# HIV Disclosure: Parental dilemma in informing HIV infected Children about their HIV Status in Malawi

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**Abstract**

**Background**

Increasingly many perinatally HIV-infected children are surviving through adolescence and adulthood as a result of improvements in the management of paediatric HIV infection, particularly the increased use of combination therapy. It is usually the parents or guardians of these children who are faced with the task of informing the child living with HIV about his or her positive status. However, many parents—particularly biological parents —find this disclosure process difficult to initiate, and this study explored some of the difficulties that these parents encounter.

**Objective**

This study set out to explore potential factors that challenge parents and guardians when informing their perinatally HIV-infected child about the child's HIV status.

**Design**

This was a qualitative narrative study that employed in-depth interviews with parents or guardians of children perinatally infected with HIV. A total of 20 parents and guardians of children who attend the outpatient HIV clinic at the Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence (COE) in Lilongwe, Malawi were interviewed. Of these, 14 were biological parents and six were guardians.

**Results**

Guardians and parents expressed uneasiness and apprehension with the disclosure conversation, whether or not they had already told their child that he or she had HIV. Participants who had not told their children recounted that they had contemplated starting the conversation but could not gather enough courage to follow through with those thoughts. They cited the fear of robbing their child of the happiness of living without the knowledge of being positive, fear of making their own status known to more people, and fear of confrontation or creating enmity with their child as impediments to disclosing their child's positive HIV status to him or her.

**Conclusions**

It is apparent that guardians—more particularly biological parents—of children perinatally infected by HIV find it difficult to inform their children about their children's HIV status. From this disempowered position, parents dread the disclosure of a positive HIV status to a child as a psychosocial process that has the potential to disturb a family's previously established equilibrium with threats of stigmatization, marginalization, and parent-child conflict. This calls for strategies that could support parents to make disclosure to the child less challenging.

## Introduction

In Sub-Saharan Africa, an estimated 2.9 million children were living with HIV by the end of 2012.[1] In 2010 in Malawi, it was estimated that among the youth aged 15-24, 5.2% of females and 1.9% of males were living with HIV.[2] The last decade has seen more children who were infected with HIV through perinatal transmission living longer, largely as a result of improvements made in paediatric antiretroviral therapy (ART), where facilities specialising in paediatric ART have been set up.[3,4] Pharmacologic agents such as zidovudine, didanosine, lamivudine, nelfinavir, ritonavir and nevirapine have increased the life expectancy of children with HIV, who are now reaching middle school-age and beyond.[5,6]

As they reach adolescence, children living with HIV should start to assume self-responsibility on issues such as treatment, sexuality and reproductive health.[7] As adulthood approaches, their awareness of their own HIV status allows them to take the lead in terms of responsibility for their own treatment and care, as well as to make appropriate choices regarding sexuality in relation to their status.[8] In Malawi, information sharing between adults and children is complicated by cultural expectations that limit what parents can share with their children, especially information regarding sexuality, finances, and illness. In this context, disclosing the diagnosis of HIV to a child is complex and brings confusion, hesitancy, and ethical dilemmas.[9] Continuing strong feelings of denial and related secrecy around HIV infection hamper the necessary openness for disclosure.[9] HIV and AIDS-related stigmatization adds an additional layer to the burden of the disease, requiring individuals to deal with the tension between the secrecy surrounding the disease and the openness required to provide and receive care and social support.[10] As parents live in fear of disclosure, they develop concealment strategies around their children's treatment and the nature of the disease.[11] Studies have shown that disclosure is positively related to social support, self-competence and decreased problem behaviour,[12] as well as adherence to antiretroviral combination therapy.[13] This implies that open communication about the diagnosis is essential, particularly at an age at which decisions about relationships, sexual activity and plans for the future are the focus of adolescent development and individualization.[14] This study aimed at exploring potential factors that discourage Malawian parents and guardians from informing perinatally HIV-infected children about their children's HIV status, with the view of using this information to facilitate strategies to help break down the identified barriers.

## Methods

### *Setting and study participants*

A total of 20 parents and guardians of children who were diagnosed with HIV and were on ART participated in this narrative qualitative study. These participants were regularly attending ART clinics at the Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence (COE), the only facility providing paediatric ART services in Lilongwe, Malawi. To increase the likelihood of capturing a variety of experiences, participants (parents and guardians) were purposively sampled during routine clinical visits. We included parents and guardians whose children or wards had and who had not been disclosed to. Written and verbal informed consent for participation was obtained.

