ill who will treat him? Are you healthy enough to run around? (55-year widowed mother of five adult children)

## 'Time will come': delaying and contemplating disclosure

For the reasons cited above, many parents delay disclosure. Disclosure follows a long process of decision-making and most parents agree they will have to confront the experience of parental disclosure in time. However, timing for disclosure is systematically postponed as explained two widows who did not disclose to their 9- and 11-year-old children though they feel they should be informed.

He should be informed, but I am waiting until he is 15 to tell him ( . . . ) I think I have to tell [my son] about it. I want to prepare him so that he can protect himself later [laughs]. One day he made use of one of my razor blades and cut himself. I was so sad . . . I called him and advised him never to use my blades, combs and worse, those of other people because of AIDS. He asked if I had the disease, I answered no . . . I told him it's because the disease can be also passed through instruments, blades, and scissors. I cannot openly tell him I have AIDS because he is still young. He is in form 6 [last year of primary school]. He has not yet reached the age where one can keep a secret. (36-year widow, one son aged 11)

When he will be 14 or 15 I will start telling him I am infected and that is the reason I am taking the medicines. Currently, he is too young . . . The way people speak about AIDS all over the places can discourage him. He may start crying that his mother will die; that his father passed away and his mom is dying because they said that AIDS kills and is contagious. He may not even want to eat and so on. Therefore, I don't

want to traumatize him ... otherwise one cannot hide it forever to his child. (37-year widow, one son aged 9)

In one instance, out of fear of negative reactions, a widow-remarried participant only disclosed to her 11-year-old HIV-positive son – who is on treatment for the prevention of opportunistic infections – and not to her three other older HIV-negative children. Only her husband and her HIV-positive son are informed. She explains she is contemplating to disclose but needs to prepare her children.

The other children are not yet informed. I don't know how they will react ... I don't know how to explain this to them. It's not easy. Because, the way people talk about this disease ... From time to time when watching TV we talk, and I often try to see, assess their reactions. I tell them what if a one of your parents is infected how would they approach him or how would they behave with him? I try to talk like that ... well, to first see what would be their reaction before I disclose my status. Otherwise I cannot disclose like that. It's a bit hard. It can also play on them. Often, they say bad things about PLHIV saying that those who are HIV positive ... Well, they say these things in front of me but they do not know that even their mother is HIV positive. Under these circumstances, I must take the time to prepare them. (39-year widow-remarried, four children aged 11–21 years)

## Reasons for sharing and involving children in the secret

According to the research, the reasons and circumstances for sharing and involving children in the secret among study participants vary widely.

### Rational disclosure

In some instances, parental disclosure was active and subsequent to a thoughtful resolution made after a time of reflection and maturation of the decision facilitated by treatment initiation as recalled two widows. They did not disclose their HIV status right after the test but did so once treatment was started.

At the time of the test, I did not disclose. It's when I wanted to start the ARV that I told myself I have to disclose to at least one person. In my case, I called my older sister and disclosed ... Currently everybody in the family including the children is informed and there was no problem. (47-year widow with married daughters and an adopted child aged 12)

I first had to get things right around me ... I mean ... the children were worried because Mama was losing weight. Therefore, when I got the ARV I told them: Mama has got the cure for her cough and diarrhoea. However, it has to be taken at specific schedules ... we set alarm clocks that ring at specific times ... (39-year widow with two sons and one daughter aged 21, 17 and 16)

### Crisis disclosure

Parents also reported situations where disclosure was precipitated by critical events. For instance, a 45-year-old woman, disclosed to all her children at once out of anger. She recalls:

One day I called in all my children and disclosed, for the simple reason that my husband insulted me by referring to my illness. He wanted to have unprotected sex with me and I refused. At the time, I was on medication and gained weight, and was even 'shining'. He said I have to manage my bizarre disease on my own. That was too much and I told him what nobody should be told. I asked him: 'what is wrong with you? Are you a real man?' When he was insulting me, the children were present. I was in tears. People calmed me down. The day after, I called in all my children and disclosed ... Everyone was informed that very day ... (Woman, 45-year with six children aged 16–30)

Disclosure happens frequently under certain extreme circumstances and especially when attribution of the infection could be easily explained without loss of face as explained a 39-year-old woman. Her husband, who is a soldier, has taken his test since 1998 and was on treatment since then but has not disclosed to her. She discovered his test result one day while she and her daughter were cleaning house.

We were arranging documents and papers and by chance, it's his own daughter who discovered his test result ... Yes, his HIV test! My eldest daughter cried and I came by and asked what's up? She said: 'Mama, here is your husband's HIV test result!' I read the result and put it on the table. I told my daughter: as you've seen, your father has taken the test, so did I when I went to Bobo and got ill. I have taken the test and I am HIV infected. She started crying I said calm down, because I won't die. (Woman, two children aged 21 and 15)

### Protective and informative disclosure

Parents had mixed feelings regarding disclosure but wanted to dispel false beliefs held by their children as illustrated a widow and mother of three children prompted to disclose to her oldest child to elicit myths about her husband's illness and death.

