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## Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment

David Kyaddondo, Rhoda K. Wanyenze, John Kinsman, Anita Hardon

### Abstract

While disclosure of HIV sero-status is encouraged in the management of the HIV and AIDS epidemic, it remains a challenge, especially among family members. This article examines the moral dilemmas and pragmatic incentives surrounding disclosure of HIV status in contemporary Uganda. Our findings are based on 12 in-depth interviews, 2 focus-group discussions, 6 key informant interviews with AIDS activists, and open-ended responses derived from 148 HIV-positive persons in a quantitative survey. The study was conducted in 2008–2009 in Kampala, Mpigi, and Soroti districts in Uganda. We found both parents and adult children facing dilemmas in disclosure, whether it was parents revealing their own HIV status to their children or the status of their perinatally infected children, or young people infected through sexual intercourse telling their parents. For both groups, there is fear of blame, stigma, discrimination, and shame and guilt related to unsafe sex, while young people also fear loss of privileges. On the other hand, there are practical imperatives for disclosure in terms of gaining access to care, treatment, and material resources. Faced with these dilemmas, HIV-positive people and their families require professional counselling to help them work through the emotional challenges encountered and identify mechanisms of support and coping.

**Keywords:** disclosure, morality, family, Uganda

### Résumé

Bien que le partage du statut VIH soit encouragé dans la lutte contre l'épidémie de VIH/sida, il reste un défi, surtout auprès des membres de la famille. Cet article examine les dilemmes moraux et les incitations pragmatiques liées au partage du statut VIH aujourd'hui en Ouganda. Nos analyses reposent sur douze entretiens approfondis, deux groupes de discussion dirigée, six entretiens avec des informateurs clés des associations de lutte contre le sida et des réponses ouvertes données par 148 personnes vivant avec le VIH dans une enquête quantitative. L'étude a été menée en 2008–2009 à Kampala, Mpigi, et Soroti en Ouganda. Nous avons observé qu'à la fois les parents et les enfants adultes sont confrontés à des dilemmes pour partager l'information, pour les parents quand ils doivent annoncer leur propre statut VIH à leurs enfants ou le statut de leurs enfants infectés pendant la période périnatale, et pour les jeunes infectés par transmission sexuelle lorsqu'ils doivent en parler à leurs parents. Les deux groupes expriment la peur d'être blâmé, la crainte de la stigmatisation et de la discrimination, ainsi que la honte et la culpabilité liées à l'expérience de rapports sexuels à risque; les jeunes craignent aussi la perte d'avantages. Par ailleurs, il existe des impératifs pratiques de partage du statut VIH pour avoir accès aux soins, au traitement et à des ressources matérielles. Face à ces dilemmes, les personnes vivant avec le VIH et leurs familles ont besoin de conseil professionnel pour les aider à surmonter les défis émotionnels qu'elles rencontrent et à identifier des possibilités de soutien et d'adaptation.

**Mots clés:** Partage, Dimension morale, Famille, Ouganda

### Background

While maintaining open communication is fundamental in the management of the HIV and AIDS epidemic, disclosure of HIV sero-status among family members remains a

significant challenge. This article focuses on the problems that parents encounter in disclosing to their children as well as problems that adult children encounter when disclosing

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to their parents. We focus on the dilemmas of disclosure between parents and children as they involve the moral issues of discussing sexuality, blame, and guilt. At the same time, disclosure of one's HIV status to family members may be a requirement in order to access care and treatment. Considering the improved access to HIV counselling and testing (HCT) as well as antiretroviral therapy (ART) in Uganda, growing numbers of people now face such dilemmas of disclosure. These issues have implications for the nature of counselling in terms of the content and focus needed to support disclosure among family members.

The widespread availability of treatment has significantly changed HIV testing practices (GoU 2010; MoH 2005; MoH & ACP 2010). The prevalence of HIV testing in Uganda has grown over the past 5 years as HCT is mainstreamed into the formal health-care system and extended to communities through home-based services (MoH 2005). Government policies as well as a number of HIV and AIDS programmes encourage people to test for HIV and to disclose their results to sexual partners. Some HIV programmes require patients to disclose to at least one person who will act as a 'treatment buddy' before treatment begins. Home-based HCT programmes have been set-up and implemented in more than 10 districts in Uganda, largely because they can reach many family members at once (Menzies, Abang, Wanyenze, Nuwaha, Mugisha, Coutinho, *et al.* 2009).

Considering the family's role in health care, disclosure within families is gaining salience as more and more people get tested for HIV and enrol in ART. Prevention of mother to child transmission is now part of antenatal care, while the principle of testing patients as part of routine diagnostic procedures has been adopted in many facilities in Uganda. HCT programmes and policies emphasize the importance of disclosure. As Serovich, Esbensen and Mason (2005) note, ART can influence decisions to disclose. While ART can aid secrecy by suppressing signs and symptoms, the daily pills and visits to health facilities can also prompt (indirect) disclosure.

