

‘What if they ask how I got it?’ Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda

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Background Limited research has been conducted outside Western settings on how HIV-positive parents decide to test and disclose their own HIV status to children. We conducted a qualitative study in 2001 and 2005 to assess parent attitudes and current counselling policy and practice regarding child testing and parental disclosure in Uganda prior to the roll-out of antiretroviral therapy.

Methods Parent perspectives were obtained through extended in-depth interviews with 10 HIV-positive parents recruited from The AIDS Support Organization (TASO), Entebbe branch. Counselling policy and practice were explored through key informant interviews with directors and two counsellors from each of five Ugandan counselling institutions with national or regional coverage.

Results Respondents had 51 children ranging from 4 to 36 years with a median age of 13. Five of 10 parents had disclosed their status to their children, usually to all, and four of these had tested one child for HIV. All those who tested any child had also disclosed their status to some or all of their children. Parents regularly worried that their children may be infected, but all preferred to wait for emergence of symptoms before considering HIV tests, citing fear of children’s emotional reaction and lack of perceived benefits from knowing status. Counselling policy directors confirmed the absence of policy and training guidelines on the subject of parent-child disclosure. Counsellors reported improvising and giving inconsistent advice on this common concern of clients.

Conclusions Concerns over disclosure to children of parent’s HIV status and testing children for HIV represent a major psychological burden for HIV-positive parents. Further research is needed, but current counselling practice could be improved now by adapting lessons learned from existing research.

Keywords HIV, disclosure, parents, children, counselling, VCT

KEY MESSAGES

- Parental worries about disclosing their own HIV status to children represent a major psychological burden for many parents and a potential barrier to testing and care for their children.
- In the absence of clear counselling policies, counsellors tend to give limited or conflicting advice to parents on this highly sensitive issue.

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Background

HIV-positive parents face a series of difficult decisions about testing and sharing information with their children. With few exceptions (e.g. Bikaako-Kajura *et al.* 2006 in Uganda, Kouyoumdjian *et al.* 2005 in South Africa, Blasini *et al.* 2004 in Puerto Rico), most empirical research on the family context of diagnosis and treatment of HIV comes from low prevalence settings in Europe or North America. The issue that has received most attention in existing literature (including all those cited above) is whether and when to disclose test results to children already diagnosed to be HIV-positive. Comparative studies of children with long-term and potentially fatal illnesses such as cancer suggest that children benefit from being told about their diagnosis earlier rather than later (Slavin *et al.* 1982; Beale 2005). Limited existing research on disclosure of HIV status suggests a more mixed picture. Battles and Wiener (2002) found significant improvements in long-term psychosocial coping among children who know their HIV-status, and Instone (2000) reported withholding disclosure over prolonged periods can result in severe emotional distress, disturbed self-image and social isolation that parents or guardians were often unaware of. However, Rotheram-Borus *et al.* (1997) reported significant negative psychosocial effects on children within 2 years of being informed of their status, though a later study by the same authors found that negative consequences were significantly reduced by psychosocial coping interventions and (inadvertently) through access to antiretroviral therapy (Rotheram-Borus *et al.* 2001). The American Association of Pediatrics considers disclosure to be essential by the time children reach adolescence, but age, psychosocial maturity, complexities of family dynamics and clinical context should be taken into consideration when deciding when and how much information to give to younger children (American Academy of Pediatrics Committee on Pediatric AIDS 1999).

Before it is possible to disclose a child's HIV status, HIV-positive parents must confront two additional decisions. The first is whether and when to test their children for HIV. We could find no published literature on this issue at all, perhaps because most studies are based on clinic populations of infected children where HIV-positive status is assumed. The second is whether and when parents should disclose their own status to their children regardless of the latter's HIV status. Qualitative research from the developed world clearly highlights that this issue represents a major dilemma for HIV-positive parents. Common barriers to disclosure cited by parents include fear of rejection or loss of respect, negative emotional reactions from their children, and inadvertent disclosure to others by them (Wiener *et al.* 1994; Kmita *et al.* 2002; Waugh 2003; Kouyoumdjian *et al.* 2005). By informing their children, HIV-positive parents may inadvertently pass on a psychological burden of secrecy (Gerson *et al.* 2001; Reyland *et al.* 2002) which has been independently associated with negative psychological outcomes (Kirshenbaum and Nevid 2002). Parents who are willing to disclose their status often do not know how or when to bring up the subject (Kmita *et al.* 2002). A common finding of these studies is the burden of HIV stigma, which may explain why disclosure of HIV status has been associated with more negative outcomes than disclosure of

other less stigmatized illnesses like cancer (Hardy *et al.* 1994; Waugh 2003).

