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### ► To cite this version:

Sara Liane Nam, Katherine Fielding, Ava Avalos, Diana Dickinson, Tendani Gaolathe, et al.. Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV-status reveal.. *AIDS Care*, 2009, 21 (03), pp.389-395. 10.1080/09540120802270276 . hal-00513467

**HAL Id: hal-00513467**

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Submitted on 1 Sep 2010

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**Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV-status reveal.**

Journal:	<i>AIDS Care - Psychology, Health &amp; Medicine - Vulnerable Children and Youth Studies</i>
Manuscript ID:	AC-2007-11-0589.R1
Journal Selection:	AIDS Care
Keywords:	HIV/AIDS, Disclosure, Children, HAART, Africa



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## Introduction

HIV-positive parents taking antiretrovirals are faced with the difficult decision of whether and what details to share about their HIV with their children. Keeping family secrets can be destructive to children's wellbeing and to the family structure (Cottle, 1980) and the related anxiety can lead to isolation and disengagement from possible sources of support for children (Siegel & Freund, 1994). Interviews with children orphaned due to HIV/AIDS in sub-Saharan Africa reveal that non-disclosure of parental HIV-status adversely affected their ability to cope with their parent's illness or subsequent death (FHI, 2003; Wood, Chase, & Aggleton, 2006). Additionally, a growing body of evidence demonstrates increased sexual and reproductive health risks among children who are vulnerable or orphaned due to HIV (Gregson et al., 2005; Nyamukapa et al., 2008).

Studies have investigated African adult HIV disclosure (Brou et al., 2007; Maman, Mbwapo, Hogan, Kilonzo, & Sweat, 2001; Maman & Medley, 2004; Norman, Chopra, & Kadiyala, 2007; Olley, Seedat, & Stein, 2004; Sagay et al., 2006; Skogmar et al., 2006) and some research describes disclosure to children of the child's own HIV positive status (Kouyoumdjian, Meyers, & Mtshizana, 2005; Myer, Moodley, Hendricks, & Cotton, 2006). A review of US studies found that by age 12-13y, 84% of HIV positive mothers had disclosed their own HIV status to their children and mean ages of children disclosed to ranged from 7-10years (Murphy, Steers, & Dello Stritto, 2001). A Belgian study found that disclosure of a parent's HIV-positive status among African migrant families was lower than disclosure among European families (5% compared to 20.5% respectively) (Nostlinger et al., 2004). However, there is little research about parental disclosure of parent's HIV status to their children in Africa.

Children who have been told their parents are HIV positive have shown lower levels of aggression and more positive self-esteem than those from whom the information has been kept (Murphy, Steers, & Dello Stritto, 2001). Other research found that adolescents with infected mothers experienced more difficulties with psychosocial adjustment (more symptoms of externalizing and internalizing problems, less social and cognitive competence) compared to those with non-infected mothers but that depression was higher among adolescents who were informed of their parents' status compared to those who were not informed

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(Armistead & Forehand, 1995; Forehand et al., 1998). The decision whether to disclose has been shown to be partly based upon the child's perceived maturity and emotional stability and is more common when children are: older; female; have experienced negative family life events or who display more problem behaviour. Parents who disclose tend to have larger social networks and to perceive that their children were experiencing HIV-related stigma, and tend to experience less stigma or alternatively to have higher perceived stress levels and be less effective at managing parenting demands. Additionally, disclosure was associated with income, perceived severity of physical symptoms and negative family life events (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Lee & Rotheram-Borus, 2002; Ostrom, Serovich, Lim, & Mason, 2006).

Decisions by parents not to disclose are reportedly in order to shelter children from stigma or to allow them a care-free childhood. Among the possible detrimental impacts of disclosure are: pressure to keep it a secret: real or perceived stigma: stress and anxiety (Cree, Kay, Tisdall, & Wallace, 2006; Murphy, 2008). Fear of the anticipation of a parent's death, of future losses, the need to adopt a more 'grown up' role as a carer have also identified as stress triggers among children in the US and Africa (FHI, 2003; Reyland, Higgins-D'Alessandro, & McMahon, 2002). But parents are aware of the dangers of non-disclosure, particularly that children might discover the HIV positive status of parent(s) from another source (Nostlinger et al., 2004).