Moreover, disclosure within families has been documented as essential for adherence to treatment regimes, mobilization of social support, and prevention of further HIV transmission (Bikaako-Kajura, Luyirika, Parcell, Downing, Kaharuza, Mermin, *et al.* 2006; Chi-Ling & Johann-Liang 1999; MoH & ACP 2008; Paxton 2002; Rwemisi, Wolff, Coutinho, Grosskurth & Whitworth 2008). HIV-positive persons who disclose their status to selected individuals can increase their access to social and material support, thereby improving both their psychological and physical health (Chesney & Smith 1999). For several AIDS programmes in Uganda, which offer social support as well as medical and material assistance to those who test positive, access to such assistance requires disclosure of one's sero-status (Whyte, Whyte & Kyaddondo 2010). Rwemisi *et al.* (2008) report that lack of disclosure creates a context of confusion and mistrust, and increases vulnerability to risky behaviour.

Disclosure is a two-way process and relational in nature. It may involve feelings of guilt, fear, and worry. In practice, disclosure

within families – even between sexual partners – is not as common as many medical practitioners wish it to be. In south-western Uganda, for example, pregnant mothers reported concern that health workers might reveal their HIV sero-status and that such information might reach their husbands (Pool, Nyanzi & Whitworth 2001).

People who test HIV positive are indeed confronted with a dilemma: to keep one's status secret to avoid possible negative social consequences or to disclose to protect others and/or access social and material support. This can easily lead to a 'crisis of confidentiality' (Whyte *et al.* 2010) – the desire to keep one's HIV status a secret amidst care and treatment.

## HIV and AIDS, morality, and family relations in Uganda

Morality concerns socially approved behaviour based on standards prescribed by culture, religion, or other social institutions. In Taylor's terms, it concerns questions that arise in society about what is good or bad, what is meaningful and important or trivial and secondary (Taylor 1989). HIV and AIDS are intimately connected to local moral ideas regarding sexuality, care, and parent-child interaction. As in other places, the HIV and AIDS epidemic has become part of Uganda's moral system, a lens through which people view the behaviour of others (Zigon 2008). In addition to the sphere of everyday local cultural practices, religious beliefs as well as campaigns to fight the epidemic have been central in shaping HIV and AIDS into a moral frame in Uganda. HIV and AIDS prevention messages promote avoiding 'irresponsible sex' and being faithful to one's partner. Similarly, in the context of greater access to treatment, infected persons will be blamed for delaying disclosure. Likewise, religious organizations have played a significant role in the fight against the epidemic in Uganda, but view HIV and AIDS as a moral issue. All these contribute to everyday moral conceptions of HIV infection, including the belief that HIV-positive people have in some way crossed the boundary of what is morally acceptable.

Cultural ideals surrounding sexuality and parent-child interaction infuse local morality and present particular challenges to sharing HIV results across generations. Open discussions with children on matters related to sexuality are not culturally sanctioned. When children become sexually active, they often keep it a secret. There is a general lack of parental guidance and counselling on matters of sexuality (Were 2007). Discretion about sexual involvement and avoiding sexuality as a topic between adjacent genealogical generations is seen as a virtue in many African societies (Whyte, Alber & van der Geest 2008). Thus, the fear of explaining how one became infected not only places parents in a dilemma (Rwemisi *et al.* 2008) but adult children as well.

There is no universal definition of children; it varies with context, time, and place (Bluebond-Langer & Korbin 2007). While Uganda's law defines childhood in terms of an individual's chronological age (under 18 years), Ugandan culture views childhood relationally. Children (*abaana* in Luganda) are seen as such by virtue of their relationship to their parents (*abazadde*), a term that includes all relatives in genealogically senior generations

irrespective of age (Kyaddondo 2008). In the context of HIV and AIDS, children can be categorized as minors, adolescents, or adult children. This study limits itself to adult children (aged 18 years and above) but views the category broadly. Having children also means more than having one's own biological children. As Ankrah (1993) notes, African families are extensive, and even neighbours are considered relatives. Due to HIV and AIDS, many children no longer live with their biological parents; some live with strangers (Nyambedha, Wandiba & Aagaard-Hansen 2003). Nevertheless, belonging or being connected to a family by blood or otherwise is an important identity entitling one to care and a share of the family's resources as well as their grief. In sickness, kinship and family networks often become even more important.

The parent-child relationship in Uganda, as elsewhere, is laden with morality. Children expect their parents to provide care, guidance, and financial support. Children may blame their parents when they themselves stumble, for example, in cases of unwanted adolescent pregnancy (Sekiwunga & Whyte 2009). Parents are expected to be moral exemplars, but they also expect to be respected – not just because they have power, but because they are exemplary (Kyaddondo 2008). Several local proverbs describe parents as always 'correct' (*omuzadde tasobywa*) in the eyes of their children. Moreover, children should bring happiness and pride to their parents (Whyte 1997) – and certainly not grief or shame. Importantly, sexuality must be discrete, with neither party overstepping the requirement for (sexual) modesty between parents and children.

