

# Perceptions, Reasons and Experiences of Disclosing HIV Diagnosis to Infected Children in Kweneng District, Botswana

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## ABSTRACT

There are limited data on what influence caregivers' HIV disclosure to children in limited resource countries given the low disclosure rates documented in literature. The study explored caregivers' perceptions and experiences of HIV disclosure to infected children. In-depth interviews were conducted with caregivers of HIV infected children between 6-16 years attending a paediatric HIV clinic in a rural district, in Botswana.

Caregivers believed that disclosure is morally right for the child. Disclosure resulted in mental relief for caregivers who were relieved of the burden of keeping a secret. Children displayed good adherence practices to ART medication. Non-disclosed caregivers described non-disclosure as emotionally draining, they lived with regret and fear that they are not be doing the right thing; and acknowledged that raising a non-disclosed child was a challenging experience. Biological caregivers experienced constant sense of guilt for having transmitted HIV to their child. Disclosure was often delayed to protect the child and family from stigma and discrimination. The benefits of disclosure should form the focus of disclosure interventions and discussions with caregivers of HIV infected children.

**Key words:** Benefits of disclosure, experiences, HIV infected children, caregivers, disclosure, Botswana

## INTRODUCTION

The total number of persons living with HIV/AIDS in Botswana in 2009, was 316 363, and 15,888 (5%) were children aged younger than 15 years of age.<sup>[1]</sup> The Joint United Nations Program on HIV/AIDS (UNAIDS) report shows that Botswana is among the low resourced countries which had achieved universal access to antiretroviral therapy (ART). The UNAIDS also reports an increase in the number of

children younger than 15 years of age receiving ART between 2009 and 2010.<sup>[2]</sup> The availability of ART resulted in HIV infected children living longer and healthier lives. Therefore, issues that were not present when their life expectancy was low, have now came up and need attention.<sup>[3]</sup> As HIV infected children on ART become older, HIV diagnosis disclosure become significant and forms part of their comprehensive HIV care.<sup>[4-7]</sup>

Studies have shown that caregivers and health care providers believe that disclosure benefits both children and their caregivers.<sup>[6,8,9]</sup> Disclosure has been shown to influence adherence to ART for HIV-positive children positively.<sup>[10,11]</sup> Disclosure also enables children to understand HIV infection to make sense of disease-related experiences and the importance of ART adherence.<sup>[12,13]</sup> Some of the endorsed reasons for disclosure to HIV infected children included wanting the children to hear the diagnosis from their mothers, and that the children had a right to know.<sup>[11,14,15]</sup> Furthermore, disclosure and knowledge about the disease becomes essential for HIV prevention as children reach adolescence and start risk-taking behaviors.<sup>[16]</sup> Non-disclosure on the other hand, can impair the child's treatment understanding and may also increase psychological and behavioral problems.<sup>[17,18]</sup>

Despite the documented benefits of disclosure to HIV infected children from well developed countries, the rates of disclosure seem to remain low in limited resource countries.<sup>[6,13,19]</sup> Current data show a slight increase in the rate of disclosure in limited resource countries; Negese et al<sup>[20]</sup> reported that 39.5% of caregivers in Ethiopia had disclosed to the children. However, the HIV disclosure to children remains relatively low in limited resource countries which have substantially rolled out ART countrywide like South Africa. Madiba<sup>[21]</sup> reported that only 39.6% of the caregivers had disclosed the HIV diagnosis to the infected child.