[I disclosed] only to my oldest child ... She used to tell me, hey, Mama, it seems to me that Dad has been poisoned since there was a time he had diarrhoea. I asked who she thinks had poisoned him? She said an uncle who did not like him ... I stopped her, went in the room and came back with my medicines. I asked her, do you know what this is? She took the medicines, unfolded the notice and read ... then looked at me and said: was it so for Dad too? (Widowed, 40-year old, three children above and below 18)

Elsewhere parents disclosed and especially to adolescent girls because they felt it would provide information that may prevent children from engaging in risky behaviour that could lead them to go through their parents' experience, and finally, because



disclosure improves communication on AIDS with them. A 45-year-old mother states her adult and young children are tenderer with her since disclosure.

On many occasions with the girls, I give them information on the ways HIV is transmitted and symptoms of the disease. I advised them to take the test. I have 6 children; currently, only one of them has not yet taken his HIV test. The advice I give to my children helps them avoid the disease. I have a daughter that a man was chasing. She is a girl who stays away from men. The trick the man found was to buy her an expensive cell phone but said she must go out with him [become his girlfriend] before he gives it to her. The man wanted to have unprotected sex with her. There, my daughter refused firmly and refused the cell phone altogether. Once back home she told me the story. (Woman, 45-year old with six children aged 16–30 years)

As already explained above, mothers often disclose to their HIV-positive children who are either on treatment for the prevention opportunistic infections or on HAART. In these cases, disclosure was often done in relation to the need to improve treatment adherence.

Even to my child I said, you know that you are sick, if you do not take the drug you will get sick and die, and you will be the loser (. . .) He is not on treatment but does take Cotrimoxazole<sup>®</sup>. He was tested HIV positive 5 years ago. He may suspect . . . I, myself never told him he has the disease. I only told him about my HIV status. He asked if it was because of his anemia that he was told to take the medication? That's because you're sick you're told to take the medication. But he takes his medication and when you see him you would not think he has a problem. (39-year widow-remarried, four children aged 11–21 years)

## Effects of parental disclosure

While parents systematically anticipated children's negative reactions, contrary to their expectations, all parents who disclosed experienced supportive reactions from their children as reported by this 39-year-old widowed.

Nowadays if you have that disease . . . you will understand whom your relatives, your friends are. They all run away from you. Your only mean to . . . it's you and your close family who will have to manage the situation. They all disappear . . . it turns only into criticism . . . In my case all the children are informed about my problem . . . none of them has rejected me. On the contrary, they always support me. In any case, your own children you have to [disclose] because they are your own blood. You always must share your problems with them. (39-year widow with two sons and one daughter aged 21, 17 and 16)

After months or years in the closet of HIV secrecy, many parents experienced relief upon disclosure to their children.

I was so happy when I disclosed to my children . . . the fact that they did not take it badly . . . Before, I was afraid they would display negative reactions once informed. (Widowed, 43-year-old)

The study pointed out that informed children are supportive of their parents and that they provided sustained moral support. A 47-year-old mother and HIV counsellor says . . .

Nobody else knows I am HIV positive apart from my family. I have not been rejected and I have never noticed a single behaviour that suggests I am side lined. It's this aspect that gives me the courage and makes me live. If I had noticed a seeming rejection from the family, it would have marked me psychologically . . . From the children I would not have been able to take it. Therefore, thank God my two daughters have not acted like that. My daughter who lives in Ouagadougou, whenever she does not hear from me comes over to see if I am doing well . . . (Woman, 47-year-old and HIV counsellor, two adult daughters)

None of those who disclosed expressed they did so to get financial support. However, the study revealed that older children do effectively provide financial support.

Once I felt ill and even my jobless daughter managed – I don't know how – to help me with 3.000 CFA. Nowadays when I want to give her money, she refuses and says I should take care of myself. (43-year single mother and HIV counsellor, three children aged 16–25)

Overall, disclosure facilitates the acceptance of one's HIV-positive status and improves care during episodes of illness, treatment adherence and well-being.

