

## **HIV disclosure in children in this millennium – Should it still be an issue?**

### **Abstract:**

**Background:** As more children with HIV survive into adolescence and adulthood, one of the most difficult issues that families with HIV-infected children face is disclosure of their children's status to them.

**Objective:** To explore factors associated with disclosure or none disclosure and whether disclosure is beneficial or not.

**Methods:** The mothers of HIV positive children who brought their children aged 5-18 years to the Paediatric Infectious Disease Clinic of the University of Port Harcourt Teaching Hospital from January to December 2015 were interviewed using a structured investigator administered questionnaire.

**Results:** Of the 100 caregivers interviewed, 26.0% have disclosed the HIV status to the children. The mean age at disclosure was 14.42 ± 2.45 years. Care givers that have disclosed were significantly older (45.58±8.32 years vs 38.18±9.2 years; p = .0002). The mean age of children whose status have been disclosed was significantly higher than those who were yet to be aware of their status (14.42±2.45years vs 10.97±3.11 years; p = 0.00001). There was no significant difference in the mode of transmission and orphan status between the two groups. Disclosure was significantly more among children who were diagnosed between 5-10years of age (14; 53.8%) (p=0.013), have taken antiretroviral drugs for over 24 months (22; 84.6%) (p=0.003) and had at least one HIV-infected sibling (21; 80.8%) (p=0.00001). Among 13 (50.0%) whose status have been disclosed and 59 (79.7%) whose status had not been disclosed, the caregiver had disclosed the child's status to others (p= 0.004). The major reason for disclosing was because the child was either asking questions on why he/she is taking drugs or he/she is refusing to take drugs (15; 57.7%) respectively. Only 6 (23.1%) caregivers disclosed because they felt the child has a right to know. Most difficult question asked by the children during disclosure was how they got the HIV (22; 84.6%). Reasons given for non-disclosure included fear of disclosure to others (74; 100%), child too young to understand (70; 94.5%) and fear of impact on child's emotional health (42; 56.7%). Majority 20 (76.9%) of the care givers felt relieved after disclosure. Twenty-four (92.3%) caregivers felt disclosure had improved child's adherence to antiretroviral therapy and determination to survive (22; 84.6%)

**Conclusion:** Disclosure is beneficial to both the child and caregiver. Healthcare providers should encourage caregivers to disclose HIV status to their children as soon as possible.

**Key words:** HIV disclosure, children, adolescent, benefits, issues

### **Introduction:**

As more children with HIV survive into adolescence and adulthood courtesy of improved access to antiretroviral drugs, one of the most difficult issues that families with HIV-infected children face is disclosure of their children's HIV status to them. In the US, the Centers for Disease Control and Prevention (CDC) reports that young people, aged 13 to 24, accounted for more than one in five of all people newly living with HIV in 2016. [1] Yet nearly half of young people who are infected do not know that they are living with HIV.

Disclosure of an HIV diagnosis to a child is a controversial and emotionally laden issue. One reason frequently cited by caregivers for nondisclosure is the fear that the child is too young to comprehend and might disclose to other people [2] Caregivers also have concerns about the negative emotional effects the disclosure will have on the child as well as the stigma and discrimination the child and family may suffer. [2, 3] Apart from the parents/caregivers responsibility of providing care to their HIV-infected children including ensuring adherence to antiretroviral drugs and coping with HIV-related illnesses, decisions about disclosure to children can pose additional challenges which can increase parental stress and physical exhaustion.

Studies have shown that disclosure could be beneficial for both the caregiver and the child [4, 5, 6] In spite of the benefits of disclosure, caregivers feel uncomfortable to approach the topic. The difficulty may stem from the fact that disclosure of HIV status to the child will mean concomitant disclosure of HIV status of the parent/s (since majority of HIV infection in children is vertically acquired). HIV positive parents thus feel shame or guilt for passing on their "illness" with all its social and medical problems, to their children.

Majority of the studies on disclosure reported a wide variation in the levels of disclosure with a lower proportion in developing countries than in developed countries, [7] and even among those whose status have been disclosed, majority were done in late adolescence [7]

Based on the evidence of health benefit and little evidence of psychological or emotional harm in the disclosure of HIV status to HIV-positive children and the expectation and understanding that initial emotional reactions dissipate with time and may respond to interventions, both the American Academy of Pediatrics Committee on Pediatrics AIDS [8] and the World Health Organisation [9] have recommended that children of school age should be told of their HIV-positive status and that younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure. Adolescents should know their HIV status in order to appreciate the consequences for many aspects of their health, including sexual behavior, and appropriate decisions about their treatment and care. Disclosure should thus be seen as a step in the process of adjusting to an illness and the life challenges it poses.