In the era of HIV/AIDS in Botswana where HIV-prevalence is estimated at 24% (UNAIDS, 2007), family structural transformations are dynamic and the relationship between children, their parents and other family members is evolving. Increasingly, women actively choose to remain unmarried in order to avoid patrilineal family expectations (such as reduced custody rights of children) and due to lack of trust in men to remain faithful in an age of HIV (Ingstad, 2002). Maternal relatives are more commonly involved in the lives of children while fathers are becoming increasingly isolated from their offspring (Livingstone, 2006). Children are often sent to live with their grandparents freeing their mother to seek employment (Ingstaad & Saugestad, 1984) or to live with aunts who may be in employment and can support their nieces and nephews through school. A large number of children have at least one parent who is HIV-positive and

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parents will need to develop strategies to discuss managing HIV illness with their children, now that it has become a chronic rather than necessarily terminal disease.

The investigators asked parents participating in a qualitative study examining factors relating to antiretroviral therapy (ART) adherence about issues related to disclosure to their children. The findings presented here offer some insight as to why the rates of disclosure of parental HIV-status to children from this African setting might be different to those from other settings.

## Methods

This qualitative study examined issues related to adherence to antiretrovirals among 32 adults from two clinical sites in Gaborone, Botswana: the specialist ART public-sector adult Infectious Diseases Care Clinic (IDCC) and a privately-run general family practice, The Independence Surgery (IS). In February 2008 the IDCC had around 9,000 HAART-patients receiving free antiretrovirals and the IS had around 1,500 patients taking antiretrovirals.

A Grounded Theory approach was adopted: in brief, this methodology allows the hypothesis to evolve as the researcher conducts the interviews thereby allowing other important themes and concepts to emerge during examination of the core topic ('adherence to antiretrovirals' in this study) (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Sampling was purposive: adults who had been on antiretrovirals for at least six months were eligible to participate and clinicians referred potential participants would provide a variety of good or poor adherence experiences. A total of 32 people were interviewed, of whom 21 were parents. One-on-one interviews lasting between 45 and 75 minutes were conducted and recorded. Translators were used when necessary. The interviewer asked participants about ideas and beliefs about HIV and antiretrovirals; stigma; disclosure; social support and isolation; ideas and practices regarding antiretroviral adherence; health seeking practices and hopes and fears for the future. In addition, participants who were parents were asked about disclosure of their own HIV-status to their children.

Data collection from all 32 participants continued until new concepts related to the topic of focus (adherence) ceased to arise. The coding was conducted manually by the Principal Investigator and interviewer for this study who identified key topics that arose from the interviews and transcripts. A

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medical anthropologist guided data collection and analysis through review of selected transcripts. A code book was developed detailing the process of coding following the principles outlined in Grounded Theory (see box 1). This paper presents the reasons why participants who were parents chose to disclose or not disclose their HIV-status from their children and highlights issues related to parent-child communication related to sexual health as important themes that emerged. We focus on children aged 5y and older in common with other research.

## **Results**

Of the 21 parents interviewed the mean age was 37 years (range:22-55y), 12 were female, 6 were from the private-sector and 13 (9 women, 4 men) were single parents. Twelve were in full-time employment, three were job-seeking and all reported feeling healthy. The 21 parents cared for 40 children; 24 aged between 5-18 years old and 16 children under-five (who are not analysed in this study). Three of the parents were responsible for six step or adopted children. Of the 24 children aged 5 or older, seven (29%) had been told about their parent's HIV-status; eight (33%) children were thought to have guessed, and nine (38%) were believed to be unaware of their parent's HIV status. (Table 1). Overall 4 parents (2 women and 2 men), had disclosed their status to their children older than 5y. Three other parents who had children living with other relatives had not disclosed their HIV status to their children.

### ***Reasons for Disclosure***

The reasons for disclosure included that the situation was already known to other family members or increasing ill-health of the parent. Two other parents became sick and felt that their children needed to know the reason for their illness or told them in order to impress upon the children the need for caution to prevent them from becoming infected through caring for a sick adult (box 2). One female participant had two children aged nine and 15 who were known to be HIV positive themselves. Two HIV positive siblings were disclosed to not by their HIV positive mother but by the family, in order to explain their own illnesses to them and to impress upon them the need to take their medicines as their mother had failed to tell her children at a time when she was depressed.