It's necessary, because when I do not feel well, it is my children who take me to the hospital; even when their father was seriously ill, they were collecting his ARV at the AIDS centre. (44-year woman mother of five children aged 15–23)

Following disclosure, parents were no longer forced to hide from their children to take their pills, to lie and to conceal the nature of their suffering. Almost all participants who disclosed reported that children remind them about dosing and schedules. Thus, forgetfulness, said to be a major determinant of non-adherence, is dealt with more effectively with the help of informed children as illustrates the following explanation by a disclosing parent:

[In the beginning] it was not easy at all . . . I was hiding . . . but everyone helped me understand they were considering HIV/AIDS like malaria. My family, I tell you . . . even the young children, they know my ARV box. I do not remove the packaging or what is written on it. I leave it as it is. When I say, bring me my medicines . . . I have nieces, my little girls, and the children of my nephews they run, take

it and bring it to me. They know what the medicines are for ... because they see me taking them. Children are amazing ... I no longer need to hide them as I used to do! (44-year widow remarried with two children aged 15 and 21)

## Easy to say, hard to do: partial disclosure and the disclosure 'grey zone'

The scenarios of non-disclosure presented above would not be complete without the mention of parents who did not formally disclose but state their children are aware of their parents' HIV status. A situation that resembles 'telling without telling' as coined by Hejoaka the 'disclosure gray zone' (Hejoaka 2012).

In a few cases, disclosure was 'passive' as children became aware of their parents status indirectly or were informed at the time of the diagnostic when they were the caretakers of parents under medical supervision ...

I did not disclose to them. They saw when I was ill. They were informed indirectly. (45-year man, children aged 7–18)

In a certain number of cases, parents believe their children are aware of their HIV-positive status the same way other people became aware of it without their formally disclosing ...

Well, as you know yourself nowadays, if you stay in bed even for one month people form an idea about you and your illness: that is HIV, maybe you've got AIDS! Therefore ... I work in this environment and I know how it is, even if you don't tell people, that it is HIV or not, people say it is HIV. As far as I am concerned, I tell myself that people think I have it. Well, I have not openly said I have taken the test and that I am infected, but I know that people think I have HIV ... [My children] witnessed the time I was ill and who knows? Well, they know that ... As I said, in general ... my children also think it is it. However, I have not openly disclosed. I have taken the test, it is like this or like that, no! (51-year widowed HIV counsellor with children aged 30, 28 and 17)

During the interviews, many parents assumed their children were aware of their status despite their not formally disclosing. More striking are the situations where evidence suggests that children are aware, but the matter is not openly discussed between the parents and children. A 56-year-old man in a discordant union with four children did not know how to disclose to his wife, but finally managed to do so. Later on, he realized she took her test without telling him. Far more lately, he also realized that his 'children have taken the test without telling him'.

Children know but we never talk about the subject matter ... Hum ... maybe for respect to their father we don't talk about it at all. They're grown up and three of them are currently studying at the university while one is still at in secondary

school. The youngest one may not know, but the other three are aware. [...] It's when sometimes I come across a test result here or there that I see that one has taken the test and that it is negative. At such times, I fold the paper and put it back where it was. Everyone at home has taken the test without telling me. All their tests returned negative. Thank God. (Man, 56-year with four children at university and secondary school levels)

Ideal age to disclose is also complex. For example, youth is associated with immaturity and it is frequently the argument put forward to explain non-disclosure. However, in some cases the youngest children were informed instead of elder children and adult family members.

I have two children ... It's the second one who is informed. My oldest daughter, I did not ... because the way she is ... I did not want to inform her and until now she doesn't know about my HIV status. (44-year widow and HIV counsellor, two children above 18)

I have disclosed to my eldest son. I did not disclose to my mother because she does not control her mouth. Even here, we are advised to disclose only to people we trust ... Once, during the group discussion a person testified about his experience after having disclosed to his own mother ... it had shortened his life ... One should disclose only to people who can keep a secret ... The last time I was seriously ill, my son went to collect my ARV. He is the only one aware of my disease. (53-year divorced and remarried with a married daughter and three secondary school-age adolescent sons)

Regarding gender, which appears to be the most significant factor for disclosure, only one participant provided her explanation why women and men differ when it comes to parental disclosure. She believes:

Generally, within a couple, the children see the man as the strictest because when the child does something he is told: 'If you do this or that when Dad comes, we will tell him!' Therefore, the relationship between the father and the children is limited. For a man to disclose to his children, he really needs to manoeuvre. Whereas, the woman who is close to the children, always at their service and caring for their every little need, has less difficulties addressing these issues with the children. However, the man may be able to do it but he needs to follow certain pathways ... strategies to disclose. For example, when in a couple, the woman passed away and the man is left behind alone, he is obliged, by whatever means, to explain to the children that their mother died from the HIV infection and that he is himself infected and needs their support. Men and parents in general, even need to understand that besides the drugs, the support one receives ... we need this support, I mean the blood tie you have with the children ... that is more reassuring than friends and it is an asset, over and above what

you get, it is the basis. (39-year widow with two sons aged 21 and 17 and a daughter aged 16)

It finally appears that beyond gender, the will to protect children, or the risk to young children of involuntary disclosure, motivates the choice to disclose of many parents. However, having a supportive social network to whom to disclose may lead parents to choose to delay disclosure to their children.