### *Data collection and analysis*

Data collection was through in-depth interviews. The 20 participants were interviewed on a one-to-one basis. An in-depth interview guide was used and interviews were audio recorded. We developed the interview guide mainly in line with the research questions. The guide captured four main topical areas: (i) the child's HIV history, (ii) HIV status disclosure, (iii) factors influencing disclosure, and (iv) means to facilitate disclosure. Further probes or follow-up questions were largely determined by the responses given by the participants. All interviews were conducted in Chichewa, the native language of the participants, and each interview lasted approximately one hour. The interviews were transcribed and translated into English soon after each interview was conducted. Data obtained from the study were analysed manually using content analysis and presented in qualitative form.

## Results

The majority of the participants were women (15 out of 20). Regarding each participant's relationship to his or her child, nine women and one man were biological parents and the remaining 10 participants comprised two aunts, three grandmothers, three uncles and two female orphanage workers. The participants' age range was 24 to 62 years. The study only targeted parents and guardians of school-going children who were attending classes ranging from standard four to standard seven; the children eventually discussed in the interviews ranged from 11 to 14 years of age. The study also established that most of the children whose parents or guardians participated had repeated at least a year in one class. Another noteworthy characteristic of this convenience sample was that only six of the 20 respondents (30%) had disclosed the HIV diagnosis to their children, and none of these six were biological parents.

Various themes emerged from the interviews. These themes are grouped into three categories in the following sections: (i) fear of confrontation with the child, (ii) fear of depriving child of happiness, and (iii) fear of indirect publicity of the parents' own HIV status.

### *Fear of confrontation with the child*

Regardless of the nature of their relationship with their child (biological parent or otherwise), participants indicated that they were reluctant to disclose to the child that he or she had HIV because they were afraid that the child would confront them with questions related to how the child became infected. Participants were unsure of how the child would react. The majority of participants indicated their belief or observation that children are sensitive and can be inquisitive. They explained that when told that they had HIV, children would be likely to ask many questions pertaining to how they became infected as this mother explained:

*If I tell my child that she is HIV positive, she will definitely ask me how she got infected. This is not easy for me to tell the child about my status. My daughter would think that I was promiscuous and this will also lead me to telling the child about sex and also about my HIV status… I have on various occasions prepared myself to tell her, usually I think about it when she is away and I would say, I will tell her when she comes home. The moment she arrives I become aware of how intelligent she is and can anticipate the questions she would ask. This thought puts me off.* (Mother of 11-year-old girl)

Participants also feared that children could ask them why they decided to conceive and then keep the child when they (the parents) knew about their HIV status and the possible effects the condition could have on any future children. Some parents said that they had heard of children who had confronted their parents or guardians to an extent that the parents felt bad for having allowed the child to grow. A grandmother explained:

*You hear of stories where a child who was told about their status, became very violent. Some would be very sad that they would not eat food for so many days, and some would ask why the parent did not just kill them while they were young so that they didn't have to live a life that is not normal... so when I think of that, and knowing my grandson, I put it off for another day.* (Grandmother of a 12-year-old boy)

The fear of being confronted, in some cases, emanated from previous experiences when some of the children demanded explanation for why they were taking medication. As children grow, they would want to know why they were taking drugs when some members of the family or children within the neighbourhood were not. During such discussions, some guardians or parents sensed that telling them the real reasons would agitate the child. One male parent explained:

*You are not comfortable to tell the child that you have HIV because you can foresee how they would react. Sometimes the child asks why do I take these medications and you can tell that the child probably suspects it could be ARVs [antiretrovirals]... you know, with knowledge from school or elsewhere, and you can tell that the child wants confirmation and then should attack you, the anger you can sense behind the conversation makes you uneasy to tell them.* (Father of a 13-year-old boy)

Many strategies are employed to avoid facing the child to talk about his or her HIV status. Even before the parents or guardians feel compelled to tell the child, the majority of children would have initiated, at some point, a scenario in which the child demands to know his or her status. The participants indicated that they would either avoid or would give an answer with an explanation that did not mention or could remotely be associated with HIV. One mother of an 11-year-old girl explained:

*My daughter has asked me several times why she takes medication. I tell her, 'remember that day you were sick, I don't want you to become sick again, that is why I give you this medication.'*

