

### **HIV Disclosure in children in a tertiary hospital in Southern Nigeria– Child’s Perspective**

#### **Abstract:**

**Background:** Disclosure of HIV status to children is essential for disease management. Studies on disclosure in children have largely described it from the health provider’s perspective or caregiver’s perspective. Caregivers’ and children’s reports about children’s feelings and distress can however differ. Understanding the disclosure process from the perspective of HIV-positive children will therefore better portray the impact it had on them.

**Aim:** The aim of the study was to explore from the child’s perspective the process of disclosure, the impact it had on them, how they have coped and suggestions on how they think it could be done better.

**Methods:** A cross-sectional study of HIV-infected children and adolescents aged 8–18 years who are aware of their status attending paediatric HIV clinic at the University of Port Harcourt Teaching Hospital (UPTH), Port Harcourt, Nigeria from April 2015 to March 2016. Data were collected using an open ended questionnaire administered by a Paediatric health care provider. Information sought included: biodata (age, gender), educational levels of the child, family characteristics (primary caregiver, orphan status), age at disclosure, process of disclosure, the impact of the disclosure, how they have coped, what they did not like about the way they were told and suggested better ways of telling the children.

**Results:** Seventy-eight HIV-positive children and adolescents who were aware of their HIV status were interviewed. Their ages ranged from 8 – 18yrs. The mean age was  $14.74 \pm 2.23$  years. Forty (51.3%) were males, 50 (64.1%) were in secondary schools, 43 (55.1%) were orphans and the mode of transmission was vertical in 70 (89.7%). In majority 33 (42.3%), the biologic mother was the primary caregiver.

Majority of the children 34 (43.6%) had their status disclosed to them between 13 and 14 years. The mother alone did the disclosure in 30 (38.5%). Thirty six (46.2%) were already aware of their status before disclosure. Disclosure was a one-off event without discussions in 48 (61.5%) and 54 (69.2%) said they were not given the opportunity to ask questions. The commonest

immediate reactions were depression 48 (61.5%), sadness 32 (41.0%) and shock 22(28.2%) and 64 (82.1%) stated that immediate reactions had decreased over time as they have come to accept their situation. Coping strategies include becoming more prayerful 48 (61.5%), being closer to parents 36 (46.2%) and making friends with other HIV positive children 18 (23.1%). All 78 (100%) agreed that disclosure has positively impacted on their taking their ARV drugs and clinic attendance. Forty eight (61.5%) have not self disclosed to others after the disclosure.

Concerning suggestions from the children, 36 (46.2%) said the most appropriate age for disclosure should be 12-13years, 54 (69.2%) suggest that both parents should do the disclosure while 60 (76.9%) said it should be explained to the children how they got infected. Their major concern was having to take drugs for life 60 (76.9%)

**Conclusion:** Disclosure process is suboptimal. Understanding the disclosure process from the perspective of HIV-infected children, therefore, is critical to developing interventions to improve disclosure. Most of the parent's fears of negative impact of status disclosure may be exaggerated. There is need for health care providers to develop a plan with the caregivers of HIV-infected children on the optimal disclosure process and how to anticipate and resolve questions the children may have following disclosure. Support should also be provided for adverse outcomes following disclosure.

**Key words:** *HIV disclosure, child, adolescent, disclosure process, impact*

## **Introduction**

Disclosure of HIV status to children is essential for disease management. Studies on disclosure in children have largely described it from the health provider's perspective [1,2,3] or caregivers perspective [4,5], but not much study has been done to characterize the actual impact of disclosure on the children as reported by the children themselves. For these children, learning about their HIV diagnosis is necessary to building trusting family relationships and an important step towards long-term disease management and transition from paediatric/ adolescent care into adult care settings. Dusabe-Richards et al [6] in their study observed that children whose status was disclosed to them took charge of their healthcare, visiting a health facility unaccompanied, ensuring adherence to their antiretroviral drugs and communicated better with their caregivers.

One of the issues that make disclosure most difficult for caregivers of HIV-positive children is knowing when and how to talk about HIV to these children, and because most paediatric HIV infection is due to vertical transmission, disclosure implies revealing parental HIV status.