## Methods

Our research is part of the Multi-country African Study on Testing and Counselling for HIV study, which compares modes and experiences of testing for HIV in four countries: Burkina Faso, Kenya, Malawi, and Uganda. Conducted in 2008–2009, our study involved a main survey at health facilities as well as in-depth interviews and focus-group discussions. The latter took place between May 2008 and September 2009 in Kampala, Mpigi, and Soroti districts (Kampala is the capital of Uganda; Mpigi is a peri-urban district on the fringes of the capital; Soroti is a rural district in eastern Uganda). In addition, key informant interviews were conducted with two HIV-positive persons and activists. Our informants in the in-depth interviews consisted of 12 people living with HIV and AIDS who had known about their HIV status for some time. They were recruited from post-test clubs and AIDS treatment centres, including two health centre IVs and two hospitals (Mpigi Health Centre in Mpigi district; Kawempe Health Centre in Kampala district; Soroti Regional Referral Hospital and Mulago National Referral and Teaching Hospital).<sup>1</sup> All informants were aged 18 years or above. Of the 12 in-depth interviews conducted, six were adults above 32 years (three females and three males); four were unmarried young people between 18 and 24 years who became infected through heterosexual relationships; and the remaining two were 19 and 20 years old and were infected perinatally.

Interviewees for in-depth interviews were identified with the assistance of health-care providers at HIV clinics, who identified persons who were: (a) known to be HIV positive; (b) over 18 years

old; (c) judged by staff to be physically able to provide responses; and (d) willing to speak to the interviewers.

We held two focus-group discussions, one with eight HIV-positive women and one with eight HIV-positive men. As a method, focus groups have been shown to be effective for discussing sensitive topics (Lindlof & Taylor 2002). The participants were leaders of HIV and AIDS support groups at Kawempe and were purposively selected; all leaders agreed to participate in the discussions.

In addition, we made use of data obtained from the open-ended questions in the client survey among users of HCT services. These data from 148 HIV-positive respondents gave insight into their experiences of testing and disclosure, and complemented data obtained through the focus-group discussions and in-depth interviews. The 148 individuals included 48 men and 100 women. Of these, 32 (21.6%) were young people between 18 and 24 years, while among the older persons 59 (40%) were aged between 25 and 34 years; 39 (26.4%) were between 35 and 44 years; and the remainder (18; 12%) were above 45 years.

The client survey was based on interviews with individuals who had been tested for HIV at HCT facilities. After obtaining the necessary authorizations, the persons in charge at each facility were contacted in advance to give them information about the study, and obtain clearance. Interviewers were trained to approach respondents, describe the study, obtain informed consent, and try to find a relatively private space to conduct the interview. Providers in HIV testing facilities informed clients about the study, so that they could freely decide about participation. Individuals could simply walk away if they did not wish to participate in the study, and hence response rates provide only an approximate indication. In general, the study was well received, with response estimated at 9 in every 10. During in-depth interviews, both parents and young people were asked for their opinions and experiences about disclosing their own status and/or that of their children. The perinatally infected young people gave narratives of how they learnt about their HIV-positive status. Focus-group participants discussed issues related to keeping their HIV status confidential and their opinions about disclosure and its consequences – either positive or negative. In the main survey, there were open-ended questions regarding disclosure or non-disclosure, choice of person to disclose to, and reactions of those people disclosed to. Topic guides were developed and pre-tested before actual data collection. Key informant interviews were conducted in English; some in-depth interviews and both focus groups were conducted in Luganda, the local vernacular. Interviews were audio recorded, transcribed, and translated before being word processed for easy handling. The in-depth interviews enabled us to access the lived experiences of persons living with HIV through their stories of testing and disclosure (Good 1994).

Data were extracted using NVivo, a qualitative data analysis computer software package. Notes from in-depth interviews and focus groups were imported into NVivo 8. NVivo was also used to organize and code the open-ended questions from the client survey. The Excel table with answers to the open-ended questions

was transformed into a text document in order to import it into NVivo. As some informants may have been swayed by what they considered to be morally desirable answers, our analysis of data collected through the in-depth interviews and focus groups involved interpretation of their expressions and triangulation of sources.

Ethical approval was obtained from the Institutional Review Board of Makerere University, Child Health and Development Centre and the Uganda National Council for Science and Technology. For both the in-depth interviews and focus-group discussions, oral consent was obtained from the respondents. In order to maintain confidentiality, only pseudonyms are used in this article.

## Findings

The subsequent sections present three scenarios of disclosure involving parents and children: HIV-positive parents disclosing their own status to their children; parents telling their perinatally infected children that they (the children) are infected; and children infected through sexual intercourse disclosing to their parents.

### HIV-positive parents disclosing to children

Disclosure of parental HIV status to children is a matter of time. When asked, the common response by parents who had not disclosed was 'not yet'. Waiting for the child to be mature enough to understand was a common parental explanation for delayed disclosure. Although no specific age was given, adolescence was commonly seen as the time when children are ready to be informed. One HIV-positive mother from the client survey noted: 'My children can know when they mature. It is useless to tell children below twelve'.

In practice, it is difficult to know the right time to disclose to children. Parents must consider many factors. The child's personality – whether he or she is deemed able to cope with the news – is important. There were cases of parents disclosing to children in their early years when the parents saw no negative consequences. From an in-depth interview, in one family an HIV-positive mother with two HIV-positive children had told her 11-year-old girl but not her 13-year-old boy, because 'he was always quiet and reserved, it was difficult to predict his reaction'.