### ***Reasons for non-disclosure***

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Reasons parents gave for not disclosing to children included feeling children were not old enough and not knowing how to address the issue. Parents worried that the knowledge would be “too painful” for the child/ren and non-disclosure to other people was also partly out of concern that the children might find out from other people and face stigma as a result (box 3).

Parents who had not disclosed expressed vague plans to talk to their children in the future, but at the time of the interview preferred to leave it to chance. Four parents said that their children saw them taking the antiretrovirals and had probably guessed what they were for, yet still there was no discussion about HIV (Box 4).

Three of these parents said their children reminded them to take their pills, checked that they had taken them or brought the pills to them with water, even though they had not told their children about their status. This made parents think that these children had guessed their status although they had not been explicitly told and the parents appreciated this expression of concern by their children (box 5).

### ***Discussing sexual health***

Parents described difficulties in addressing the issues of HIV and sexual relationships with their children. Parents expressed a preference to leave sexual and reproductive health topics for school to address, although they were not clear about what was taught at school in relation to these issues. For those that did discuss such topics, only one mother directly addressed preventing pregnancy and protecting oneself from HIV or other sexually transmitted infections (box 6).

Three parents felt it was not necessary to talk to their children about protecting themselves from HIV because they were “good” children and such studious and well-behaved children were not at risk of HIV. Conversely, parents felt they would be more likely to discuss the ‘dangers’ of HIV and pregnancy if a child was considered “naughty” or “troublesome” or who spent time with friends whom parents considered inappropriate. Two parents described discussing HIV in general as an educational intervention or to prepare the children for the uncertain future (box 7).

### **Discussion**

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This study found that HIV positive parents taking antiretrovirals had difficulty discussing their HIV-status with their children, as has been found among African immigrants overseas (Myer, Moodley, Hendricks, & Cotton, 2006). This study is limited by its small sample size but even so the depth of information gathered reveals parental inhibition about discussing reproductive and sexual health with their children. In common with other research (Lee & Rotheram-Borus, 2002), parents in this study disclosed their HIV-status in response to their own worsening health and appeared more likely to disclose to older (median age 11y), rather than younger (median age 14y) children. Parents also confirmed findings from other studies of the reasons not to disclose their HIV status. This included wanting children to have a carefree childhood, children being too young; not wanting to worry older children and not wanting children to be hurt by the reaction of others (Nostlinger et al., 2004).

Research from the US has found that adolescents who knew their parent's HIV-status fared no worse in terms of emotional distress, self-esteem or parental bonding than those who had not been told (Lee & Rotheram-Borus, 2002). In contrast, unstable family circumstances and failure to discuss family life issues have been negatively associated with adolescent sexual behaviour in West Africa (Odimegwu, Solanke, & Adedokun, 2002).

Respect for ones elders, and adult avoidance of discussion about intimate issues has created an uncommunicative environment about sexuality in Africa even in the era of HIV (Babaloa, Vondrasek, & Brown, 2001). In Botswana, it is generally considered inappropriate for children to discuss sexual matters with their mothers, even more so with their fathers. Although parents in this study were aware that their children were taught about HIV at school, they did not know what they were learning. The difficulty that parents have in talking to children about their HIV has also been recorded in Zambia where it resulted in poor succession planning (FHI, 2003).

The need for family-based, intergenerational HIV-treatment programmes has been recognised (Rotheram-Borus, Flannery, Rice, & Lester, 2005). Parents need age-appropriate support about when, how and what to tell their children about their own HIV-status, and about the disease generally. Parents need guidance on managing children's responses, and on planning for the future. Additionally, in the development of support mechanisms to advise guardians on how to discuss HIV and sexual health in general with



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children, the changing family roles and typical intergenerational modes of communication need to be taken into consideration. This might contribute to providing vulnerable children (and orphans) with access to life skills to mitigate the impact of their vulnerability through identifying suitable support mechanisms for them in addressing these issues. For example, an appropriate counselling model might consider the feature of the role of parental siblings and their off-spring in the typical upbringing of Batswana children. This would include involving children's aunts, uncles and cousins in the disclosure process and in their education in matters related to HIV and reproductive health. The feature of openness between alternate generations as seen in other African settings (Whyte, Alber, & Geissler, 2004) is not a typical feature in Tswana culture. With the increasing number of grandparents taking care of their grandchildren, mechanisms also need to address communication between grandparents and grandchildren.