I think I will necessarily have to disclose since one has to live with it... there is no cure yet. Why hide it? In fact, it is because they are still young. I don't know how they will react, would they even understand? [Silence]. The other one, hum, he just turned 18 and thus legally, he is not yet an adult. We must therefore wait a little bit... I'm not making it a mystery. I mean, since I became aware I was infected, I informed all my family, all my relatives... since my spouse died just after. About the children, that is something different. They are... they were young. Well, it's somehow difficult. The oldest [daughter] will take her level exam this year; the second [daughter] prepares her end of primary school exam. Well, frankly, we have not openly discussed it with them. Maybe they suspect, but I don't know. However, with all the others, I mean my father and mother passed away; but we are many, I have brothers and sisters and they are informed. (51-year widowed man remarried, two children, aged 18 and 12)

Social networks include peer support groups and local NGO members where PLHIV receive support from others and/or trained counsellors. The fact that half of all parents HIV infected that are counsellors themselves did not disclose to their children shows that disclosure in an everyday social environment that is strongly vetted in HIV and AIDS work is not easy. It also points to the development of an institutionalized parental disclosure-counselling framework.

## Discussion

The current trends towards disclosure can be attributed to availability of life saving drugs (HAART), which have transformed the prognosis of the HIV infection, making disclosure to patients easier for health-care personnel. Nowadays, the challenges to disclosure are shifted to PLHIV who are prompted by health-care professionals to disclose to relatives, and by law, to spouses or sex partners (Sanon, Kaboré, Wilen, Smith & Galvão 2009). Sustained education and interventions for attitudinal change, coupled with institutional support, especially through local NGOs, have contributed to stigma reduction and to the creation of an enabling environment (Norman, Chopra & Kadiyala 2007; Roura, Busza, Wringe, Mbata, Urassa & Zaba 2009).

Yet, though progress is being made towards understanding of its importance, parental disclosure to children is so far not adequately addressed. Indeed, children are generally not perceived as preferential recipients of adult HIV disclosure as pointed out by Hawk (2007) in a literature review on maternal HIV infection disclosure to non-infected children; 'disclosure to children occurs

less often than disclosure to women's mothers, sexual partners, extended family, and health care providers'.

Parental HIV disclosure to children is often presented in the literature as a particularly challenging and tricky experience for parents. Nevertheless, our study shows that over time, almost half of our participants disclosed to their children. This rate of parental disclosure is significantly higher than the mean level of 30% reported in previous studies (Armistead *et al.* 2001; Murphy *et al.* 2001; Palin *et al.* 2009). Some parents disclosed to their children before they started HAART, especially during acute illness episodes or family conflict situations. After treatment initiation and while they could have kept the secret because of the recovery of their health many parents disclosed their status to their children and explained their treatment requirements. Finally, children often witnessed their parents' treatment practices, enquired and were explained about.

## De-essentializing: parental HIV disclosure is not a specific issue

Family secrets such as parents' HIV status often bring about noxious atmosphere in the family, especially when children already suspect. Far from underestimating the difficulties and complexities of breaking the 'bad news' to children, we argue that parental disclosure to children should neither be naturalized nor essentialized. Rather, the patterns of parental disclosure should be put in perspective with those of disclosure to adults. They should be discussed under a broader context of a changing epidemic and evolving opportunities for response to the needs of PLHIV.

Under circumstances where most PLHIV find it hard to disclose to adults - including spouse or partners - parental HIV disclosure to children cannot be expected. The problem lies with disclosure in general and not with disclosure to children in particular. Many parents do not want to disclose to their children as they anticipate blame or traumatic experiences subsequent to disclosure. This is not surprising since disclosure to third parties already represents a dilemma (Emler 2008; Mbonu, van den Borne & De Vries 2009). Telling others about one's HIV-positive status may lead to the degradation of social bonds and raises questions on the sense of family, prior family dynamics, relationships and integration of the PLHIV, as exemplified by Issiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Dabis, *et al.*' (2001) report on a study in Burkina Faso that pertains that women were reluctant to inform their partners because of fear of being stigmatized by relatives and friends.

## HIV non-disclosure to children: a matter of age?

Parental disclosure is selective and the older the child is a strong reinforcing factor related to disclosure. However, our study shows that some children and even the youngest ones may be informed, and that parental non-disclosure cannot be explained by children's age alone. Furthermore, in some instances not all children are informed and it is not always a question of age since young children may be informed while older children are not, even children that have fully reached adulthood. Thus, the age of the children may not be in itself the primary challenge to disclosure but rather, parents' perceptions about their children of any age, since even children aged 15 or even 18 years and above, are often

considered as 'young'. It is thus much more a question of generational rapport than biological age as such.