Parents weigh the possible consequences before deciding to disclose to their children. Biological parents informing their children that they (the parents) are HIV positive can imply that the child is as well (depending on the age of the child).

Parents may not reveal their HIV sero-status to children for fear of losing parental power over and respect from their children. Morally, parents are expected to care for their children until they can care for themselves. This gives them power and commands respect. But upon learning of their parents' HIV-positive status, some children may consider them as no longer capable of shouldering their parental responsibilities. One HIV-positive father recounted during an in-depth interview:

*My last daughter, who is about eleven years, got very concerned when I disclosed to her that I was HIV positive.*

*... She asked me whether I would die soon but I told her no. Before disclosure, she used to ask me for sweets but when she learnt that I was positive, she stopped and whenever they could tell her at school to come home for school fees she would cry and tell the teachers that daddy was sick and could not get the money. Now she sees me as an irresponsible person who cannot cater for her properly. When she goes to her uncles she asks them for money saying that daddy is sick.*

While it is possible that the daughter may have been trying to be considerate, her behaviour was interpreted by her father as judging him as physically weak and unable to bear his parental obligations – thereby triggering his fears of rejection by his children and becoming isolated. Although none of the parents we met reported this kind of isolation, some informants reported cases of children who came to hate their parents after their disclosure. This was particularly linked to social stigma, especially if information had spread beyond the family. One AIDS activist reported, 'I know one case here where the daughter hates her mother because she disclosed her status and her photo was put in newspapers'.

Fear of blame – the commonly accepted idea being that HIV infection is due to engaging in unsafe sex – motivates some parents to avoid or postpone disclosing to their children. Fathers in particular fear that their children will blame them for having had multiple partners. Announcing that one is HIV positive is to open oneself up to accusations of sleeping around, endangering the lives of one's children as well as their mother. Some of the current campaigns to prevent HIV transmission in Uganda focus on reducing the number of sexual partners; radio messages portray those infected with HIV as having acquired it from sexual partners outside marriage, termed 'side dishes'. Prevention efforts thereby reproduce this form of moralization of HIV infection. Parents fear being judged by their children as sexually irresponsible.

Not all parents were discrete about their – or their children's – HIV status. During the focus-group discussions, some parents expressed their felt moral obligation to inform their children in the interests of proper succession planning – to transfer some of the family assets and responsibilities – or for soliciting support. The availability of antiretrovirals (ARVs) has made disclosure somewhat easier; knowledge that one can receive treatment and not suffer greatly from opportunistic infections reduces the stigma, making HIV like 'any other illness'. Some parents on ART used non-verbal methods, such as open display of their HIV medicines, to disclose their sero-status to family members. It was not clear, however, if the family members fully understood these non-verbal methods of disclosure. HIV-positive individuals often stated that they had not told anyone, but that family members nevertheless knew. For example, children and other family members can learn the truth by seeing the infected person frequenting treatment centres and/or taking his or her daily medications. Some parents even send their children to fetch their medicines from where they are stored in the home. On the other hand, the availability of treatment allows HIV-positive individuals to keep their sero-status a secret, including

from family members, since they look healthy. During a focus-group discussion, one parent noted that with ARVs, 'it is very hard to tell that one is infected by looking at him or her unless you do an HIV test'.

Parents who had disclosed to their children emphasized the importance of obtaining social support. In several cases, disclosure to children prompted their active involvement. Some children (even pre-adolescent ones) became valuable sources of support for their parents, as reported by one male during an in-depth interview:

*My last born who is eight years is the one who reminds me to take the drugs. ... I told the children about our status and to remind me to take the drugs. At times they boil water for swallowing drugs and if someone buys my daughter bananas she reserves one for me for swallowing the tablets.*

### Parents disclosing to perinatally infected children

The difficulties parents face in talking about HIV and AIDS with their children are sometimes overwhelming. As a result, many parents hesitate to inform their HIV positive children about their sero-status. Alongside the belief that children are too young to comprehend matters related to HIV and AIDS, some parents want to avoid worrying their children, fearing that the knowledge will affect them psychologically. Several respondents noted that this is especially a challenge for mothers, as was re-affirmed by one AIDS activist: 'It's mainly women who are challenged in terms of disclosing to children. For a woman, to take it in that the child is positive is very challenging'. A mother informing her child that he or she is HIV positive is tantamount to revealing her own HIV status, which in itself can have serious consequences.

Martha is one of the children in our study who became infected through mother-to-child transmission. She was not informed until she was 16 years old; by the time we met her, she was 20. Born into a polygamous family, she was the youngest of her mother's three children. Her two elder siblings and mother had died of AIDS but Martha claims that she and her father did not know it was AIDS at the time. She later heard rumours that her mother had been receiving treatment from The AIDS Support Organization, Uganda.