### *Fear of depriving child of happiness*

The majority of participants indicated that they could not reveal the HIV status to the children simply because they did not want the children to get worried. They argued that telling their child about his or her HIV status would initiate worries that would ultimately lead to the child becoming ill, as one mother suggested:

*I am aware that there are some benefits for the child to know his HIV status. On the other hand, once the child is told, maybe the child would become so worried that it would make the child sick, you know, when the child is constantly thinking about it.* (Mother of a 12-year-old boy)

Participants argued that these children should be allowed to live blissfully ignorant of their HIV status: to live a normal life and to have normal dreams like any other child. Furthermore, it was thought that a child's educational performance could be compromised if the child concluded that a positive HIV status meant he or she could not live long enough to benefit from endeavours like education. A grandmother who referred to her 11-year-old granddaughter as "my child" explained:

*My child is very brilliant in class and if I tell her that she has the virus, she will think that she is going to die, therefore she will be worried and may stop concentrating in class hence her performance will go down.*

Another grandmother (of a 13-year-old girl) explained:

*My daughter—the late mother of this granddaughter I am staying with—was staying in Blantyre with her husband. It all started with her husband. The husband died after a long illness. Two years after the death of the husband, my daughter got very sick. She was sick for a long time, about nine months. I was in Blantyre nursing my daughter for a long time. It was at this time that I was told that my daughter was HIV-infected and the condition was serious, and she was definitely dying. One evening my daughter told me that her daughter (the granddaughter) was also HIV-infected and she was already on treatment. That evening my daughter handed all the medicines and health passport of her daughter to me with instructions that, in the event of her dying, I should continue taking the child to the hospital for treatment. My daughter died within two days of disclosing the HIV status of my granddaughter. When I brought my granddaughter here, I take her to the hospital every two*

*weeks to receive medicine and treatment.*

*However, the problem I have is that I have not disclosed to her that she is HIV-infected. The reason is that I don't know how to go about disclosing this sad news to the child. Though I have told the head teacher of the school about the condition of my granddaughter, I have not gathered enough courage to face my granddaughter with this news. I hope I will ask the doctor at the hospital to assist me to disclose the sad news.*

### *Fear of indirect publicity of parent's own HIV status*

Efforts are made by families to conceal the presence of HIV in the family. Participants indicated that whether they were positive themselves or not, day-to-day management of the disease is fashioned by secrecy. Disease concealment involves making sure that people within their neighbourhood and/or some members of the family are not informed or do not have access to things such as hospital documents and ART bottles that would indicate that a member of the family had HIV. Most participants, both HIV-positive parents and HIV-negative guardians, indicated that they were reluctant to tell their child his or her HIV status for fear the child would disclose the status to other people and make others aware of HIV in the family:

*In the locations we live, people are always wanting to know something wrong or bad happening in other people's families, so if they know a family has a member who is HIV-positive, then they will be happy to make that something to connect themselves with other people.* (Mother of an 11-year-old boy)

Another participant commented:

*In our community, for people to know that your child is HIV-infected, it would be creating problems for your household and also for the child. At school, the infected child would be the laughingstock of the whole school. It also means that the child would be shunned by friends and this would lead this child to not concentrating on lessons, which would also lead to the child dropping out of school. At the household level, the community would automatically deduce that the parents are also infected, and as such, the affected household would be shunned off.* (Uncle of a 12-year-old boy)

Most biological parents stated that it was for their own HIV status concealment that the child's had to be kept secret, and that revealing the secret to the community would bring misery to the child, the parent, and the affected household.