Few studies have measured the actual impact of disclosure on caregiver's and children's clinical, emotional and psychosocial outcomes. [4] The aim of this study was to determine the prevalence of HIV disclosure and to explore the factors associated with HIV-status disclosure/non disclosure to HIV-infected children aged 5 years to 18 years receiving care at University of Port Harcourt Teaching Hospital, Nigeria, as well as to determine the impact (merits or demerits) of disclosure/non-disclosure on the care givers and the children. This is with the expectation that the findings of this study will facilitate the formulation of relevant counselling strategies to parents/caregivers of HIV-infected children.

## **Methodology:**

This was a cross-sectional study conducted over 12 months from January to December 2015. A structured investigator-administered questionnaire was administered to the caregivers who brought their HIV positive children (aged 5 years to 18 years) to the Paediatric Infectious Disease Clinic at UPTH. The following information was obtained: Biodata of the caregivers and the children, parental HIV status, likely mode of transmission for child, age at disclosure and likely age to disclose the child's HIV status for those who are yet to disclose, reasons for disclosure or nondisclosure and impact of disclosure on child and caregiver. In order to allay respondents' fear of inadvertent disclosure of an infected child's status, the caregivers were interviewed in a private room without their children.

The outcome of interest was prevalence of HIV disclosure/non-disclosure and the impact of disclosure/non-disclosure (positive or negative) on the caregivers and the children. Data was entered in Microsoft Excel and descriptive statistical analysis was performed and results presented based on the disclosure status. Statistical significance was declared at  $p$  value  $<0.05$ . Ethical approval was from the hospital Research and Ethics Committee as well as verbal consent from the caregivers.

## **RESULTS**

A hundred caregivers were interviewed. Of these 26 (26.0 %) have disclosed the HIV status to the children while 74 (74.0%) have not. Majority 64 (64.0%) of the primary caregivers were the biologic mothers of the children and this was significant ( $p=0.012$ ). Seventy five percent of the caregivers were aged between 30 and 49 years with a mean age of  $40.1 \pm 9.56$  years. Majority 91 (91.0%) had at least secondary education.

Among those caregivers that have disclosed, majority were the biologic mothers in 12 (46.1%). The mean age of caregivers who have disclosed was significantly higher than those who are yet to disclose ( $45.58 \pm 8.32$  years vs  $38.18 \pm 9.2$   $p = .0002$ ). There was no significant difference in the educational level or HIV status of the mother between caregivers that have disclosed and those that have not, however disclosure was significantly more among children of fathers with negative or unknown status. (Table 1)

**Table 1: The General characteristics of the caregivers by their disclosure status**

Care giver characteristics	Disclosed No. (%) N=26	Not Disclosed No. (%) N=74	Total No. (%) N=100	Chi square (*Student t-test)	p-value
<b>Primary caregiver</b>				10.85	.01
Biologic mother	12 (46.1)	52 (70.3)	64(64.0)		
Biologic father	6 (23.1)	12 (16.2)	18 (18.0)		
Grand parents	1 (3.8)	6 (8.1)	7 (7.0)		
Aunts/Uncles	7 (27)	4 (5.4)	11 (11.0)		
<b>Age range (years)</b>					
<b>Mean (±SD)</b>	45.58±8.32	38.18±9.2	40.1±9.56	3.595*	.000255
<30	2 (7.7)	9 (12.2)	11 (11.0)		
30-49	16 (61.5)	59 (79.7)	75 (75.0)	13.4372	.00378
≥ 50	8 (30.8)	6 (8.1)	14 (14.0)		
<b>Educational level</b>				2.7156	.257227
Primary	4 (15.4)	5 (6.8)	9 (9.0)		
Secondary	16 (61.5)	42 (56.7)	58 (58.0)		
Tertiary	6 (23.1)	27 (36.5)	33 (33.0)		
<b>HIV status of mothers</b>				0.3812	.536988
Positive	22 (84.6)	66 (89.2)	88 (88.0)		
Negative	4 (15.4)	8 (10.8)	12 (12.0)		
<b>HIV status of fathers</b>				6.8492	.032562
Positive	12 (46.2)	19 (25.7)	31 (31.0)		
Negative/Unknown	14 (53.8)	55 (74.3)	69 (69.0)		