Martha had experienced episodes of serious illness. She developed herpes zoster (*kisipi*) when she was about 13 years. Her father requested the nurse to conceal the truth from her, and to say it was severe malaria. 'When I got *kisipi*, my stepmother started insulting me and one day I overheard her ask my father why he doesn't take me for blood testing [for HIV]'. Her stepmother would tell others how Martha's mother had died of AIDS. Martha thus began to suspect that she may also be infected. She was continuously falling ill and her father (who was HIV positive) was constantly worried, praying aloud to God to keep him alive for another 5 years so that he could look after her. However, he never disclosed to her.

While in secondary school, Martha was diagnosed with TB and admitted to Mulago hospital. 'I was very weak, but I overheard the doctor telling my father that we do an HIV test'. Martha reckons that she had been tested before when she had herpes zoster, but was not told the result.

*Daddy had hidden the earlier results we had got [during the first test when Martha had herpes zoster] and he did not tell me. Now I told him to tell me the results, after this second test. I was fed up of falling sick very often and I had now found out that my stepmother was also HIV positive. My father refused to tell me the results. I pulled them from him by force, read them and saw that I was positive and then I learnt my status, because I could understand the words written. That's when my daddy told me the truth and said that he wanted me to complete senior six before telling me.*

Martha was started on ARVs but says that after she had learnt of her HIV status her father was always in tears. 'He used to tell me that we should forgive him for suffering something that I was not responsible for'. Martha's story exemplifies the social and moral dilemmas parents face in disclosing HIV sero-status to perinatally infected children. There are strong feelings of guilt, particularly for infecting one's own child. It hurts to reveal the truth to a child who has always looked up to you but now considers you a bad character. Worse still is the feeling that the child is innocent but is nonetheless affected.

Adults sometimes prefer to keep the HIV sero-status of children a secret to protect them from stigma and discrimination. In Uganda, many children with HIV do not live with their biological parents. If the sero-status of such children is known, they may face stigmatization, as was the case for Martha with her stepmother.

Children such as Martha may be tested several times but not disclosed to. The integration of HCT within the health care system creates room for hiding the nature of tests performed, since the health facility also administers many tests other than for HIV. In contrast to when HCT takes place in stand-alone facilities, it is now possible for parents to conceal an HIV test from children.

Intense parental feelings of guilt complicate disclosure in perinatally transmitted HIV. Parents may wrestle with their feelings until they finally give up and disclose. Martha's father tried to conceal her HIV sero-status for several years. When he could no longer do so, a painful apology to his daughter ensued for his 'bad behaviour'. The common knowledge in Uganda is that HIV is transmitted through heterosexual relations. For sexually inactive children who are informed that they have HIV, the common question is: 'How did I contract the disease though I have never had sex?' Parents dread this question.

As with their own status, parents may disclose to their children without mentioning the words HIV or AIDS, but through the nature of the care that they suggest. Parents trying to avoid direct discussion of HIV may simply tell their children, 'You are sick (*oli mulwadde*)'. Some children suspect that they are

HIV positive before being informed. In some cases, they may have heard rumours, comments from other family members, or had villagers hinting about their sero-status or that of their parents. Sometimes parents make these comments as they worry about their own health or that of their children. At other times, comments are meant to stigmatize, as was the case with Martha's stepmother.

Some children suspected of being HIV positive are taken for testing in health facilities without being told where they are going and why. As children, they are expected to be obedient. In one case, 14-year-old Stella was in the seventh grade and living with her grandmother after losing her mother to AIDS. As she was always sick, her grandmother decided to take her for an HIV test. Stella, however, was never told where she was going and what she was going to do there. 'My grandmother said, "You are not going to school today, there is somewhere I want us to go". She didn't tell me where we were going'. Stella was tested and found to be HIV positive, and though she was initiated on ARVs she was not informed – at least at first. After being on ARVs for some time, she began to resent it as she no longer felt sick:

*I asked my grandmother, 'Why am I swallowing these drugs? I am not sick; I have no pain anywhere, why am I taking these drugs?' My grandmother responded, 'You must swallow those drugs, they will help you, haven't you realized that you are no longer sickly?' I told her that I don't have any pain, the sicknesses that I used to suffer from are no longer there, I have recovered. If I get those sicknesses again, that's when I will start taking the medicines. My grandmother insisted that I take the drugs and I refused. She took me back to hospital and told the counsellor that I had refused to take the drugs. The counsellor said, 'Let's tell her the truth'. And my grandmother agreed.*

Fear of difficult questions sometimes makes parents avoid disclosing to perinatally infected children. Stella asked many questions when she was informed that she had HIV. Had the counsellor not been there, they would probably have been difficult for her grandmother to answer. The dialogue below, as narrated by Stella, describes the encounter during the disclosure process:

*'What do you mean that I am sick?' I asked. The counsellor responded, 'You have slim [HIV]'. I asked them, 'How is it that I am infected with AIDS? How did that come about?' The counsellor responded, 'When your mother was giving birth to you, she gave birth to you when you were already infected'. I retaliated, 'You mean when my mother was giving birth to me, I was already infected?' The counsellor said, 'Yes, it's true. But you are not going to die, don't get worried, just take this medicine and you will remain alive'. Then I said, 'Ok, I will take the drugs'.*

Stella's grandmother had visited a counsellor to seek advice; the talk helped her through the difficult decision to disclose to her granddaughter. Most importantly, the presence of the counsellor eased the process of disclosure and facilitated communication between grandmother and granddaughter. The professional counsellor was better equipped to talk about the issues

surrounding HIV and AIDS, possibly because she was less emotionally attached. Socially and culturally, it is common in Uganda to use intermediaries to communicate sensitive issues, such as those related to sexuality.