While Botswana strives to achieve an AIDS-free generation by 2016, the children of this new generation will bear the responsibility of coping with a parents or carers who have HIV. Additionally, in order to achieve the vision of 2016, children need to be equipped with the necessary life skills to assist them in protecting themselves from contracting and transmitting HIV. Ensuring the provision of appropriate forums for discussing sexuality could play an important part in promoting safer sexual practices among children and young adults. This requires dialogue not only through schools, churches, peers and the media but also within and between family members. Parents and other carers will need structured support in dealing with disclosure to children and in discussing matters related to the reproductive health of children.

## **Acknowledgements**

(omitted here to maintain anonymity)

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**Box 1: Basic Principles of Grounded Theory.**

*“Grounded Theory is an approach that is inductively derived from the study of the phenomenon it represents... it is discovered, developed, and provisionally verified through systematic data collection and analysis pertaining to that phenomenon {where} data collection, analysis and theory stand in a reciprocal relationship with each other” {Glaser & Strauss}. Analysis takes place through a series various coding processes that can occur simultaneously with data collection allowing for the theory to develop and be questioned during the interviews.*

**Open Coding** is the analytic process through which concepts are identified and their properties and dimensions are discovered in data

**Selective coding** is the process of integrating and refining theory.

**Axial Coding** is the process of relating categories to their subcategories, where coding occurs around the axis of a category, linking categories at the level of properties (Characteristics of a category, the delineation of which defines & gives it meaning) and dimensions (The range along which general properties of a category vary, giving specification to a category and variation to theory).

**Box 2**

*“I’ve told my kids. Because they had to take care of me – they have to be aware, when I was very sick and I didn’t want to put them at that risk. So I had to tell them.”*

(38y old single mother of 12y and 16y old).

**Box 3**

*“I love my kids so much – they are still at school, and I wouldn’t like for them to be hearing that ‘your mum is positive’, and what, what, what. All these kind of things.”*

(38y old single mother of 14y and 16y old).

**Box 4**

*“I guess the boy might know, but they [the children] don’t ever ask me about it.”*

(48y old single mother of a 17y old son and carer of 14y old niece).

**Box 5**

*“I love it when my kids remind of the medication. Even [the girl] she will just run to the bedroom and give me a glass of water.”*

(38y old single mother of 14y and 16y).

**Box 6**

*"I haven't shared anything with her [my daughter]. Fortunately I've never been sick... I always teach her how she should handle herself. At school when somebody gets injured I told her that she should she shouldn't touch somebody's blood and she knows that – she's been told at school also. [I tell her] to respect people who are positive - to like them. Those who come out, like maybe she will meet one children at school and that one kid is positive or her mum is positive - to love them...it's something ... that could happen to anybody,...even to her. So, she has to take care of herself.. I started talking to her about relationships when she was 9. The whole reason was [that] kids ask things. You should guide your child to choose what kind of a friend [she] should make. People think that when you talk to a child about a relationship, you are teaching her to do that [develop sexual relationships], but you are not. But you are teaching her [is] that she should be careful in choosing friends."*

(37y old single mother of a 13y old).

**Box 7**

*"The eldest girl who is 15, ah! She doesn't really seem to be interested in most of those things...she's the type of person who gets 99% at school every time...so in her I don't see much of a problem...she's quite well educated. She's very disciplined...The problem may arise form the last born [11y] – hey! That one she needs lots of guidance...she was clever at school, but she's not good, and, eish! some of [her friends] are older than her, you know, so she joined those instead of learning [from] her sister. ... this one is going to give us problems, so we need to find information and start guiding her now.'*

(38y old father of three).

**Table 1: Median ages of children 5years or older who have not been told, were thought to have guessed or have been told about their parent's HIV status.**

	Children's knowledge of parent's HIV status:			Total
	Have not been told	Thought to have guessed	Have been told	
Number of children (%)	9 (38%)	8 (33%)	7 (29%)	24 (100%)
Median Age, years (range)	9y (5-17y)	14.5y (11-17y)	14y (9-17y)	12 (5-17y)

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