### HIV and gender

The main result of the quantitative analysis shows after adjustment that mothers are five times more likely to disclose their HIV status than fathers were. This finding corroborates previous studies in other geographic and socioeconomic spheres (Lee & Rotheram-Borus 2002). Countless studies on gender and health-seeking behaviours already report the asymmetry between women and men. Regarding HIV and AIDS, solid evidence points to a gender specificity in voluntary counselling and testing (Le Coeur, Collins, Pannetier & Lelièvre 2009; Obermeyer & Osborn 2007), disclosure to partners (Ndiaye, Boileau, Zunzunegui, Koala, Aboubacrine, Niamba, *et al.* 2008; Tijou, Querre, Brou, Leroy, Desclaux, & Desgrées-du-Loû 2009) and in access and use of HAART (Bila & Egrot 2009). Furthermore, the HIV infection causes what Bury (1982) coined a 'biographic disruption' in the context of chronic diseases and which implies transformation of social and intimate relations within families. In such a difficult situation, it may be relatively easier for mothers, who may have built stronger emotional ties with their children, to disclose as compared to fathers who, owing to their perceived status of role model in the family, may anticipate fear, loss of face and diminished respect. Many women in our sample were single, widows or divorcees (some remarried). Children often live with the mother in case of divorce or widowhood and this may be a contributing factor to disclose. This may have repercussions on the disclosure results obtained. In such family configurations, mothers may confide in their children, as children daily share their intimacy and often are their trusted interlocutors.

The possible transmission of HIV from mother-to-child adds to the complexity of the gender dimension. Indeed, some children may be infected by HIV themselves. Therefore, disclosing parent's HIV status to one's child induces questions about the child's own HIV status (either positive or negative). Some participants have indeed, lost a child or more children and presumably due to AIDS; for others the HIV status of other children was either negative, not known by the parents themselves or they assumed their children were HIV-negative because they had survived until at least 6 years. However, the fact that almost all of the few women with HIV-positive children disclosed to them raises the question of possible differences in ease in disclosure according to the female gender of the parent, a history of single parenthood and the HIV status of the child. A possible explanation of HIV disclosure to HIV-positive children, which goes together with parental disclosure, is the need to enhance children's adherence to their treatment. Our findings point on the need for further research comparing disclosure to affected and infection children, and whether the need(s) and reasons to disclose differ when a parent does not live with the child, as well as whether the sex or HIV status of the child to whom a parent discloses matter.

### Non-disclosure and the institutional vacuum for parental HIV disclosure

Our analysis also suggests that non-disclosure is still common even among parents who were HIV counsellors. We found the

most important reasons for non-disclosure similar to those established in a number of countries outside Africa where there are significant cultural and socioeconomic differences of those prevailing in this study (Armistead *et al.* 2001; Hawk 2007; Pilowsky, Sohler & Susser 2000; Schrimshaw & Siegel 2002; Wiener, Battles & Heilman 1998). Those commonalities invite us to refer cautiously to culturalized and localized explanations of HIV non-disclosure to children. Culture may obscure the social, psychological, institutional and political dimensions of HIV disclosure.

Indeed, many parents stated that they were not opposed to disclosing to their children, rather they did not know in concrete terms how best to tell them. This lack of skill to disclose points out on the political and institutional vacuum in HIV disclosure counselling about parent-to-child disclosure counselling. As some scholars have described, parents are left alone to face the burden of parental HIV disclosure to children because of the lack of institutional support (Rujumba, Mbasaalaki-Mwaka & Ndeezi 2010; Wong, Macleod, Gilks, Higgins & Crowley 2006). From an institutional perspective, HIV disclosure to children is characterized by a 'double standard' (Hejoaka 2008, 2012). Well-trained health-care workers within an institutionalized and standardized framework deliver diagnosis disclosure and counselling services for disclosure to third parties. However, none of our participants discussed parental disclosure to affected children during their counselling sessions.

According to the study results, from a temporal perspective, HIV disclosure is time bound and parents who have not yet disclosed feel that they will eventually have to disclose their HIV status to their children. Telling their offspring about their illness is thus a challenge that parents living with HIV will systematically have to confront eventually. In addition, the parents state that keeping the secret can become unbearable over time. All of these realities point to parents and children needing specific and sustained counselling support to meet the challenges of parent to child disclosure. Addressing these challenges may start during the initial HIV counselling and testing and sustained throughout subsequent follow-up care, and more importantly after treatment initiation and follow-up visits.