HIV disclosure entails communication about a potentially life threatening, stigmatizing, and transmissible illness, and many caregivers fear that such communications may create distress for the child. The American Academy of Pediatrics [7] and the World Health Organisation (WHO) [8] strongly encourages disclosure of HIV-positive status to school-age children (incrementally according to their cognitive development) and adolescents. As children on antiretroviral therapy (ART) become older, issues of treatment adherence, sexual health, bereavement and transition to adult care cannot be adequately addressed without disclosure [9].

Children react to HIV disclosure in different ways depending on the child's cognitive development, family background and how the disclosure was done (planned or accidental). Caregivers' and children's reports about children's feelings and distress can however differ [10]. Caregivers have reported both negative and positive social, psychological, and behavioral impacts of disclosure on children, including improved adherence to antiretroviral drugs [3, 11], better self esteem [6], improved family relationship [12] and depression [13]. Parents who are distressed may tend to see more distress in their children. Thus, children's self-reports about their feelings or distress may be more reliable than caregivers' reports.

Through understanding the disclosure process from the perspective of HIV-positive children, both health care providers and caregivers can learn about what works well, what needs to be strengthened, and what is missing in current disclosure practices in order to formulate interventions to improve disclosure.

This study therefore, focused on the experiences of HIV-infected children in a comprehensive HIV paediatric care and treatment program in University of Port Harcourt Teaching Hospital (UPTH), a tertiary hospital. The study aimed at exploring from the child's perspective, how the disclosure was done, the impact it had on them, how they have coped and suggestions on how they think it could be done better. It is hoped that findings from this study will facilitate development of interventions to support families and paediatric health care providers through the process of disclosing HIV status to infected children.

#### **Method:**

We conducted a cross-sectional study on HIV-infected children and adolescents aged 8–18 years who are aware of their status (with child specifically mentioning that he/she has been told they have HIV) attending Paediatric HIV clinic at the University of Port Harcourt Teaching Hospital, Port Harcourt, Nigeria from April 2015 to March 2016. Data were collected from open ended questionnaires administered by the paediatric health care providers to children whose caregivers admitted has been disclosed to (and child corroborated) and children who self-reported knowing their HIV status. After the purpose of the study was explained, verbal consent was obtained from each caregiver. Informed consent and informed assent were also obtained from the children as appropriate. Information sought included: biodata (age, gender), educational levels of the child, family characteristics (primary caregiver, orphan status), how they found out, at what age they found out, what they did not like about the way they were told, the impact of the disclosure, suggested better ways of telling the children, questions they would have loved to ask and how they have coped and processed the information. All children interviewed were on antiretroviral regimens at the time of the interview.

The interviews were done privately without the caregivers to make the children more relaxed, unbiased and free to answer honestly. Participants were also informed that participation was on voluntary basis and that they can withdraw at any time if they are not comfortable with the questions in the questionnaire and that there will be no negative implications for health-care services they would receive should they opt to withdraw.

Names or personal identifiers were not included in the questionnaires to ensure participants' confidentiality. They were also reassured that their responses will not be shared with the caregivers (except with their permission) and of the availability of support should they require any. Ethical clearance was obtained from the Ethics Committee of the hospital.

## **Results:**

### **General characteristics of the HIV infected children:**

We interviewed 78 HIV positive children who were aware of their HIV status. Their ages ranged from 8 – 18yrs. The mean age was  $14.74 \pm 2.23$  years. There were 40 (51.3%) males and 38 (48.7%) females. Fifty (64.1%) were in secondary schools while 19 (24.4%) were in tertiary institution. Forty-three (55.1%) were orphans (that is either mother dead or father dead or both

parents dead). Mode of transmission was vertical in 70 (89.7%). In majority 33 (42.3%), the biologic mother was the primary caregiver. (Table 1)