## Discussion

This study exposes the inner conflict and fears that parents of perinatally HIV-infected children experience when contemplating disclosure to a child of the child's HIV-positive status. Uncertainty surrounding how the child would react upon being informed raises various fears that the parent feels unable to deal with. These fears dictate the nature of the parent-child relationship, with the lingering secret and the ethical dilemma surrounding its disclosure a major defining aspect of the parent-child dynamic in this context. Parents are aware that time is not always on their side, as maturity makes the children increasingly knowledgeable about HIV in general and of their own health situation, which naturally leads to questions whose answers would reveal their status. From this disempowered position, parents dread the disclosure of a positive HIV status to a child as a psychosocial process that has the potential to disturb a family's previously established equilibrium with threats of stigmatization, marginalization, and parent-child conflict. The desire to maintain the happiness of both the parent and the child seems to be overarching reason why parents find it challenging to discuss a child's positive HIV status with that child. This interest manifests itself in all the three thematic categories described above: (i) fear of robbing the child's peace or happiness, (ii) fear of indirect public disclosure of the parents' HIV status, and (iii) fear of confrontation with the child. Whether a biological parent or another guardian makes the status disclosure seems to have a profound bearing on how difficult the disclosure process can be. This study has established that guardians looking after children living with HIV can be categorized into two groups: (i) biological parents, and (ii) other guardians, including grandparents, uncles, aunts and non-familial caregivers. Issues to do with disclosing the HIV diagnosis to the children are considered differently depending on the category of those caring for the infected. Each category of guardian would take into account different factors before informing the children of their HIV diagnosis. It seems that it is more difficult for a biological parent to disclose his or her child's positive HIV status to that child, ostensibly because a biological parent is more directly responsible for, and answerable to, the potential reactions of the children. Among the prominent factors that put these parents in this dilemma is the fear to initiate confrontation with the child. Parents believe that children are bound to confront them with various questions regarding how they became infected. They believe that if the children were to know the truth about their HIV diagnosis, they may regard the parents as the source of infection, which could cause a bitter confrontation between parent and child. Most parents find it difficult to mentally and emotionally prepare for such a conflict with their own children. Parents are concerned that the children would be deprived of happiness once they become aware of their HIV-positive status. The need to protect the child from worries is important to the parent because of concerns of how the child's emotions affects the child's health,[7] especially in the context of what is perceived (usually misconceived) to be a terminal illness. Studies have concluded that the age of a child is a crucial factor when determining whether or not to inform a child about his or her HIV infection,[7,15] and to that effect, it has been recommended that a child who is living with HIV should be made aware of his or her status before 10 years of age.[16] A delay in informing the child about the HIV status can have serious consequences. Adolescents living with HIV are expected to assume a sense of independence and self-responsibility, which are life-saving qualities in the context of compliance to a life-long regimen of antiretroviral medications. Delay in informing children of their HIV diagnosis compromises this independence and self-responsibility, possibly predisposing adolescents to poor self-care habits and drug compliance. Fear of stigmatization and discrimination leads many individuals living with HIV to conceal their status. Parents living with HIV may be less inclined to disclose their child's positive HIV status even to the child, because of the risk that the secret of the child's and—by extension—the parents' HIV status may be spread to others throughout the community. Once this news is spread, it could bring about humiliation to both the child and the parents in the community. The observation that children who were being taken care of by guardians who are not their biological parents were more likely to be informed of their HIV diagnosis than those under the care of biological parents highlights the importance of self-preservation in this process. Considering that guardians normally volunteer to care for their adopted children living with HIV, the guardians would welcome any assistance in providing quality care to

these children. As such, adoptive guardians may perceive that disclosing a child's positive HIV status to the child helps them with accessing appropriate treatment and care. Issues to do with fears of confrontation with the child, and indirect publicity of the parents' own HIV status are less applicable to this category of guardian. The major concern of the adoptive guardians is the fear of depriving the child's happiness and exposing the child to stigmatization and discrimination once the child's status is known to people outside trusted boundaries. If disclosing the HIV diagnosis to the child living with HIV would in any way assist in the provision of appropriate health care, the guardians would likely take that option. Other investigators have argued that these guardians opt to reveal the HIV diagnosis to the affected children on the basis of lack of knowledge about HIV so that they should solicit assistance. Additionally, as the adoptive guardian's HIV status is not directly linked to the child's, these guardians may feel that they have nothing to lose regarding their dignity which would make the disclosure process easier than for a biological parent worried about knowledge of his or her own HIV status in the community.[17]

Similar research has argued that parents who disclose the status to their children experience less depression than those who do not.[18] The argument has also been made that the majority of guardians and parents would prefer caregivers or health workers to disclose the HIV diagnosis to their children.[19] Physicians and trained healthcare workers may play an important role in the disclosure process, if they are indeed involved, because of the finding that children living with HIV who receive inaccurate information regarding their status are often at a disadvantage when it comes to caring for themselves at adolescence.[20]

A limitation of this study is that it does not include views of the children themselves regarding their health, as only parents and guardians of these children were interviewed from one study site in Lilongwe district. However, given that this site receives clients from many parts of the district, it can safely be said that the participants represent typical circumstances common to many parents in Lilongwe district.