Most of the world's 2.2 million HIV-infected children under 15 years of age live in developing countries, with more than two-thirds of these found in Africa alone (UNAIDS/WHO 2004). With the rollout of ART only just beginning in Africa, the question of appropriate counselling policies for parent-child testing and disclosure should be a priority concern for counselling policy and practice.

We conducted an exploratory qualitative study in Uganda to investigate barriers to HIV-positive parents testing children and revealing their own HIV status to children. Analysis is based on in-depth interviews with 10 HIV-positive parents and key informant interviews with policy makers and counsellors from five major organizations involved in HIV counselling and testing with national or regional coverage.

Methods

Semi-structured in-depth interviews, each lasting about an hour, were conducted among 10 HIV-positive parents between July and August 2001 at the Entebbe branch of The AIDS Support Organization (TASO), a leading non-governmental support organization for HIV-positive clients in Uganda. Informants were recruited from Entebbe Cohort (EC), a longitudinal study of HIV-positive clients granted ethical approval by the Uganda Virus Research Institute and the Uganda National Council for Science and Technology (Watera *et al.* 2006). Since the interview was conducted by non-clinic staff, additional oral consent was obtained from clients prior to interview. There were no refusals.

Key informant interviews for the policy component of the study were obtained from directors and two counsellors from each of five large not-for-profit organizations that provide counselling services at a national or regional level in Uganda. These include TASO, AIDS Information Centre, Mildmay Centre (a national referral centre specializing in paediatric HIV issues), Kitovu Mobile AIDS Home Care and the Medical Research Council Unit on AIDS in Uganda. The director of the National AIDS Control Programme was also interviewed regarding government policy on parent-child issues. Each of these organizations was contacted again in 2005 to update information and comments on existing policy.

No children were interviewed in this study due to ethical constraints of interviewing within the EC study. Client interviews were conducted in vernacular Luganda, while policy interviews were conducted in English. All interviews were taped, transcribed and translated into English where necessary. Thematic analysis of interview texts was conducted by two independent analysts.

Results

Testing HIV status of dependent children

Table 1 shows the distribution of sample respondents and their families according to parental disclosure and child testing criteria. Two men and eight women were interviewed,

Table 1 Sample characteristics by child testing and parental disclosure status at interview

Parent ID	Sex	Age	Marital status	Years since knowing status	No. of surviving children	Sex and age of surviving children (<i>italic</i> = disclosed to, bold = tested, <i>italic</i> + bold = both, HIV status, +=positive, -=negative)	Children tested	Children disclosed to
No child testing or parental disclosure								
1	M	35	divorced	6 yrs	1	M: 6	0/1	0/1
2	F	27	widowed	4 yrs	2	M: 6, 8	0/2	0/2
3	F	28	widowed	2 yrs	3	M: 4, 7, 11	0/3	0/3
4	F	39	widowed	4 yrs	6	M: 18 F: 9, 13, 15, 20, 24	0/6	0/6
5	M	43	married	4 yrs	13 ^a	M: 8, 9, 12, 12, 13, 19 F: 4, 5, 5, 6, 6, 9, 21, 23	0/13	0/13
Median/(total)		35		4 yrs	3/(25)	11 ^b		
Any child testing or parental disclosure								
6	F	43	widowed	9 yrs	5	M: 18 yrs F: 10, 12, 20, 22	0/5	3/5
7	F	32	widowed	11 yrs	3+ 1 died	M: 16 F: 12, 14 D: 1+ at test, 3 at death	1/4	3/4
8	F	38	widowed	7 yrs	5	M: 8 F: 13, 15-, 19, 24	1/5	5/5
9	F	53	widowed	3 yrs	6	M: 18, 21, 27+ F: 32, 34, 36	1/6	6/6
10	F	38	widowed	9 yrs	7 ^c	M: 10-, 17 yrs F: 14, 16, 19, 20, 25 yrs	1/7	7/7
Median/(total)		38		9 yrs	5/(26)	18 ^b		

^aChildren from three wives.

^bMedian age of children disclosed to (lower panel) and not disclosed to (upper panel).