**Table 1: General characteristics of the HIV infected children**

<b>Child characteristics</b>	<b>No ( %)</b>
<b>Age range (years)</b>	
<b>Mean (±SD)</b> 14.74±2.23 years.	
8-10	4 (5.1)
11-13	20 (25.6)
14-18	54 (69.2)
<b>Gender</b>	
Male	40 (51.3)
Female	38 (48.7)
<b>Education</b>	
Primary	9 (11.5)
Secondary	50 (64.1)
Tertiary	19 (24.4)
<b>Mode of transmission</b>	
Vertical	70 (89.7)
Horizontal (blood 6; sexual 2)	8 (10.3)
<b>Orphan Status</b>	
Both parents alive	35 (44.9)
Father/mother/both/ dead	43 (55.1)
<b>Primary Caregiver</b>	
Biologic mother	33 (42.3)
Aunts/Uncles/Elder sibling	21(27.0)
Biologic father	16 (20.5)
Grandparents	5 (6.4)
Others (adopted mum)	3 (3.8)

### The process of the disclosure:

Majority of the children 34 (43.6%) had their status disclosed to them between 13 and 14 years. The mother alone did the disclosure in 30 (38.5%) although most of the children 54 (69.2%) consider that both parents are the most appropriate to disclose to the child while 12 (15.4%) thinks the mum and 12 (15.4%) thinks the dad should be the most appropriate to tell the child. Thirty six (46.1%) of them had already heard it inadvertently (i.e the child became aware of their illness purely through an incident that is accidental) before the formal disclosure. In 6 (7.7%) the children think the caregiver is still unaware that they are aware of their status. In 12 (15.4%), the disclosure was involuntary (as the primary caregiver was forced into disclosing to the child due to circumstances like child refusing to take ARVs or asking questions about regular illnesses and frequent clinic visit). Disclosure was a one-off event without discussions in 48 (61.5%). Although sixty-six (84.6%) said that children should be told of their HIV status, 12 children (15.4%) however said a child should be spared and not be told of his/her HIV status. Thirty six (46.1%) said the most appropriate age for disclosure should be 12-13years, 24 (30.8%) suggested 8-10 years while 5 (6.4%) suggested 5-7years. (Table 2).

**Table 2: The process of the disclosure**

<b>Child characteristics</b>	<b>No. %</b>
<b>Age at disclosure</b>	
≤ 10	2 (2.6)
11-12	10 (12.8)
13-14	34 (43.6)
15-16	24 (30.8)
17-18	8 (10.2)
<b>How long have you known</b>	
<12 months	42 (53.8)
>12 months	36 (46.2)
<b>Type of disclosure</b>	
Accidental	36 (46.1)
Prepared	30 (38.5)
Involuntary	12 (15.4)

<b>Who did the disclosure?</b>	
Mum alone	30 (38.5)
Dad alone	6 (7.7)
Mum and Dad	6 (7.7)
Doctor (with caregivers consent)	9 (11.5)
Doctor and parent (s)	6 (7.7)
Other relatives (Aunt, uncle, grandparents)	15 (19.2)
Found out by myself (caregiver unaware)	6 (7.7)
<b>How were you told?</b>	
One off event with no discussion	48 (61.5)
More than one sitting and we had discussions	24 (30.8)
Found out by myself (caregiver unaware)	6 (7.7)
<b>Do you think a child should be told of his HIV status?</b>	
Yes	66 (84.6)
No	12 (15.4)
<b>Do you think you should have been told earlier?</b>	
Yes	36(46.2)
No	42(53.8)
<b>Were you satisfied with the information you were given?</b>	
Yes	36(46.2)
No	42(53.8)
<b>Were you satisfied with the way you were told?</b>	
Yes	30 (38.5)
No	48 ( 61.5)
<b>Were you told how not to spread it to other people?</b>	
Yes	18 ( 23.1)
No	60 (76.9)

**How thirty six children inadvertently got to know their status:**

The responses of the thirty six children (who claimed they were aware of their status before they were told) on how they found out are presented in Table 3. Nineteen (52.8%) of the accidental disclosure were by health care workers.