### Children caring of their ill parents: 'they are also sick because they suffer with me'

Children play a proactive role in adherence support of their parents' treatment. Our data suggest that none of the parents who disclosed to their children experienced stigma from their children. This reality is in contradiction to their presuppositions that children do not have the necessary knowledge and emotional skills to understand and cope with the infection. It contradicts their perceptions that children cannot keep a secret. Rather, the children of ill parents become treatment supporters and do keep the secret. However, in the study environment where HIV counselling services for children is lacking or weak in parent-to-child disclosure support, children may show distress when they find out and now share the burden of the 'bad news' without being morally and psychologically assisted. Children contribute in a unique way to meet the challenges of parental care and



treatment requirements, and other everyday life duties of family members regardless of them not being aware of the HIV status of their siblings or parents living with HIV (Evans & Becker 2009; Hejoaka 2009; Knodel, Kespichayawattana, Saengtienchai & Wiwatwanich 2010). While parents felt relieved following disclosure, the potential negative impacts of this shift of the secrecy onto children cannot be ruled out. Children providing care to chronically ill parents may suffer in the long run from psychological deprivation (Skovdal & Ogutu 2009). This should be addressed by further research.

If children and adolescents are exposed to mass media campaigns and limited school-based AIDS programmes dealing with attitude change towards classmates or teachers living with HIV, there are few or neither specific and explicit interventions nor communication addressing stigma within the family targeting children of HIV-positive parents.

Overall, none of the study participants received counselling in parental disclosure to affected children. Some parents do not disclose because they do not know how to. Some of the non-disclosers are not against HIV disclosure *per se*. Their non-disclosure stance was much more related to their lack of knowledge and their perception of the difficulties of disclosing any serious and stigmatizing disease. The evidence of a significant number of situations where parents perceived that their children knew about their infection without formal disclosure suggests that the issue is unspeakable, uneasy to put in words or tell. It suggests a need to rethink disclosure not only in terms of intentions and motivation, but also in terms of ability and skill to effectively disclose. All of this underscores the importance of adequate counselling on this issue.

### Reintegrating basic counselling principles into HIV disclosure

The practice of counselling has become successively poor in relevant content and more and more bureaucratic. The focus of counselling in voluntary counselling and testing is on prevention (practically making disclosure a public health imperative) and on enabling access and adherence to treatment. If counselling is to help people to live their illness positively, it should also take into account their evolving needs such as assistance to disclosure to their children (Murphy, Roberts & Hoffman 2003).

Our study shows gender and intergenerational challenges to parental disclosure. It suggests the need for a reflexive counselling approach with emphasis on social interactions and a stronger family-oriented perspective instead of a standardized and informative encounter with broad public-health objectives.

### Limits of the study

The relatively small sampling included people aware of their HIV-positive status, on treatment for many years. In general, the participants were in a life normalization process. They are not necessarily representative of the variety of individual or family situations of PLHIV in Burkina Faso. Although in a few cases, the data captured situations where the children were themselves HIV positive and confirm the findings of Hejoaka (2012); further research is still

needed to fully document disclosure practices in such situations where counsellors may also have a stake. Elsewhere, the urban context of our study does not capture the reality in rural areas where gender role and adult/child ratio of dependency may be different. However, the approach enabled us to discuss parental disclosure and the roles children may play in support to adherence. It also enabled us to shed light on temporal and evolving needs, which differ from those of people newly tested or in environments where ART is not yet feasible. Though not fully representative, the analytic induction approach towards the data analysis allows to ground the findings in the data and to support a paradigm shift from acute care to chronic illness care models, and the need for rethinking counselling practices in light of PLHIVs' evolving needs and the institutional and policy implications of such.

## Conclusion

Beyond cultural differences, stigma and specifically perceived stigma towards PLHIV is alive despite progress made in the treatment area. Our findings suggest concerns and fear of being stigmatized are enduring. Despite improved health status, PLHIV remain vulnerable to severe stigmatization if their HIV-positive status comes to the open.

Our study explored parental disclosure to children, which is experienced as relief by disclosing and leads to children becoming treatment supporters. Over time, in a selective and incremental process, many parents disclosed to their children. Against a background of parental pre-disclosure fears of blame and stigma, and anticipation that their children may not be able to keep the secret or bear the news, children appear as privileged interlocutors, or mandatory interlocutors for single parents who may not have access to trusted adults with whom to share their secret. Once informed of their parents' HIV-positive status children, in every case, played a significant and positive role in their parents' care and treatment support. These findings contradict parents' anticipation of stigma and rejection from own children.

Albeit, the potentially positive care and treatment outcomes, disclosure to children costs parents a lot in the absence of proper parental counselling support. Affected children also need counselling support since they may display dissonance regarding care and support to parents. They may be eager and at the same time afraid to help, which likely results from the fear arousal approach to HIV-prevention campaigns. Further explorations of current counselling practices, which deal most often on treatment literacy, are needed to explore and reinforce parental disclosure to their children, key actors in care and treatment support.