^cThree oldest children were fostered.

and reported 51 surviving children ranging from age 4 and 36 years. All parents reported frequent worries about their children's HIV status regardless of whether they had tested or disclosed. All had assumed at least one of their children could have been infected but feared to test, anxiously waiting instead for the emergence of physical symptoms of illness:

'They may not be having HIV but I fear to test them in case they have it.' (43-year-old mother of five children aged 10 to 22)

Reluctance to test was justified in several ways. Most common was uncertainty about the benefits of testing children, particularly before they reached sexual maturity. Second was feeling unprepared for HIV-positive results which all secretly feared by the time they decided to test a child:

'I wanted to have them tested but two months ago I lost my favourite brother on whom I relied for assistance [tears well in her eyes]... So I feared to have them tested in case they tested positive and caused me more misery.' (28-year-old mother of three aged 4 to 11 years)

Several participants mentioned separation from family and not disclosing HIV status to an estranged spouse as a barrier to testing children.

The common cue to action was repeated illness in all cases preceded by the death of an older sibling. Whether they had

tested or not, all parents interviewed discussed testing as a way to confirm suspicions that their child was HIV-positive rather than to resolve uncertainty about their status. The one parent whose child tested negative seemed surprised when the result came back negative:

'I doubted the results. She follows my late child who died of AIDS. But the test result raised my hope and I became extra careful about infection at home.' (38-year-old widow and mother of four aged 10 to 19 years)

Only four of 10 parents reported taking any child for an HIV test. No parent had tested more than one child. One was age 27 at the time he was actively persuaded by the mother to test after repeated illnesses. The rest were all below age 12 at the time of testing; all but one tested positive. All parents who had offspring tested reported a sense of relief and even pride regardless of the test result:

'I felt relieved because it is not an easy thing to do. It took a lot of courage. I managed to prolong my child's life although he is now dead.' (32-year-old widowed mother of three aged 10 to 16)

Disclosure of parental HIV status to children

Half of parents interviewed and all those reporting having tested a child for HIV had disclosed their own HIV status to some or all of their children. Four out of five disclosers had shared their status with all their children, including some as

young as 8 years. One parent had disclosed to all but the two youngest children who she felt were 'not ready' to be told. Age of children was clearly a key consideration for parents, as seen in Table 1. The median age of disclosed-to children was 18 years (IQR 14–22) compared with 10 years for children who had never been told their parent's status (IQR 8–15). None of the children under age 8 (n=7) had been told their parent's HIV status.

Justifications for disclosure were mainly altruistic in the interest of children or surviving kin. Disclosers mentioned desire to avoid unexpected shock from anticipated illness or death, making sure family members knew the real cause of death rather than suspecting malicious witchcraft, and protecting children from stigma and hurt feelings if they learn the cause from someone else. Eight of 10 parents, including four of those who had not disclosed, considered telling children would be a beneficial way to warn them about the dangers of HIV infection:

'If I tell young ones that I'm HIV positive when I look healthy, they get to know that anyone can transmit HIV and take care. In the process they survive...' (38-year-old mother of four aged 10 to 19)

Self-interest may have played a role in decisions to disclose as well. There was general agreement that disclosure made it easier to ask for and receive support from relatives or grown children once they knew the seriousness of the problem. All those interviewed reported being uncertain about children's reaction before disclosing their status, but four of five parents who had subsequently disclosed reported supportive reactions from their children:

'I told all my children. They even facilitate my travel to TASO for both treatment and drama.' (53-year-old mother of six aged 18 to 36)

Reasons for not disclosing included uncertainty about the appropriate age at which to tell children, lack of perceived benefits for children, and inability to see beyond the emotional pain of disclosure:

'I feel so sad about it and I know that they would be sadder, cry and do all those heart breaking things that I am not ready for.' (39-year-old mother of six aged 9 to 22)

One worried his children might share the secret with others. Others mentioned fear of embarrassment or loss of respect from their children:

'How can I? Who do I begin with? The old one or the young one? What if they ask how I got it?' (43-year-old father of 13 aged 4 to 23)

The fear of shocking or shaming children by admitting HIV infection competed in the minds of parents with worries that it would be even more hurtful and stigmatizing for children to find out the truth from others. Except for one father who preferred his personal counsellor disclose to his children on his

behalf, all parents concurred that a parent should be the one to disclose their status to a child:

'I wanted them to get it from me directly because they would be unsure of the cause of my death if I died before I told them...It makes them feel good that I told them instead of knowing it from someone else.' (38-year-old mother of five aged 8 to 24)

Meanwhile clients reported receiving inconsistent advice from counsellors on whether or when to disclose to children or to test children. Some encouraged early testing and disclosure while others were more cautious, advising clients to wait until physical symptoms developed:

'My counsellor at first thought that I could not emotionally handle knowing my child's status if he tested positive, but I insisted and they allowed me to have him tested.' (53-year-old mother of six aged 15 to 36 years)

As seen in Table 1, there is a nearly perfect correlation between testing and disclosing parental HIV status to children. No non-disclosing parent had tested any child despite the often intense level of worry expressed. All surviving children who had been tested knew their parent's HIV status, although at least one was tested by age 2 and disclosed to by age 8. Disclosers tended to be longer term members of TASO (median 9 years vs. 4 years for non-disclosers). Those who disclosed also reported more faith in the efficacy of treatment and services available at the time (which did not include ART) than parents who did not disclose:

'I saw that if I tested him he'd get the basic health and material benefits given by these HIV support organizations.' (38-year-old mother of four aged 10 to 19)

Counselling policy and practice

Uncertainty about the benefits of child testing and parental disclosure on the part of HIV-positive parents was matched by absence of clear policy guidelines on this issue among all counselling institutions reviewed for this study, as noted by the Project Manager of the STD/AIDS Control Programme at the Uganda Ministry of Health:

'When we started addressing issues of counselling as regards HIV/AIDS, the immediate activities people tended to implement were counselling for care and also counselling in terms of emotional support. The issue of children didn't feature very much...Policy for paediatric HIV AIDS as such is not in place I should say.'

On one hand, directors of these organizations shared the belief that the ultimate decision about disclosure within the family should be left to parents themselves:

'It's a tough issue. A difficult one for a lot of people. Our guidelines here are... We work with the care giver because we feel that it is the care giver's right and responsibility to tell the child.' (Counselling policy director)

On the other hand, all of the directors recognized the relative inattention to counselling issues directly or indirectly affecting children and the need to develop strategies to address this area. One organization that specializes in paediatric issues had started to develop guidelines for parent-child disclosure issues based on the collective experience of their own counsellors, but no official document had been released by the time of this analysis in 2005:

'We realized that not much is being done [to address the plight of children]. We need a policy.' (Counselling policy director)

Meanwhile, counsellors were left to their own devices on how to advise parents on such emotionally sensitive issues:

Interviewer: *'Did your training as counsellor include parental disclosure and child testing?'*

Counsellor: *'No, no, no. It didn't.'*

Interviewer: *'So how do you go about it?'*

Counsellor: *'We usually inform ourselves...'*

While counselling policies for organizations like TASO often encourage disclosure to significant others, there was no systematic encouragement of parental disclosure to children. Counsellors' advice varied, sometimes within the same organization:

'I encourage them to do so [disclose] if they have older children, for example those who are 20 and above.' (Counsellor interview)

'I don't see the benefit [of disclosure], but for weak parents it can be helpful because sometimes the children escort their parents [to get care].' (Counsellor interview)

Discussion

Regardless of whether they had tested or disclosed to their children, the dual issues of testing and disclosure to children were deeply emotive for all parents interviewed. Parents who had tested their children reported feeling a sense of relief afterwards, even when children had tested positive for HIV, though no parent was inspired to test other children. Interestingly, testing and disclosure were closely correlated; no parent who tested a child did not eventually disclose to their children. Together with the qualitative evidence presented here, this suggests that the inability or unwillingness to confront the issue of the adult's own HIV infection with his or her children may be an important barrier to child testing in its own right in this setting. Such findings would have strong implications for counselling policies and merit confirmation on a larger scale.

Given the depth and centrality of parental concerns revealed in qualitative interviews here and in previously cited studies (Manopaibon *et al.* 1998; Akpede *et al.* 2002), it seems safe to assume that testing of and disclosure to children represents a substantial psychological burden for HIV-positive parents once they know their status. On ethical and public health grounds alone, HIV-positive children should be informed of their status before reaching adolescence when sexual activity normally begins (American Academy of Pediatrics Committee

on Pediatric AIDS 1999), and there is evidence to suggest waiting too long to disclose to younger children carries independent risks for psychosocial adjustment (Instone 2000). As with their counterparts in Europe (Kmita *et al.* 2002), Ugandan parents interviewed often delayed testing and disclosure to children not for lack of willingness or concern but for lack of skills and guidance about how to broach such a sensitive topic.