**Table 3: How thirty six children inadvertently got to know their status**

<b>How did you find out</b>	<b>N=36 (%)</b>
Overheard the doctor discussing the test result with my mum in my presence	9 (25)
Overheard the nurse in the clinic telling another patient that the clinic is HIV clinic	8 (22.2)
I found out the name of the drugs and searched for what they are used for	8 (22.2)
Overheard my aunt mention to someone over the phone that I have HIV	3 (8.3)
Overheard my mum while quarrelling with my dad mention that we all have HIV	2 (5.6)
While on admission I overheard the hospital maid telling another patient that I have HIV	2 (5.6)
Found out from reading my case note	2 (5.6)
My cousins whom I stay with told me that their mum (my aunt) told them I have HIV & also told them to stop sharing things with me	1 (2.8)
My maternal aunt living with us told me that I have HIV the day I quarreled with her and that she was just pitying me because I will soon die	1 (2.8)

**Questions they will like to ask:**

Fifty-four (69.2%) said they were not given the opportunity to ask questions while 12 (50%) of the 24 who admitted being given opportunity were not satisfied with the answers they were given. Some of the questions they would have loved to ask are: How did I get it? 62 (79.5%), Will the drug cure me? 53(67.9%), How long will I take the drugs? 44 (56.4%) and Will I die from it? 42(53.8 %) (Table 4)

**Table 4: Questions they will like to ask**

<b>Questions you'll love to ask</b>	<b>No. (%)</b>
How did I get it?	62 (79.5%)
Will the drug cure me?	53 ( 67.9)
How long will I take the drugs?	44 (56.4)



Will I die from it?	42 (53.8)
Will I pass it on to my children?	31 ( 39.7)
Will it be ever eradicated?	15 (19.2 )
Did I do something bad to get it?	10 (12.8 )
Will I be able to further my education and career?	10 (12.8 )
Why am I the only one that has it?	6 (7.7)
Who else has it?	6 (7.7)
Is God punishing me for something bad I have done?	5 (6.4)

### **How did you feel immediately you were told (or found out)?**

The emotional and other psychosocial effects of disclosure were also assessed, since this is one of the reasons often cited by care givers for both disclosure and non-disclosure to children. The commonest immediate reactions were depression 48 (61.5%), sadness 32 (41.0%) and shock 22(28.2%). (Table 5)

**Table 5: How did you feel immediately you were told (or found out)?**

<b>Your immediate reaction when you were told?</b>	<b>No ( % )</b>
Depressed	48 (61.5)
Sad and Cried	32 (41.0)
Shocked	22 (28.2)
Did not believe it	14 (17.9)
Angry	12 (15.4)
No reaction	10 (12.8)
Coping better (a lot of things became clearer)	8 (10.3)
Felt like dying	5 (6.4)

### **How did you feel afterwards/ What are your concerns / worries about being HIV-infected:**

On how they felt after wards after processing the diagnosis, 64 (82.1%) stated that immediate reactions of worry, sadness, shock, confusion and anger had decreased over time as they have come to accept their situation, 11(14.1%) felt stigmatized (treated differently) while 9 (11.5%) still cannot come to terms with taking medications every day.

On whether they felt different because of their status, fifty two (66.7%) children responded that they did not feel that having HIV made them different from other children. Their major concerns about being HIV infected were the fact that they will take drugs for life 60 (76.9%), may not get married 42 (53.8%) and that they may be rejected by friends if they got to know 36 (46.2%) (Table 6)

**Table 6: What are your concerns / worries about being HIV-infected?**

<b>Major concerns about being HIV-infected</b>	<b>No (%)</b>
Taking drugs for life	60 (76.9%)
May not get married	42 (53.8%)
Rejected by friends if they get to know	36 (46.2%)
People knowing their status	33 (42.3)
May die soon from this illness	24 (30.8)
May not have children	18 (23.1)
Life not worth living any more	12 (15.4)
May transmit it to her children	9 (11.5)
Living with chronic illness	6 (7.7)
Some of my friends no longer talking to me	6 (7.7)

**What they did not like about the way they were told?**

Table 7 highlights what they did not like about the way they were told especially telling them that they will die if they do not take their drugs 61 (78.2%) and Table 8 shows their suggestions of making disclosure better.