Tables 2 and 3 show the general characteristics and care and treatment of the HIV infected children by their disclosure status. The mean age of the children was  $11.88 \pm 3.3$  years with 73 (73%) of them in the adolescent age group (10-18 years). Fifty-seven (57%) were males, 86 (86%) were vertically infected and 49 (49%) were orphans. Fifty-four (54%) were diagnosed from 5 years of age, 32 (32%) had at least one other infected sibling and almost all 94 (94%) were on ARV.

The mean age of children whose status have been disclosed was significantly higher than those who were yet to be aware of their status ( $14.42 \pm 2.45$  years vs  $10.97 \pm 3.11$  years;  $p = 0.00001$ ). There was no significant difference in the mode of transmission and orphan status between the two groups.

**Table 2: General characteristics of the HIV infected children by their disclosure status**

<b>Child characteristics</b>	<b>Disclosed No. (%) N=26</b>	<b>Not Disclosed No. (%) N=74</b>	<b>Total No. (%) N=100</b>	<b>Chi square (*Student t-test)</b>	<b>p-value</b>
<b>Age range (years)</b>					
<b>Mean (±SD)</b>	14.42±2.45	10.97±3.11	11.88 ±3.3	5.07285*	.00001*
<10	1 (3.8)	26 (35.1)	27 (27.0)	17.645	.000147
10-13	7 (27)	29 (39.2)	36 (36.0)		
14-18	18 (69.2)	19 (25.7)	37 (37.0)		
<b>Gender</b>				0.1426	.705723
Male	14 (53.8)	43 (58.1)	57 (57.0)		
Female	12 (46.2)	31 (41.9)	43 (43.0)		
<b>Education</b>				18.3307	.000105
Primary	4 (15.4)	44 (59.4)	48 (48.0)		
Secondary	16 (61.5)	27 (36.5)	43 (43.0)		
Tertiary	6 (23.1)	3 (4.1)	9 (9.0)		
<b>Mode of transmission</b>				0.7984	.371558
Vertical	21 (80.8)	65 (87.8)	86 (86.0)		
Horizontal	5 (19.2)	9 (12.2)	14 (14.0)		
<b>Orphan Status</b>					
Both parents alive	12 (46.2)	39 (52.7)	51 (51.0)	0.3302	.565545
Father/mother/both dead	14 (53.8)	35 (47.3)	49 (49.0)		

Disclosure was significantly more among children who were diagnosed between 5-10years of age (14; 53.8%) (p=0.013) and who had at least one HIV-infected sibling (21; 80.8%) (p=0.00001) and have taken antiretroviral drugs for over 24 months (22;84.6%) (p= 0.003). Among 13 (50%) whose status have been disclosed and 59 (79.7%) whose status had not been disclosed, the caregiver had disclosed the child's status to others (p= 0.004). Other persons to who the child's status has been disclosed to included pastors 54(54%), uncles/aunts 29 (29%), grandparents 16 (16%) and siblings 13 (13%); reasons being for spiritual 54 (54%) or financial support 40 (40%) and for protective purposes.

**Table 3: Care and treatment**

<b>Care and treatment</b>	<b>Disclosed No. (%)</b>	<b>Not Disclosed No. (%)</b>	<b>Total No. (%)</b>	<b>Chi square</b>	<b>p-value</b>
<b>Age at Diagnosis</b>					
<5years	6 (23.1)	40 (54.0)	46 (46)	8.71	.013
5-10years	14 (53.8)	19 (25.7)	33 (33)		
11-18 years	6 (23.1)	15 (20.3)	21 (21)		
<b>Duration of Diagnosis</b>					
<5 years	10 (38.5)	48 (64.9)	58 (58)	5.5061	.01895
>5years	16 (61.5)	26 (35.1)	42 (42)		
<b>No. of HIV+ sibling</b>					
None/only child	5 (19.2)	63 (85.1)		38.40	.00001
1	15 (57.7)	9 (12.2)	68		
2	5 (19.2)	1 (1.35)	24		
3	1 (3.8)	1 (1.35)	6		
			2		
<b>Duration of ARV</b>					
<24 months	4 (15.3)	36 (48.6)	40	8.87	.003
>24 months	22 (84.6)	38 (51.4)	60		
<b>Status disclosed to others</b>					
Yes	13 (50)	59(79.7)	72	8.44	.004
No	13 (50)	15 (20.3)	28		