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## References

- Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: are mothers telling their children? *Journal of Pediatric Psychology*, 26(1), 11–20.
- Bila, B. & Egrot, M. (2009). Gender asymmetry in healthcare-facility attendance of people living with HIV/AIDS in Burkina Faso. *Social Science and Medicine*, 69(6), 854–861.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167–182.
- De Baets, A.J., Sifovo, S., Parsons, R., & Pazvakavambwa, I.E. (2008). HIV disclosure and discussions about grief with Shona children: a comparison between health care workers and community members in Eastern Zimbabwe. *Social Science and Medicine*, 66(2), 479–491.
- Emlet, C.A. (2008). Truth and consequences: a qualitative exploration of HIV disclosure in older adults. *AIDS Care*, 20(6), 710–717.
- Evans, R. & Becker, S. (2009). *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol, Policy Press.
- Gerson, A.C., Joyner, M., Fosarelli, P., Butz, A., Wissow, L., Lee, S., et al. (2001). Disclosure of HIV diagnosis to children: when, where, why, and how. *Journal of Pediatric Health Care*, 15(4), 161–167.
- Hawk, S.T. (2007). Disclosures of maternal HIV infection to seronegative children: a literature review. *Journal of Social and Personal Relationships*, 24(5), 657–673.
- Hejoaka, F. (2004). Révéler à l'enfant la maladie du parent. Le cas de l'infection à VIH au Burkina Faso. Paris, DEA d'Anthropologie Sociale et Ethnologie. Ecole des Hautes Etudes en Sciences Sociales, 116p.
- Hejoaka, F. (2008). *HIV Disclosure to Children in Low-resource Countries: A Forgotten Issue on the International AIDS Policy Agenda*. Oral Abstract Session 'Children and Youth Facing HIV/AIDS'. Abstract n° MOAX0405 presented at the XVII International AIDS Conference, Mexico.
- Hejoaka, F. (2009). Care and secrecy: being a mother of children living with HIV in Burkina Faso. *Social Science and Medicine*, 69(6), 869–876.
- Hejoaka, F. (2012). L'enfant gardien du secret. Vivre et grandir avec le SIDA et ses traitements à Bobo-Dioulasso (Burkina Faso). Thesis, Centre d'Etudes Africaines (CEAF), Hautes Etudes en Sciences Sociales, Paris.
- Issiaka, S., Cartoux, M., Ky-Zerbo, O., Tiendrebeogo, S., Meda, N., Dabis, F., et al. (2001). Living with HIV: women's experience in Burkina Faso, West Africa. *AIDS Care*, 13(1), 123–128.
- Kennedy, D.P., Cowgill, B.O., Bogart, L.M., Corona, R., Ryan, G.W., Murphy, D.A., et al. (2010). Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS and Behavior*, 14(5), 1095–1105.
- Kmita, G. & Baranska, M. (2004). The process of disclosure of an HIV/AIDS problem in the family to children – an exploratory study. *Medycyna Wieku Rozwojowego*, 8(3 Pt 1), 623–640.
- Knodel, J., Kespichayawattana, J., Saengtienchai, C., & Wiwatwanich, S. (2010). The role of parents and family members in ART treatment adherence: evidence from Thailand. *Research on Aging*, 32(1), 19–39.
- Le Coeur, S., Collins, I.J., Pannetier, J., & Lelièvre, É. (2009). Gender and access to HIV testing and antiretroviral treatments in Thailand: why do women have more and earlier access? *Social Science and Medicine*, 69(6), 846–853.
- Lee, M.B. & Rotheram-Borus, M.J. (2002). Parents' disclosure of HIV to their children. *AIDS*, 16(16), 2201–2207.
- Lugalla, J.L.P., Madihi, C.M., Sigalla, H.L., Mrutu, N.E., & Yoder, P.S. (2008). *Social Context of Disclosing HIV Test Results: HIV Testing in Tanzania*. Dar es Salaam, Tanzania, Centre for Strategic Research and Development and Calverton, Maryland, USA, Macro International Inc.
- Mbonu, N.C., van den Borne, B., & De Vries, N.K. (2009). Stigma of people with HIV/AIDS in sub-Saharan Africa: a literature review. *Journal of Tropical Medicine*, 2009(2009), 14.
- Murphy, D.A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clinical Child Psychology and Psychiatry*, 13(1), 105–105.
- Murphy, D.A., Roberts, K.J., & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV+serostatus to their young children. *Journal of Child and Family Studies*, 12(3), 307–318.
- Murphy, D.A., Stritto, M.E.D., & Steers, W.N. (2001). Maternal disclosure of mothers' HIV serostatus to their young children. *Journal of Family Psychology*, 15(3), 441–450.
- Nam, S.L., Fielding, K., Avalos, A., Gaolathe, T., Dickinson, D., & Geissler, P.W. (2009). Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal. *AIDS Care*, 21(3), 389–395.
- Ndiaye, C., Boileau, C., Zunzunegui, M.V., Koala, S., Aboubacrine, S.A., Niamba, P., et al. (2008). Gender-related factors influencing HIV serostatus disclosure in patients receiving HAART in West Africa. *World Health and Population*, 10(3), 43–54.
- Norman, A., Chopra, M., & Kadiyala, S. (2007). Factors related to HIV disclosure in 2 South African communities. *American Journal of Public Health*, 97(10), 1775.
- Nostlinger, C., Jonckheer, T., de Belder, E., van Wijngaerden, E., Wylock, C., Pelgrom, J., et al. (2004). Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care*, 16(5), 641–648.
- Obermeyer, C.M. & Osborn, M. (2007). The utilization of testing and counseling for HIV: a review of the social and behavioral evidence. *American Journal of Public Health*, 97(10), 1762–1774.
- Palin, F.L., Armistead, L., Clayton, A., Ketchen, B., Lindner, G., Kokot-Louw, P., et al. (2009). Disclosure of maternal HIV-infection in South Africa: description and relationship to child functioning. *AIDS and Behavior*, 13(6), 1241–1252.
- Pilowsky, D.J., Sohler, N., & Susser, E. (2000). Reasons given for disclosure of maternal HIV status to children. *Journal of Urban Health*, 77(4), 723–734.
- Rotheram-Borus, M.J., Lee, M.B., Gwadz, M., & Draimin, B. (2001). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health*, 91(8), 1294–1302.
- Roura, M., Busza, J., Wringe, A., Mbata, D., Urassa, M., & Zaba, B. (2009). Barriers to sustaining antiretroviral treatment in Kisesa, Tanzania: a follow-up study to understand attrition from the antiretroviral program. *AIDS Patient Care and STDs*, 23(3), 203–210.
- Rujumba, J., Mbasalaki-Mwaka, C.L., & Ndeezi, G. (2010). Challenges faced by health workers in providing counselling services to HIV-positive children in Uganda: a descriptive study. *Journal of the International AIDS Society*, 13(1), 9.
- Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). What if they ask how I got it? Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy Plan*, 23(1), 36–42.
- Sanon, P., Kaboré, S., Wilen, J., Smith, S.J., & Galvão, J. (2009). Advocating prevention over punishment: the risks of HIV criminalization in Burkina Faso. *Reproductive Health Matters*, 17(34), 146–153.
- Schrimshaw, E.W. & Siegel, K. (2002). HIV-infected mothers' disclosure to their uninfected children: rates, reasons, and reactions. *Journal of Social and Personal Relationships*, 19(1), 19–43.
- Skovdal, M. & Ogutu, V.O. (2009). 'I washed and fed my mother before going to school': understanding the psychosocial well-being of children providing chronic care for adults affected by HIV/AIDS in Western Kenya. *Globalization and Health*, 5(1), 8.
- Steele, R.G., Nelson, T.D., & Cole, B.P. (2007). Psychosocial functioning of children with AIDS and HIV infection: review of the literature from a socioecological framework. *Journal of Developmental and Behavioral Pediatrics*, 28(1), 58–69.
- Tijou, T.A., Querre, M., Brou, H., Leroy, V., Desclaux, A., & Desgrées-du-Loi, A. (2009). Couples, PMTCT programs and infant feeding decision-making in Ivory Coast. *Social Science and Medicine*, 69(6), 830–837.