**Table 7: What they did not like about the way they were told?**

<b>What you did not like about the way you were told</b>	<b>No (%)</b>
I was told I will die if I don't take my drugs	61(78.2%)
Mum just called me and told me I have HIV just like that	24 (30.8%)
I was not told how I got it	15(19.2%)
Instead of discussing with me, the doctor was discussing with mum & ignored me	12(15.4%)
Dad just called me and told me I have HIV just like that	12(15.4%)
I was told lies why I was taking the drugs for a long period	12(15.4%)

Although I have found out, am still waiting to be formally told	6 (7.7)
Overhearing it when my parents were quarrelling	3(3.8%)
Dad told me I will die like my mum if I don't take my drugs	3(3.8%)
I was told publicly by my cousins	3(3.8%)
My aunt said she was pitying me because I will soon die	1(1.3%)

**Table 8: Suggested better ways of telling the children**

<b>Suggested better ways of telling the children</b>	<b>No (%)</b>
Don't tell them they will die if they don't take their drugs	62 (79.5%)
Explain to the child how he got it and don't hide it	60 (76.9%)
Always answer their questions truthfully and not evade the questions	51 (65.4%)
Should first discuss HIV with child, prepare his mind and tell him another day	42 (53.8%)
Draw child closer, make him feel comfortable and happy before disclosing to child	42 (53.8%)
Tell them the truth about why they are taking their drugs	39 (50%)
Encourage them while discussing it with them, give opportunity for questions	36 (46.2%)
Parents should buy them snacks, make them relaxed before telling them	30 (38.5%)
Pray with them before telling them	27 (34.6%)
Tell the child alone, not in presence of others	27 (34.6%)

On how they have coped since disclosure, the majority 48 (61.5%) said they have become more prayerful, 36 (46.2%) reported being closer to parents especially the mum and 18(23.1%) made friends with HIV positive children. All 78(100%) agreed that disclosure has positively impacted on their taking their ARV drugs and clinic attendance and have developed strategies to conceal their status from persons whom they felt should not know about it. Twelve (15.4%) however became more reserved and avoided friends and some discussions with friends while 8 (10.3%) are still bitter with the dad for abandoning them and their mum.

Another aspect which is worrisome is that although 54 (69.2%) said they intend to inform their life partners but 12 (66.7%) out of 18 that are already in a relationship do not know the status of their partners and have not disclosed their status to their partners, the reason being that they may abandon them.

Asked on who else they have told about their status, 48 (61.5%) have told no one else, 18 (23.1%) confided in their pastors while 12 (15.4%) told their siblings. Three (3.8%) said they would have loved to tell their friends (but don't know if the friend will run away from them), 3 (3.8%) will like to tell their grandparents and 3 (3.8%) will like to tell their aunt/uncle but are unsure how they will react. None of the children agreed to tell the school authorities or classmates.

## **DISCUSSION**

Disclosure refers to a state in which an HIV-infected child or an adolescent gains knowledge of his/her HIV status. Such disclosure tends to increase a child's understanding about his/her condition and facilitate active participation in care and treatment. Disclosure process should span through understanding the disease, its progress, its origins, its name, its consequences, and its management. Optimal disclosure is disclosure that is prepared, and not accidental, health-promoting with the child/adolescent made fully aware of his or her own illness and its consequences, age-appropriate, timely, starting as early as possible, family centered, takes place within a supportive and enabling environment and is linked to appropriate support [4,15]. A child is never "not ready" for some level of disclosure even if it means just starting with learning something about their body and health. Any child seeing a doctor often and taking medicine every day knows that something is wrong. It is best to start talking with the child early as honestly as possible, bringing up a little at a time, such as why they are visiting the doctor or taking medicine.