Disclosure entails communication about a potentially life threatening and stigmatised illness, and many caregivers fear that disclosure may create distress for the child or even potentially damage the caregiver-child relationship.<sup>[11,14,15,22]</sup> Consequently, caregivers delay disclosure for fear that disclosure might have negative

psychological consequences for the child, fear that the child might express anger at the parent for infecting them, and fear that the child might disclose his or her HIV-diagnosis to others and subject the family to stigma and discrimination.<sup>[6,23,24]</sup> Some caregivers delay disclosure because they felt that they were not ready to disclose, they were unskilled in dealing with disclosure to a child, and did not know how to tell the child about their HIV diagnosis.<sup>[24-26]</sup>

Given the limited data on HIV disclosure to infected children in resource limited countries including Botswana, it is not clear what influences caregivers' communication with infected children about HIV disclosure. This paper reports on the caregivers' perceptions about disclosure and their experiences of HIV disclosure to infected children attending a paediatric HIV clinic in a rural district, in Botswana.

## **MATERIALS AND METHODS**

**Study Design and setting:** The study employed an exploratory qualitative approach to conduct-in-depth interviews with caregivers of HIV-infected children between June and December 2010.

The study was conducted at the Infectious Disease Care Clinic (IDCC) in Thamaga Primary Hospital. The clinic offers comprehensive ART to adults and children infected with HIV. Thamaga is a rural village located in the southern part of Botswana, about 85km from Gaborone (the capital city of Botswana). The hospital has five ART satellite clinics, and by July 2010 the hospital ART clinic had a total of 1 580 patients on ART, of which 82 were children aged between 5 and 19 years

Caregivers were purposely selected to participate in the in-depth interviews (IDIs). The criteria for selection were being the caregiver of an HIV infected child aged between 6–16 years and receiving paediatric ART. For the purpose of this study, we

defined a caregiver as the biological mother, biological father, grandmother, grandfather, foster parent, or other relative who performs primary care-giving functions for the child routinely or on a daily basis. A list of caregivers of HIV infected children who met the inclusion criteria was extracted and compiled from the Patient Management database. The lead researcher contacted caregivers of children who were due for medical check-up to recruit them for participating in the IDIs.

**Data collection:** Two interview schedules were developed by the authors, one for caregivers who had disclosed, and one was for caregivers who had not disclosed the HIV diagnosis to the child. The schedules addressed caregiver's perceptions about disclosure, reasons for HIV disclosure and non-disclosure, caregiver's experience with disclosure and non-disclosure, information given to the child about their illness and medication. The interview schedules were translated into the local language, Setswana. The interviews were conducted by the first author who was assisted by a trained research assistant. Interviews were recorded with the permission of the caregivers and conducted in Setswana. A total of 20 interviews were conducted. The interview schedule also captured caregiver's demographic information, relationship with the child, as well as the age, gender, and the disclosure status of the child.

**Ethical Considerations:** Ethical clearance was obtained from the Medunsa Research and Ethics committee of the University of Limpopo, and the Ministry of Health's Research Ethics Committee in Botswana. Permission to conduct the study was granted by the management of the Thamaga Primary Hospital. The interviews were conducted in the absence of the children to prevent them from accidentally learning about their HIV diagnosis. Participation was voluntary and

caregivers were assured of confidentiality. An informed consent was obtained from the caregivers before the interview.

**Data analysis:** The first author listened to the audio files repeatedly before they were transcribed verbatim. The first author and the research assistant were responsible for verbatim transcription and translation of the transcripts into English. Both are conversant with Setswana and English. Data analysis was conducted by the authors using thematic analysis. The authors read several transcripts independently and jointly to identify emerging codes to develop a code list. This was followed by a review of the emerging themes to reach consensus on the definition of the themes and sub themes. The transcripts were exported into NVivo version 8, qualitative data analysis software, for the application of codes. The transcripts were recoded if a new code emerged or an existing code was revised.

We ensured the credibility of the findings by conducting the interviews in the local language; we also recorded the IDIs, transcribed the transcripts verbatim, verified raw data during translation, and used NVivo computer software for data analysis

The demographic data was used to describe the caregivers and their children.