Disclosure to Stella came out of necessity rather than choice. Stella's refusal to continue her medication pressured her grandmother to reveal the truth. Several informants told us about cases where 'premature' disclosure was forced by the situation, before parents considered the time right for the child. This can be due to a specific event, such as episodes of serious illness, as was the case with Martha. It can also transpire due to children's inquisitiveness (for example, regarding why they are on medication).

### Young people infected through sexual intercourse disclosing to their parents

It is not only HIV-positive parents who experience difficulties revealing their status to their children. Many of the HIV-infected adult children we interviewed preferred to keep their status a secret from their parents. In particular, adult children who suspect that they were infected through sexual relationships find it difficult to disclose their HIV sero-status to their parents.

If infected through premarital sex, young adults are also faced with issues of blame, guilt, and shame. One of our male informants (19 years old) told us how he had contracted HIV through having a sexual relationship with his female employer in Kampala. He had left his parents in the countryside to search for a job in the city. The job he landed was that of a house helper to a female boss who had lost her husband, reportedly to AIDS. Our respondent told us how he was enticed into sex by his boss. It was the neighbour who warned him that his boss had lost her husband to AIDS, but it was too late. He took a test and found that he had contracted HIV, and decided to return to his parents' home in the village. However, he did not disclose his HIV status: 'I went home but did not tell my parents what had happened to me. . . . I felt so guilty'.

In another case, Jane contracted HIV while still at school. When she suspected that she was infected, she decided to go for a test. She informed one of her sisters about her decision to test but when the results came out positive, she hid it from her sister, out of fear that her parents would come to know. Jane acknowledged feeling guilty, perhaps for both being positive and lying to her sister: 'I used to shed tears whenever I could meet my mummy and sisters because I felt guilty of being positive'.

In the context of close relationships between family members and neighbours, health workers and members of the community, it is sometimes difficult to keep one's HIV status a secret. It is not uncommon for information about one's HIV status to flow from one person to another. Morally, it is inappropriate to see something bad happening to a child and keep quiet. Young people get very frustrated when others disclose their HIV status to their parents. Jane's partner, who was then also a student, had similar fears of his parents finding out. Jane eventually joined an HIV-positive support group. Her boyfriend opposed

this because 'he feared that his parents would see me [as a member] and know that I was positive and yet he did not want them to know'. Her boyfriend ultimately abandoned the relationship, maintaining that it would have meant revealing to his parents that he was also positive.

Young people feel that they should conceal their HIV sero-status to avoid causing emotional distress to their parents, especially when their parents have already gone through stressful situations such as loss of loved ones or have health problems of their own. Whether used as an excuse or not, some HIV-positive adult children reported fearing that disclosure would harm their parents and exacerbate their agony. One young woman who had disclosed to her family, with the exception of her parents, noted:

*I do not want my mother and father to know that I am HIV positive, but my sisters and others do know. We [me and my sisters] are scared that if our mother knows that I am positive she will die, because she has hypertension.*

The concerns and emotions involved in learning about HIV infection, and the freedom to talk about sexuality, differ among siblings and with parents. It is culturally easier to discuss sex with siblings; similarly, parent-child relationships are probably more emotive than those between siblings. Nevertheless, disclosure to certain family members may mean exposing one's status to others in the family network. Telling sisters or other family members may therefore be a strategy to indirectly disclose to parents. Sometimes the afflicted individual needs to rely on others (in the family network) to make decisions, pass on information, or deal with the associated emotions.

Some young people infected through sexual relations worry that disclosing to their parents could lead to the loss of entitlements, including support for schooling, care, and their inheritance (especially boys). They fear that their identity, expectations, and responsibilities will change in the eyes of their parents. As one male reported, being HIV positive could close opportunities and lead to the loss of rights and entitlements:

*For me my father is alive and I am the heir, but if he knows that I am positive he might remove the heirship from me thinking that I will die before him. I must first weigh the possible outcome of disclosing and to whom.*

Although ART access has increased in Uganda and many HIV-positive individuals live better and prolonged lives, some people still believe that once infected with HIV, death is imminent. Uganda is a patrilineal society where wealth is passed down mainly through male children. Some HIV-positive young people worry that their parents will no longer consider them the best option for inheritance, out of fear that their lives will be cut short.

While challenges remain for young people to disclose to adults, some of our informants had revealed their HIV sero-status to their parents and other members of the family. Most AIDS

service organizations in Uganda promote disclosure and encourage openness. HIV-positive clients acknowledged receiving advice from counsellors to tell people they 'trust', as well as people from whom they can receive support. The tendency among young people, both male and female, was to think of their parents, particularly their mothers: 'The counsellor advised me to choose among my people the ones who I trust and who will be helpful to me. ... My mother was the best alternative'. Others added that they told their mothers 'because she is the person who is always around me'.