Most of the children will prefer disclosure to be between 12 and 13 years. This was in keeping with findings from another study [16]. Disclosure of HIV status should not be a one-time event when the child is informed that he has HIV without preparation, but rather a process, involving ongoing discussions about the disease as the child or adolescent matures cognitively, socially, emotionally, and sexually. In this study, over 60% of the children said it was a one-off interaction with no opportunity to ask questions. Vaz et al [17] also reported that from the perspective of children in their study, disclosure was largely a discrete event rather than a process. Disclosure can be a traumatic event for many children (especially for those who learnt of it inadvertently in an unsupportive manner) and can be accompanied by feelings of anger, hopelessness and rebellion. Thirty-six (46.2%) children in this study had already learnt of their

HIV status accidentally. It is usually done unintentionally when HIV diagnosis is being discussed among adults and a child or adolescent overhears or when it is used to taunt the child during misunderstandings or when the caregiver becomes frustrated about the non-adherence and as a way of “protecting” the child, blurts out that child has HIV and will die if not adherent to drugs. Accidental disclosure in this study occurred more through healthcare providers and other family members and increased inquisitiveness of the child (a fact that most adults tend to overlook). Children who ask direct questions are ready to hear about their diagnosis and will seek that information elsewhere if the caregivers are not forthcoming in providing it. If children find out their infection status from someone other than a parent, they may feel unable to confide in their parent or feel a need to conceal that they are aware of their diagnosis as was the case in six children in this study. Many children report feeling relieved once they are told their diagnosis, and most express the wish to have been told earlier.

Concerning who should disclose, a lot of children will prefer both parents to disclose to them. This was also in agreement with studies on caregivers and health care providers who also agree that the primary caregivers were the most appropriate individuals to disclose to their children [18, 19, 20]. Most of the children will prefer disclosure by both parents which corroborated with findings by Okawa et al [16].

The commonest immediate emotional impacts of the disclosure were depression, sadness and shock. This was in keeping with the fears of the caregivers in delaying disclosure [21, 22] and findings from other studies [16, 23, 24]. Namukwaya et al [25] observed that disclosure of HIV status to children led to them being terrified, worried, confused, and intensely emotional. However, unlike what the caregivers fear, 82.1% children overcame these immediate feelings and were able to move on with their lives especially as they now understand what they are suffering from and why they need to take medication. This was also the finding by Namukwaya et al [25] who reported that young people did not report prolonged feelings of blame or anger toward their caregivers about their own infection. In a prospective study that evaluated an intervention by Blasini et al [23], they found out that at 6 months post-disclosure, 70% of youth reported normalcy, and only 2.5% still reported depression and would have preferred not to know; all others reported that they were glad to have found out their status. These psychological effects noted in this study may not be unconnected with the accidental and involuntary manner the disclosure was done in majority of the children. Also, knowledge of such life changing

illness may be compounded by other adolescent-specific factors such as increased incidence of depression. Lester et al [26] in their study showed that while parents reported increased anxiety in HIV-infected children following disclosure, the children's own report did not show corresponding increases in anxiety and depression in relation to HIV disclosure. The negative psychological impact of disclosure can be prevented to a great degree with adequate preparation and provision of follow up and support. Even when they do experience some negative reactions upon learning their HIV status, these reactions are immediate and short lived and in the longer term, disclosed children are neither more distressed nor do they display more behavioral problems than children who have not been told their HIV status [17]. Non-disclosure may thus not necessarily protect children from psychological distress. Results from a study among children and adolescents with perinatally acquired HIV infection, showed no statistically significant differences between pre-disclosure and post-disclosure quality of life [27]. This implies that despite initial distress, they had resilience to accept and live with the HIV diagnosis. Evidence from other studies [6, 12, 16, 28] and in this study, shows that informing children about their HIV diagnosis can have positive psychosocial and clinical outcomes like improved adherence to both clinic attendance and antiretroviral drugs, improved relationship with caregivers, decreased psychological effects and acquisition of coping skills. Mburu et al [13] observed that disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. Hejoaka [29] also reported that HIV status disclosure to children helped them to develop strategies to conceal the medicines and the disease.

Caregiver's fears that the children will disclose their status to other people once they know their own status, and that they will, as a result, experience stigma and discrimination [20,30] appears exaggerated from the findings from this study and another study [16]. Majority of the children would rather keep their status to themselves or disclose only to close family members or pastors (mainly for spiritual support). Almost two-thirds of the children responded that they did not feel that having HIV made them different from other children which would also suggest that they do not feel stigmatized or discriminated.