## RESULTS

**Sample Description:** Demographic characteristics of caregivers are presented in Table 1. A total of 20 caregivers of children on paediatric ART participated in in-depth interviews. They ranged in age from 21 to 70 years. Almost all 18 (90%) were females. Almost half 9 (45%) had primary school education, 4 (20%) had junior secondary school education, 4 (20%) had senior secondary school education, two (10%) had never been to school, and only 1 (5%) caregiver had tertiary education. More than half 11 (55%) were HIV positive, 5 (25%) were HIV negative, and 4 (20%) did not

know their HIV status. Almost half 8 (40%) of the caregivers were the biological mothers of the children, 1 (5%) was a biological father, 7 (35%) were other relatives including aunts and uncles, and 4 (20%) were grandparents. Most 12 (60%) caregivers had told the child of their HIV diagnosis while 8 (40%) had not told the child.

**Table 1: Socio-demographic profile of the caregivers.**

Variable name	Frequency	Percentage
<b>Age</b>		
21 - 30	3	15
31 - 40	7	35
41 - 50	4	20
51 - 60	4	20
61 - 70	2	10
<b>Gender</b>		
Male	2	10
Female	18	90
<b>Level of Education</b>		
Never been to school	2	10
Primary school	9	45
Junior school	4	20
Senior school	4	20
Tertiary	1	5
<b>Relationship with the child</b>		
Biological mother	8	40
Biological father	1	5
Grandmother/father	4	20
Other family member	7	35
<b>Caregiver's HIV status</b>		
HIV negative	5	25
HIV positive	11	55
Status unknown	4	20
<b>Has the child been disclosed to</b>		
Has disclosed to the child	12	60
Has not disclosed to the child	8	40

Demographic information on children was collected from the caregivers and is presented in Table 2. There were more 12 (60%) girls than boys 8 (40%). The children ranged in age from 6 to 16 years. Almost all 18 (90%) were attending primary school, and only 2 (10%) were at junior secondary school.

### **Themes**

#### **Perceptions about disclosure**

Caregivers were asked their opinions about disclosure to HIV infected children, disclosed and non-disclosed caregivers were

of the opinion that disclosing the HIV diagnosis to children was a good thing to do.

*Though I have not told the child that she is living with the virus I do believe it is a good thing to tell the child. But like I said it will only be right if you tell them at the right time otherwise you can only hurt them while you think you are doing a good thing (Non-disclosed Aunt of an 11year old).*

*Well, I think it is a good thing to tell the child about their positive HIV status..., it is not proper for the child to keep on drinking pills without knowing why they are taking the medications, it is not right for them to just take the pills without knowing why they take them (Non-disclosed biological mother of an 8year old).*

#### **Reasons for disclosure**

Some caregivers disclosed the HIV diagnosis to their children because they believed that the child had the right to know of his/her HIV diagnosis.

*I felt I had to tell her about her HIV positive status because at the hospital, they always emphasized to her that she should make sure she drinks the pills every day and on time (Disclosed grandmother of 11year old).*

*You see, I did not want to keep her in the dark about her knowing that she has AIDS. I also wanted her to be aware and have the right information (Disclosed grandmother of 9 year old).*

Some caregivers disclosed because the child was asking questions about the reason they were taking medication and the reasons for going to the hospital for medical check-ups.

*The child constantly wondered why he is taking these pills and why he takes them at a regular time like 7 o'clock. Therefore, it becomes pressing to us as caregivers, hence we had to tell the child more about the pills and how they work in their body (Disclosed aunt of a 12year old).*

Caregivers also decided to tell the child about their HIV diagnosis because they feared that the child could get to learn of his/her HIV status from other sources.

*We had fears that the more we delayed telling her about her illness the more chances that she might end up getting some wrong information from other people (Disclosed grandmother of a 13year old).*

Some caregivers reported that they decided to disclose because the child was curious about their condition and was asking questions about their illness.