The fact that mothers are more present in family settings may not be the only reason why they are preferred for disclosure; people also saw mothers as emotionally closer to children and more trustworthy than fathers. While it was feared that mothers would be the most emotionally affected upon learning of their child's HIV status, expectations of care were most directed at mothers, who are often the first line care-givers. Parents were sometimes disclosed to because HIV-positive young adults felt that they would eventually need to know anyway; in case they fell sick and needed help, they would first turn to their parents.

Morality is evoked not only when one wants to keep one's HIV status discrete, but also when one wants to disclose. Some children reasoned that disclosure to parents was a moral obligation: parents need to know by virtue of their social position. 'Mothers need to know their children's condition', stated some of our young respondents. While in some cases talking seemed easier when a family member was seriously ill or hospitalized, the feeling that HIV is a widespread problem affecting many other people was also a source of encouragement to disclose, especially for young people.

Morality is equally important for those disclosed to. They are judged on how they receive and respond to the news: did they ridicule the afflicted individual or provide care and support? Here, the availability of ARVs has opened up space for new ways of talking about HIV and AIDS, particularly for those disclosed to. Better access to treatment indeed seems to make it easier to comfort infected family members; the response of several family members might be to recommend initiation of treatment. As one young man reported his father's reaction: 'He comforted me and said it was not only me ... he advised me to go for treatment'.

While support was generally given after disclosure, for some it came with emotional discomfort: 'It was not easy at first. It was shocking news to them but they had to contain it. It had happened. I had acquired HIV'.

## Conclusion

This study has illustrated the challenges and complexities involved in disclosing one's HIV status in family settings, particularly between parents and children. Disclosure here is not just a simple communication of HIV sero-status, but a moral, relational, and practical decision. Disclosure may follow the weighing of potential risks and rewards, but may equally be a pragmatic decision dictated by circumstances.



Kleinman (1995) notes that moral decisions are practical dilemmas in social life; Zigon (2008) shows how morality is evoked depending on situations and events. We have shown that the decision to disclose to one's child or parent is also an issue of interpersonal relations involving guilt, blame, and shame – for parents, since they may have infected their own children, and for children, since they may have engaged in premarital sex.

The local cultural context in Uganda does not encourage the open discussion of sexuality between parents and children. It is thus no easy matter for parents to disclose their HIV status. It is because of considerations of morality that young people receive almost no sex education, yet they are sexually active (Sekiwunga & Whyte 2009). The idea that HIV is mainly transmitted through sex, with all its moral baggage, plays a significant role in parents' hesitation. Nevertheless, the need for care and support, and to plan for the future, may force parents' hands.

Disclosure of perinatally acquired HIV is highly emotive and parents may choose not to disclose to their children to avoid emotional distress. For fear of confronting the fact that their children are HIV positive, some parents may postpone finding out their children's sero-status until they fall ill, as was the case with Martha and Stella. However, the obligation to provide health care can take precedence over the desire for discretion. For example, in the process of providing the obligatory care, Stella's grandmother and Martha's father encountered situations of powerlessness where disclosure became a necessity.

Young people infected through sexual intercourse also base their decisions to disclose to their parents on the envisioned costs and benefits of disclosure. When possible repercussions outweigh the rewards, they will prefer secrecy. Here, young people are not simply hiding their HIV status from their parents, but are also trying to uphold an idealized image of the child in their parents' eyes – a child who does not engage in premarital sex. The image of being a 'good child' helps to retain their entitlements. Nevertheless, the need for care and support during sickness may prompt young people to disclose to their parents.

While HCT and ART services become more widely available, social and moral dilemmas remain. As Whyte (1997) notes, secrecy about one's illness or that of family members is discouraged in Uganda, for how could the ill person then receive help? However, those who have the illness continue to struggle with the imperatives of cure and care on the one hand, and on the other the social and emotional complications which disclosure might bring, fuelled by fears of blame, shame, and guilt regarding unsafe sex.

All of this has implications for the nature of counselling that could support the disclosure of HIV within family settings. We can conclude that counsellor support may be required to objectively evaluate and determine to whom, when, and how to disclose. Furthermore, even though policies and providers encourage parents and children to openly discuss HIV, numerous moral, emotional, and material concerns remain – the communication of which would be eased by professional assistance. The use of intermediaries, in this case trained counsellors, is already socially and culturally sanctioned for communicating sensitive issues.

Although most respondents reported positive outcomes after disclosure, such as being comforted, and receiving treatment, reminders to take medicines, and other material support, revealing one's HIV status to one's child or parent, or disclosing a perinatally acquired HIV-positive status to a child, has strong social meanings and introduces a new identity to the relationship. Coming to terms with this new identity takes time and may require assistance from a trained professional to deal with feelings of guilt and blame. Such support would not only benefit the disclosing individual, but also the surrounding persons who may too be mentally and emotionally affected. Service providers can help them work through these emotional issues, while assistance in identifying mechanisms of support and coping may lessen the challenges encountered during disclosure.