Fifty four (69.2%) said they were not given the opportunity to ask questions and even those that were given the opportunity felt dissatisfied with the answers they were given. This may either be because most of the caregivers may have limited knowledge on the process of disclosure (how,

when and what to tell child) and expertise on how to disclose HIV status to a child[21] or the caregiver is still battling to come to terms with their own HIV-positive status [5]. Culturally also, children are not expected to ask too many questions especially questions related to sexuality. As almost 90% of the children were vertically infected, it was not surprising that the caregivers shied away from one pertinent question the children will love to ask “How did I get it?” Children will usually have a long list of questions, some of which can be answered by the primary caregiver or health care provider and some will have to be figured out by the children themselves as time goes on. Suppressing questions or not allowing the children to voice out their concerns might isolate them and promote poor coping skills. Children and adolescents with adequate support and openness to their questions on the other hand usually learn to cope and adjust, and the manner in which they are given answers, will play a huge role in assisting the child or adolescent to take responsibility for their health, and in providing the emotional and social guidance that is required. A Brazilian study found that prolonged silence, poor adult-child communications, and self-discovery resulted in psychosocial distress, self-stigma and adherence problems among HIV-positive youth [31].

Another reason why the child/adolescent HIV status should be disclosed to them is a sure upcoming onset of sexual activity and the need for sexual and reproductive health education. In this study, 12 (66.7%) out of 18 that are already in a relationship do not know the status of their partners and have not disclosed their status to their partners, the reason being that they may abandon them. A Ugandan study [32] showed that only 49% of the adolescents in a relationship had disclosed to their partners. Respondents in a small qualitative study based on a UK transition program reported not disclosing their status to others, including sexual partners [33]. They expressed their concerns about status disclosure in their romantic/sexual relationships.

This observation that the sexually active adolescent’s knowledge of their HIV status did not necessarily result in safer sex and status disclosure to sexual partner is very worrisome as it has important consequences for HIV sexual prevention efforts and HIV control.

The children’s major concern was the fact that they will be taking pills for life as was also found by another study [16]. This concern should be addressed by both the caregiver and the healthcare provider so that it will not impart adversely on adherence and viral suppression. Opportunities should always be given to children to express their concerns as this will help them gain additional information to address any questions they may have about their illness and health.

Explaining to the child to see the medicine as a normal part of daily routine (just like washing, eating, brushing teeth, or getting ready for bed) can help allay the worries. If the caregiver is also on medication, taking medication at the same time as the child can help the children accept it. Other strategies include simplifying the drug regimen in terms of reducing the pill burden (small pill size, once daily formulation and single-tablet fixed dose combination regimen), improving palatability and the use of behavior modification techniques (like application of positive reinforcements and the use of small incentives for taking medications).

One of the things the children did not like about how they were told was that they will die if they do not take their drugs. Most adolescents are starting to establish their identity, independence, and relation to peers and they feel invincible, thus reminder that they will die and be separated from family and friends especially if they have experienced the death of a family member can be a source of great anxiety, hopelessness and fear. Battling with a stigmatizing illness, taking pills daily and being reminded that they will die can be quite daunting.

The major limitation of the study is that the accuracy of the responses by the child/adolescent may be affected by recall bias because of the time gap between the disclosure event and participation in the survey.

**Conclusion and Recommendation:** Findings from this study has portrayed that status disclosure process is suboptimal. Understanding the disclosure process from the perspective of HIV positive children, therefore, is critical to developing interventions to improve disclosure. It is possible that parents may be overly concerned about possible psychological harm to their child or their child's negative reaction toward them and underestimating the child/adolescent's resilience and ability to handle the disclosed information and accept and live with HIV.

Health care providers should develop a plan with the caregivers of HIV-infected children that will provide information to the caregiver and outline the process of HIV disclosure before the child discovers his or her own diagnosis. Caregivers should be counseled to anticipate and resolve questions the children may have following disclosure. Support should also be provided for adverse outcomes following disclosure.



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