*I told him that there is something called HIV germ and it is not curable. He then asked me how he gets it and how he ended up having it while he is still a child. Well I told him that I do not know and maybe his parents can better explain how he got the infection (Disclosed aunt of a 12year old).*

**Table 2: Socio-demographic profile of the children (n = 20).**

Variable name	Frequency	Percentage
<b>Age</b>		
6 – 10 years	12	60
11 – 16 years	8	40
<b>Gender</b>		
Male	8	40
Female	12	60
<b>Level of Education</b>		
Never been to school	0	0
Primary school	18	90
Junior school	2	10

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

Data show that some of the caregivers did not disclose because they believed that the child will not keep his/her HIV diagnosis a secret.

*If she is disclosed to at a young age..., she might not know how to keep a secret about her illness and go on to talk about her AIDS disease with other children (Non-disclosed mother of a 10year old).*

Some caregivers did not disclose because they felt that the child was not old enough to understand the HIV diagnosis,

and delayed disclosure to such an age where they feel he/she will understand.

*Maybe when she is around 15 years that is when she will be mature enough to understand AIDS information well as most children who are 15 years old understand certain things better (Non-disclosed biological mother of a 10year old).*

In addition, caregivers reported that they decided against disclosing the HIV diagnosis to the child as they did not want to upset the child.

*My fear is that my disclosure efforts might be misunderstood as the child is still young to understand some things about HIV/AIDS. I sometimes fear that I might hurt the child by telling her that she is HIV positive, you see, by the time she gets to understand it she will be hurt (Non-disclosed mother of a 10year old).*

Disclosure was also delayed because caregivers had fears that their child will be discriminated against in the society once people get to know that the child has HIV *You see, being HIV positive is something that is not really accepted in my society, we people living with HIV, are always called names and even isolated. Now imagine how a 10 year old child will handle this kind of discrimination if adults are struggling with it. So I think it is best I wait until she is old enough to keep the secret (Non-disclosed biological mother of a 6year old).*

*Once other people know..., the whole village will know..., and we will be called all sought of names. I am just waiting for him to be mature enough to know that this disease should be our deepest secret in the family (Non-disclosed biological mother of a 10year old).*

*Every child in that school she goes to know about AIDS and that people with it are going to die. So if her friends know, they are going to make fun of her that she is not going to live for long as she has AIDS (Non-disclosed aunt of an 11year old girl).*



Data also show that caregivers delayed disclose because they feared that the child might blame them for passing HIV to them once they explain to the child how they got infected.

*It still causes pain to me because I know very well that the reason why this child has the virus is because I did not enroll in PMTCT which could have helped prevent HIV transmission to the child and also breastfed him (Non-disclosed biological mother of a 9year old).*

*According to the nurses, the virus passed from me to the child during pregnancy. So, I really have a difficult time in explaining this to the child as I fear he might blame me (Non-disclosed biological mother of a 10year old).*

#### **Disclosure information shared**

Caregivers who disclosed were asked to share the information they told the child about their condition. The data show that most disclosed caregivers gave the child accurate information about HIV and AIDS.

*We told him that he has a germ called HIV. Therefore, he has to take ARV treatment which he will need to take for the rest of his life so that the germ does not wake up (Disclosed aunt of a 12year old).*

*I did not hide anything from her, I told her the truth that she is living with HIV (Disclosed mother of a 9year old).*

#### **Information told the undisclosed child**

Caregivers who had not disclose were asked to share the information they told the child about their illness. Data show that caregivers told their children that they were ill but gave HIV a false name or gave an inaccurate explanation of the illness.

*She just knows that she has to take her pills so that she does not fall sick so that she can grow up and be able to attend school without falling sick time and again (Non-disclosed biological mother of a 6year old).*

*She was somewhat refusing to drink the medication, and I told her that if she does not take the medication she will be sick and this forced her to start drinking them without any fuss (Non-disclosed biological mother of a 10year old).*

#### **Experience with disclosure**

The data show that some caregivers experienced emotional relief after disclosure. They see the disclosure process as having reduced the emotional stress associated with not disclosing the HIV diagnosis to the child.