For those whose status has been disclosed, the mean age at disclosure was  $14 \pm 1.93$  years with majority 21 (80.8%) being between 13 and 17 years. Among those caregivers who are yet to disclose, the age they intend to disclose the child's HIV status for majority is from 13 years of age (64; 85.1%) with 19 (25.7%) wishing to disclose after the child is 18 years of age. (Table 4)

**Table 4: Age at disclosure (for disclosed) and age intend to disclose (for not disclosed)**

Age range (years)	Age at Disclosure No. (%)	Age intends to Disclose No. (%)
≤ 10	1 (3.8)	6 (8.1)
11-12	4 (15.4)	5 (6.7)
13-14	12 (46.2)	25 (33.8)
15-17	9 (34.6)	19 (25.7)
≥ 18	0 (0)	19 (25.7)

**Table 5: Reasons for disclosure and non-disclosure**

Reasons for Disclosure or Non-Disclosure	No. (%)
<b>Reasons for Disclosure</b>	
Asking why he should be taking drugs	15 (57.7)
Refusing drugs	15 (57.7)
Doctor insisted	10 (38.5)
Started asking several questions about his illness	9 (34.6)
Found out inadvertently	6 (23.1)
Others (Mum died from HIV so he can take drugs)	6 (23.1)
Felt he should know	6 (23.1)
Was admitted, felt it will help him take his drugs	3 (11.5)
<b>Reasons for Non-Disclosure</b>	
Inadvertent disclosure to others	74 (100)
Too young to understand	70 (94.5)
Impact on emotional health	42 (56.7)
Discrimination/stigmatization	36 (48.6)
Negative effect on his will to live	12 (16.2)
Don't know how to start	12 (16.2)
Don't feel he should know	9 (12.1)
Child may think bad of parents	8 (10.8)

The major reason given by caregivers for disclosing was because the child was either asking questions on why he/she is taking drugs or he/she is refusing to take drugs (15; 57.7%) respectively. Only 6 (23.1%) caregivers disclosed because they felt the child has a right to know. For those who are yet to disclose, inadvertent disclosure to others (74; 100%), child too young to

understand (70; 94.5%) and possible adverse impact on emotional health of the child (42; 56.7%) were the main reasons for not disclosing. (Table 5)

The questions the child asked after disclosure which were considered most difficult by the care giver were how they contacted the HIV 22 (84.6%), whether the drugs will cure him 21 (80.8%) and whether he is going to die 21 (80.8%). (Table 6)

**Table 6: Most difficult questions asked by child following disclosure**

<b>Most difficult questions they asked following the disclosure</b>	<b>No. (%)</b>
How did he/she contact it?	22 (84.6)
Will the drugs cure him/her?	21 (80.8)
Is he/she going to die?	21 (80.8)
Does his/her sibling have it	15 (57.7)
Why is it only him/her that have it	12 (46.2)
Why does he/she have the illness	12 (46.2)
Will people run away from him/her	6 (23.1)
None	4 (15.4)

Majority 20 (76.9%) of the care givers felt relieved after disclosure while majority of the caregivers who were yet to disclose felt guilty 49 (66.2%) and afraid 30 (40.5%) (Table 7)

**Table 7: Psychological impact of disclosure or non-disclosure on the caregiver**

<b>Psychological impact of disclosure or non-disclosure</b>	<b>No. (%)</b>
<b>How you felt after disclosure</b>	
Relieved	20 (76.9)
Depressed	4 (15.4)
Guilty	4 (15.4)
Afraid	2 (7.7)
<b>How do you feel not telling him yet</b>	
Guilty	49 (66.2)
Afraid	30 (40.5)
Not happy/depressed	28 (37.8)
Anxious	25 (33.8)
Relieved	13 (17.5)
Nothing	6 (8.1)

Among the children whose status has been disclosed, the caregivers felt there was a positive impact as 24 (92.3%) had excellent/good adherence to ARVs following disclosure while 22 (84.6%) reported that the child was more motivated to take ARVs, was more determined to survive, had improved social interaction and had improved general health. The major negative



impact on the child reported by the care givers were depression (10; 38.5%) and child scared and cried the whole day (9; 34.6%).