UNAIDS (2012). Rapport d'activités sur la riposte au SIDA du Burkina Faso 2012 (GARP 2012). Global AIDS Response Progress Reporting 2012. March 2012. <http://www.unaids.org/fr/dataanalysis/monitoringcountryprogress/progressreports/2012countries/file,68400,fr.pdf>

Wiener, L.S., Battles, H.B., & Heilman, N.E. (1998). Factors associated with parents' decision to disclose their HIV diagnosis to their children. *Child Welfare*, 77(2), 115–135.

Wiener, L., Mellins, C.A., Marhefka, S., & Battles, H.B. (2007). Disclosure of an HIV diagnosis to children: history, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics*, 28(2), 155–166.

Wong, V., Macleod, I., Gilks, C., Higgins, D., & Crowley, S. (2006). The lost children of universal access—issues in scaling-up HIV testing and counselling. *Vulnerable Children and Youth Studies*, 1(1), 44–55.

Wood, K., Chase, E., & Aggleton, P. (2006). Telling the truth is the best thing: teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe. *Social Science and Medicine*, 63(7), 1923–1933.

Xu, T., Yan, Z., Rou, K., Wang, C., Ye, R., & Duan, S. (2007). Disclosure of parental HIV/AIDS to children in rural China. *Vulnerable Children and Youth Studies*, 2(2), 100–105.