*It has taken the burden of secrecy from me (Disclosed aunt of a 12year old).*

*It has really lifted the heartache I was living with, as I was always wondering how she was going to feel when she finds out about her illness and how she was going to accept the status (Disclosed grandmother of a 13year old).*

*It gave me a lot of emotional pressure, and it was becoming unbearable for me to keep it secret and always hiding the truth from the child no matter how young she may seem (Disclosed biological mother of a 9year old).*

#### **Caregiver's experience with non-disclosure**

Non-disclosed caregivers were asked to share their experiences of not telling the child about their HIV diagnosis.

*The failure to tell the child about his HIV positive diagnosis is really draining me emotionally and mentally (Non-disclosed biological father of a 9year old).*

*I regret that I might not be doing the right thing by not telling her that she is living with HIV (Non-disclosed biological mother of a 6year old).*

*Almost everywhere people talk about HIV and ARVs, in the radios and televisions. This gets me panicking because he might even end up learning about his pills from what he sees in the magazines (Non-disclosed biological mother of a 10year old).*

### **Benefits of disclosure**

When asked about the child's behaviour and practices after being told of their HIV diagnosis, most caregivers reported that they were impressed by their children's adherence to ART medication.

*It has reduced the burden on me; as I no longer supervise him time and again, he now knows that at a certain time he has to have eaten and drunk the pills (Disclosed aunt of a 12year old).*

*She does not give us any problems her attitude towards her medication has improved tremendously; she takes the medication very well, we do not even remind her that she must take the medication; she understands the whole process (Disclosed aunt of a 15year old).*

Caregivers who had disclosed viewed disclosure as being very beneficial, caregivers believe that children who know about their HIV diagnosis showed acceptance of their HIV diagnosis.

*The good thing is that he now can monitor his own behaviour like delaying sex by waiting in order to grow up and fully understand him before he can do some things like having sex (Disclosed aunt of a 12year old).*

*Before disclosure, she was a very withdrawn girl and always worried about her never-getting-better health. Also, her adherence to the tablets has improved as she now knows why she is taking them, that if she misses taking them she can get sick and die (Disclosed grandmother of a 13year old).*

## **DISCUSSION**

This study explored the perceptions, reasons and experiences of HIV diagnosis disclosure to infected children. Similar to previous findings, the caregivers describe disclosure as difficult and emotional,<sup>[11,14,17]</sup> but they believed that it is morally right for the child.<sup>[12,27]</sup> Caregivers who had disclosed

the HIV diagnosis to their children had a positive experience with disclosure. Disclosure resulted in great mental relief for the caregivers. They no longer have to wonder if the undisclosed child was going to ask difficult questions about their illness or medication. Similar findings were reported in previous studies<sup>[12,19,25]</sup> that some parents reported feelings of relieve of the burden of keeping the secret after disclosure.

The study found that caregivers who had disclosed in this study reported seeing some benefits in doing so. After knowing their HIV diagnosis children displayed good adherence practices to their ART medication and overall acceptance of living with HIV. Some of the caregivers reported that their children started drinking their ART medication with minimal supervision, while others reported that they had less difficulty in persuading their children to go for medical check-up. These findings are consistent with previous studies.<sup>[11,28]</sup> Knowing more about the disease assisted children to know more about their illness, the effects of missing doses, and acceptance of their HIV diagnosis. Better self-care among children who were told about their HIV diagnosis was the most frequently cited advantage of disclosure in a previous study.<sup>[29]</sup>

Caregivers were influenced by various factors to disclose to children. They viewed disclosure as being important and felt that the child has the right to know of their diagnosis. They disclosed because of the child's reluctance to adhere to ART medication, the child's refusal to continue taking ART medication, the child's persistent questions about taking medication, and the child wanting to know why they were routinely going to hospital for medical review. Similar reasons were reported in other studies.<sup>[6,11,14,30,31]</sup> Similar to findings in a study by Madiba,<sup>[11]</sup> caregivers of older children in this study

also used disclosure to educate their children about HIV transmission and unsafe sexual practices, so that the children will avoid risky behaviour as they mature.