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## Note

1. A health centre IV is a mini hospital. It has a theatre and admits patients. District hospitals offer all the services offered at a health centre IV, plus specialized clinics such as those for mental health and dentistry.

## References

- Ankrah, E.M. (1993). The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care*, 4(1), 17.
- Bikaako-Kajura, W., Luyirika, E., Parcell, D.W., Downing, J., Kaharuza, F., Mermin, J., et al. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behaviour*, 10(Suppl. 1), 85–93.
- Bluebond-Langer, M. & Korbin, J.E. (2007). Challenges and opportunities in the anthropology of childhoods: an introduction to 'children, childhoods, and childhood studies'. *American Anthropologist*, 109(2), 241–246.
- Chesney, M.A. & Smith, A.W. (1999). Critical delays in HIV testing and care: the potential role of stigma. *American Behavioral Scientist*, 42(7), 1162–1174.
- Chi-Ling, L. & Johann-Liang, R. (1999). Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care and STDs*, 13(1), 41–45.
- Good, B.J. (1994). *Medicine, Rationality and Experience: An anthropological Perspective*. Cambridge: Cambridge University Press.
- GoU (Government of Uganda) (2010). UNGASS Country Progress Report Uganda. January 2008–December 2009. [http://www.aidsuganda.org/Publications/UNGASS%20RPORT%202008\\_2009.pdf](http://www.aidsuganda.org/Publications/UNGASS%20RPORT%202008_2009.pdf) (Accessed 14 January 2011).
- Kleinman, A. (1995). *Writing at the Margin*. Berkeley, CA, University of California Press.
- Kyaddondo, D. (2008). Respect and autonomy: children's money in Eastern Uganda. In E. Alber, S. van der Geest & S. Whyte (Eds.), *Generations in Africa: Connections and Conflicts* (pp. 27–46). London, Transaction Publishers.
- Lindlof, T.R. & Taylor, B.C. (2002). *Qualitative Communication Research Methods* (2nd ed.). Thousand Oaks, CA, Sage.
- Menzies, N., Abang, B., Wanyenze, R., Nuwaha, F., Mugisha, B., Coutinho, A., et al. (2009). The costs and effectiveness of four HIV counselling and testing strategies in Uganda. *AIDS*, 23(3), 395–401.
- MoH (Ministry of Health) (2005). *Uganda National Policy Guidelines for HIV Counselling and Testing*. Kampala, Ministry of Health.
- MoH ACP (Ministry of Health & AIDS Control Programme) (2008). *National Antiretroviral Treatment Guidelines for Adults, Adolescents and Children* (2nd ed.). Kampala, Ministry of Health.
- MoH ACP (Ministry of Health & AIDS Control Programme) (2010). *Status of Antiretroviral Therapy in Uganda, Quarterly Report for January–March 2010*. Kampala, Ministry of Health & AIDS Control Programme.
- Nyambetha, E., Wandiba, S., & Aagaard-Hansen, J. (2003). Changing patterns of orphan care due to AIDS in Western Kenya. *Social Science and Medicine*, 58(1), 83–96.

- Paxton, S. (2002). The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Education & Prevention*, 14(4), 282–294.
- Pool, R., Nyanzi, S., & Whitworth, J.A. (2001). Attitudes to voluntary counseling and testing for HIV among pregnant women in rural south-west Uganda. *AIDS Care*, 13(5), 605–615.
- 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 and Planning*, 23(1), 36–42.
- Sekiwunga, R. & Whyte, S.R. (2009). Poor parenting: teenagers' views on adolescent pregnancies in Eastern Uganda. *African Journal for Reproductive Health*, 13(4), 113–127.
- Serovich, J.M., Esbensen, A.J., & Mason, T.L. (2005). HIV disclosure by men who have sex with men to immediate family over time. *AIDS Patient Care and STDs*, 19(8), 506–517.
- Taylor, C. (1989). *Sources of the Self: The Making of Modern Identity*. Cambridge, Cambridge University Press.
- Were, M. (2007). Determinants of teenage pregnancies: the case of Busia District in Kenya. *Economics & Human Biology*, 5(2), 322–339.
- Whyte, S.R. (1997). *Questioning Misfortune: The Pragmatics of Uncertainty in Eastern Uganda*. Cambridge, Cambridge University Press.
- Whyte, S.R., Alber, E., & van der Geest, S. (2008). Generational connections and conflicts in Africa: an introduction. In E. Alber, S. van der Geest & S.R. Whyte (Eds.), *Generations in Africa: Connections and Conflict* (pp. 1–26). London, Transaction Publishers.
- Whyte, S.R., Whyte, M., & Kyaddondo, D. (2010). Health workers entangled: confidentiality and certification. In H. Dilger & U. Luig (Eds.), *Morality, Hope and Grief: Anthropologies of AIDS in Africa* (pp. 80–101). Oxford, Berhahn Books.
- Zigon, J. (2008). *Morality: An Anthropological Perspective*. Oxford, Berg.