Such combined evidence, mostly from a Western context, would seem to support stronger promotion of early testing and parent-child disclosure of HIV status, thus bringing HIV counselling in line with that for paediatric cancer. Where felt or enacted stigma remain important concerns, however, early disclosure may simply risk transferring the psychological burden of secrecy from parents to children, evoked by Reyland *et al.* (2002) in the image of constantly 'walking a tightrope' between candour and caution. The benefits of testing and disclosure to children may also depend on the availability of appropriate counselling and health services, which is rightly or wrongly assumed in literature from industrialized countries but certainly cannot be assumed outside this context. Yet even in settings with relatively strong HIV counselling services like Uganda, there are still no clear counselling policies or training guidelines in this area. As respondents in this study, parents are left to wait anxiously until physical symptoms of illness to make the decision.

Since the completion of fieldwork, Uganda has achieved some progress in the area of HIV counselling for caregivers and children. In July 2005, the Ministry of Health released new national counselling guidelines that for the first time advocated testing for children of HIV-positive parents (Uganda Ministry of Health 2005). The counselling organization TASO has begun revising its own counselling guidelines and is planning to include a chapter on testing and counselling children, although emphasis remains on training counsellors to disclose to children themselves, not how to instruct parents to do so. For literate parents, 'memory books', where parents are encouraged to write their life histories, have been adopted by some counselling organizations as one strategy to assist disclosure to children (Witter 2004). In collaboration with the US Centers for Disease Control (CDC), TASO have also begun implementing a home-based care approach for HIV care. By encouraging testing and mutual disclosure in families where one member was known to be HIV-positive in one Ugandan setting, the home-based approach achieved virtually universal HIV testing coverage among children under age 14, where virtually none had been tested in the past (Were *et al.* 2006).

This study has several important limitations. The most obvious is the small sample size from one geographic area and the cross-sectional design that may demonstrate the depth and breadth of parental concerns without the ability to generalize results. Lack of children's perspective on the experience of parental disclosure is another important gap. The main fieldwork was conducted prior to the on-going roll-out of ART in Uganda, which is certain to alter calculus of disclosure and child testing significantly for parents. Since access to ART is still far from assured, the findings of this study are still relevant for counselling and testing services, and also

form an important baseline to assess the influence of ART on parent-child HIV issues.

Despite these limitations, two firm conclusions may be drawn. The first is the need for more research on testing and disclosure decisions within HIV-infected families in Africa and other settings where vertical transmission contributes significantly to HIV infection rates. Ideally such research should include the perspectives of children as well as caregivers, since it is possible benefits for one may come at the expense of the other, as shown by Bikaako-Kajura *et al.* (2006). The possibility raised by this study that child testing and parental disclosure are effectively linked has never been reported in the published literature and would raise the importance of parental disclosure as a child health issue if confirmed. Interestingly, Uganda Ministry of Health officials have recently acknowledged that demand for child ART services was less than half of projected needs (Uganda MoH/ACP 2007). Clearly insufficient numbers of infected children have been entering the care pathway in time to benefit from new medications, a route that begins with initial demand for counselling and testing.

The second conclusion is the urgent need to address the general neglect of a problem that represents a significant emotional burden to HIV-positive parents. As with other aspects of HIV epidemic, Uganda has been an innovative leader in Africa and the world in the development of counselling strategies for HIV/AIDS. Yet even in this progressive environment, policy directors for the largest counselling and testing organizations admit parent-child disclosure issues had received little if any attention until recently, and much work remains to be done. As a result, counsellors in this study reported improvising and giving inconsistent advice.

The issues are complex, and solutions may be context-specific, again underlining the need for more research in this area. Nevertheless there are a number of valuable lessons from previous research that could be used to guide existing policies without further delay. Most of the recommendations on disclosure to children published by the American Association of Pediatrics seem equally appropriate for developing country contexts. Adapting these to local conditions, and considering a family counselling approach which has been successfully tested in Africa, would seem a logical starting point. Some of the suggestions from limited research on HIV-positive children conducted in resource-poor settings, such as encouraging family involvement and peer-group support for parents (Bikaako-Kajura *et al.* 2006; Jones *et al.* 2006), may be integrated into a more general counselling model for all HIV-positive parents. Otherwise, most research has occurred in a clinic care context where health care providers are assumed to play a central role in the disclosure process. In situations where health infrastructure is limited and children's HIV status unknown, this approach may be not only less feasible but less acceptable. Most parents in this study felt that they and no-one else should be the ones to disclose their own status to their children. HIV counsellors and other health care providers should be equipped to provide parents with advice and skills to engage in the process of disclosing their own HIV status to their children, offering assistance only where appropriate and desired.

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