Caregivers who had not disclosed the HIV diagnosis to their children described non-disclosure as an emotionally draining state. They further conceded that raising a non-disclosed child was a very difficult experience. They live with regret and fear that they might not be doing a morally correct thing by not disclosing. Caregivers also experienced constant anxiety and feared that the child might accidentally get to learn about the ART medication and HIV diagnosis from media. These findings are in line with data from a study that looked at parental emotional functioning in relationship to disclosure of HIV diagnosis to children, the data indicated that parents who disclosed reported less distress than non-disclosing parents.<sup>[32]</sup>

Several studies show that communication by caregivers to their infected children was characterized by deceit and use of false names to describe their illness.<sup>[6,29,31]</sup> In this study, caregivers who had not disclosed told children inaccurate information about their illness. Providing deceptive information is a strategy used when caregivers feel unprepared for full disclosure.<sup>[4,12,33,34]</sup> In this study, caregivers experienced difficulty in addressing poor adherence to ART medications by the non-disclosed children. These children had no idea why it was important for them to adhere to lifelong treatment since their relevance was never communicated to them.

Caregivers who had not disclosed acknowledged the importance of HIV disclosure to children and expressed their wish to disclose in the future. However, caregivers had fears that the child might not be able to keep their HIV diagnosis a secret from their friends. They feared that once

children tell others about their HIV diagnosis they would suffer isolation and name-calling at school and in the community. Similar findings were reported.<sup>[6,12-14,24]</sup> Madiba and Mokwena<sup>[24]</sup> argue that the decision to keep the HIV status secret was founded on the desire to protect children from ridicule, teasing, and social rejection, especially in an environment where stigma and discrimination are rife.

Some biological caregivers feared that the child might blame them for infecting them with HIV and hence delayed disclosure. These findings were also reported in previous studies.<sup>[6,14]</sup> The child's disclosure often leads to the biological caregiver having to answer difficult questions about their own personal history with HIV infection. According to Madiba and Mokwena,<sup>[24]</sup> answering the question on HIV infection would compel biological caregivers to give a detailed explanation of their sexual activities in an attempt to explain the nature of the illness to their infected children. In this study, caregivers reported a sense of guilt about having transmitted the HIV infection to their child. One biological mother blamed herself because she opted not to enroll in the PMTCT program which could have protected her child from infected. Madiba and Mokwena<sup>[24]</sup> also found that caregivers delayed disclosure because they had to first deal with feelings of guilt for not protecting their children from the HIV infection. In this study some of the caregivers

## CONCLUSION

Caregivers who had disclosed and caregivers who had not disclosed the HIV diagnosis to their children perceived disclosure positively and believed that it benefits both the child and the caregiver. Caregivers who had disclosed the HIV diagnosis to their children had a positive



experience of disclosure which resulted in great mental relief for the caregiver. Caregivers also reported that disclosure positively benefited the children too. After disclosure, children displayed good adherence practices to their ART medication and overall acceptance of living with HIV. Caregivers who had not disclosed experienced non-disclosure as emotionally draining, they also experienced raising a non-disclosed child as very difficult. They lived with regret and fear that they might not be doing the right thing. Furthermore, caregivers experienced a constant sense of guilt for having transmitted HIV to their child.

Biological caregivers often kept the child's HIV diagnosis secret to protect their own HIV status. Pediatric ART programmes should incorporate disclosure into the clinical management of HIV infected children, and the benefits of disclosure should be made a focus of the disclosure discussions with caregivers. Disclosure guidelines should also target biological caregivers to support them to deal with their personal challenges to disclose to their infected children.

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#### ***Conflict of Interests***

The authors declare that they have no conflict of interests.

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