## Conclusion

This study has revealed that guardians, particularly biological parents, of perinatally HIV-infected children find it difficult to inform their child of the child's HIV status. This parental dilemma suggests that improved psychosocial support services that can assist in the disclosure process should be available to parents and guardians of perinatally HIV-infected children. As such, this calls for strategies that could support parents to make disclosure to the child less challenging.

## References

1. UNAIDS Report on the global AIDS epidemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS). Geneva 2010.

2. National Statistical Office (NSO) and ICF Macro. 2011. Malawi Demographic and Health Survey 2010. Zomba, Malawi, and Calverton, Maryland, USA: NSO and ICF Macro.

3. Kuczmarski RJ, Ogden CL, Guo SS, et al. 2000 CDC growth charts for the United States: Methods and development. National Center for Health Statistics. Vital Health Stat 11(246). 2002

4. World Health Organization (2011) Global HIV/AIDS response: epidemic update and health sector progress towards universal access-progress report 2011. Geneva: WHO 2011.

5. American Academy of Pediatrics Committee on Pediatric AIDS (1999) Disclosure of illness status to children and adolescents with HIV infection. American Academy of Pediatric AIDS. Pediatrics. 103(1):164-6.

6. Newell, M L, Bernardi, S, Gabiano, C et al. (1998) A Survey of policy and practice of therapeutic interventions for HIV-infected children in Europe XII International Conference on AIDS , Geneva. Abstract 42253.

7. Giacomet V, Albano F, Starace F, de Franciscis A, Giaquinto C et al. (2003) Adherence to antiretroviral therapy and its determinants in children with human immunodeficiency virus infection : a multicentre, national study. Acta Paediatr 92: 1398-1402

8. Hejoaka F .Care and secrecy: Being a mother of children living with HIV in Burkina Faso. Social Science & Medicine 29: 869 – 876. 2009

9. Watermeyer J. (2013) Are we allowed to disclose? : A healthcare team's experiences of talking with children and adolescents about their HIV status. Health Expectations doi:10.1111/hex.12141

10. Battles H B, and Wiener L S. (2002) From Adolescence Through Young Adulthood: Psychosocial Adjustment Associated with Long-term Survival of HIV. J Adolescent Health. (30) 161 – 168

11. Rotheram-Borus, M. J., Hermie Draimin, B., Reid, H. M. and Murphy, D. A. (1997) The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. AIDS, II, 1159-1164.

12. Wiener, L. S., Battles, H. B., Heilman, N., Sigelman, C., and Pizzo, P. A. (1996) Factors associated with disclosure of diagnosis to children with HIV/AIDS. Paediatric AIDS and HIV Infection to Adolescents. 7: 310 – 324.

13. Mutwa P R, Van Nuil J I, Asiimwe-Kateera B, Kestelyn E, Vyankandondera J, et al. (2013) Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-infected Adolescents in Rwanda: a Qualitative study. PLOS ONE 8(4): e60073. doi:10.1371/journal.pone.0060073

14. Kidia K K, Mupambireyi Z, Cluver L, Ndhlovu C E, Borok M, et al. (2014) HIV Status Disclosure to perinatally-infected Adolescents in Zimbabwe: A qualitative study of Adolescents and Healthcare Worker Perspectives. PLoS ONE 9(1): e87322. doi:10.1371/journal.pone.0087322

15. Vreeman R C, Gramelspacher A M, Gisore P O, Scanlon M L, Nyandiko W M. (2013) Disclosure of HIV status to children in resource-limited settings: a systematic review. Journal of the International AIDS Society, 16:18466

16. Gibb, D (1998) HIV and AIDS Paediatric Guidance for the UK. AVERT, Horsham.

17. Saunders, C. (2012) Disclosing HIV status to HIV positive children before adolescence. Br J Nurs 21(11)663-9

18. Keymanthri M, Lefebvre A. (2006) HIV disclosure in children. AIDS Patient Care: Cape Town (1) 41-45.

19. Funk, D and Bretano, T. (2006) Patterns of Disclosing and Perceptions of the Human Immunodeficiency Virus in Infected Elementary School-age Children. Archives of Paediatric adolescent medicine. (151) 978-988.

20. Bikaako-Kajura W, Luyirika E, Purcell D W, Downing J, Kaharuza F. (2006) Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-infected Children in Uganda. AIDS Behavior 10(4):S85-S93