**Table 9: Psychological impact of disclosure on the children (as reported by caregivers)**

<b>Psychological impact of disclosure on the children</b>	<b>No. (%)</b>
Excellent/good adherence to ARVs	24(92.3%)
Motivated to take ARVs	22 (84.6)
More determined to survive	22 (84.6)
Improved Social interaction	22 (84.6)
Improved General health	20 (77)
Better self esteem	18 (69.2)
More relaxed	15 (57.7)
Depressed	10 (38.5)
Cried the whole day	9 (34.6)
Scared	9 (34.6)
Hatred	7 (26.9)
Showed no reaction	5 (19.2)
Rebellious	5 (19.2)
Anger	3 (11.5)
Others (coping better)	3 (11.5)

### **Discussion:**

Disclosure of HIV status is an important part of the process of living with HIV, and is crucial to the continuum of HIV care. This study explored the prevalence of disclosure and the factors associated with disclosure or non-disclosure and whether disclosure was beneficial or not. The disclosure rate in this study was 26%. This was similar to the 26% reported by Vreeman et al in Kenya [4], 22.3% by Mumburi et al in Tanzania [10] and 21% by Kallem et al [11] in Ghana but higher than 14% in a study by Arun et al in India. [12] It was however lower than 33.1%, reported by Gyamfi et al [2], 49.4% by Mengesha et al [13], 43.1% by Lester et al [14] and 39.6% by Madiba et al [15] in South Africa.

In a review of articles from Sub-Saharan Africa the prevalence of HIV disclosure ranged from as low as 9% to 72%. [16] The rate of disclosure of HIV status to infected children and adolescents remains generally low in developing countries probably because of cultural norms that children are not permitted to ask many questions. In another review article by Pinzón-Iregui et al, [7] while the overall prevalence of disclosure was 29.5% , it was 20.4% in low-middle income countries and 43.1% in developed countries. In some instances where caregivers have provided

information to the children, some had given partial information without mentioning HIV, while some deliberately provided information that deflected attention from HIV. [5]

The prevalence of disclosure to younger children was much lower than that in older children in this present study (7.7% vs 92.3 %). This was corroborated in the study by Vreeman et al [4] who reported that while 62% of 14-year-olds knew their status, only 21% of 8-year-olds knew. This may be because caregivers feared the psychological implications of disclosing HIV status to children, and worried that young children may not understand and might reveal the diagnosis to others, which could lead to unwarranted family discrimination and that older children are more capable of accepting the diagnosis and keeping it a secret.

The mean age at disclosure was 14 years which was older than in other reports [10, 13, 17] The mean age at disclosure was 10.6 years in a study by Mumburi et al in Tanzania [10]; 8.7 years in a Nigerian study by Brown et al [17] and 11.2 years in Ethiopia [13]

Majority of the caregivers that have disclosed did so either because the child was asking a lot of questions or refusing to take the ARVs. Only few disclosed because they felt the child has a right to know. The questions considered by the caregivers to be most difficult following disclosure was How did he contact it? Will the drugs cure him? Is he going to die? These were considered most difficult because over 85% of the children were vertically infected and disclosure of the child's status automatically discloses the parents' status and that they got HIV from the mum/parent. More so, HIV is still largely incurable.

Inadvertent disclosure to others, too young to understand and impact on emotional health were the commonest reasons given by the care givers for not disclosing and as was also reported by other authors [7,10, 17] Curiously, in almost 80% of those children who are yet to know their status, the caregivers have disclosed to others. This is worrisome as the main reason for nondisclosure to the child was fear of disclosure to other persons.

Several factors especially age and developmental maturity influences the decision to disclose an HIV diagnosis to a child or adolescent. In this study, factors that influenced disclosure were older age of child and a higher education of child. Turissini et al [18] Vreeman et al [4] and Murnane et al [19] reported similarly in their studies that the older the child, the more likely they were to know their status. Madiba [15] reported that 50.85% of their study participants learned of their HIV status between the ages of 11-17 years. Older children were more likely to know their status because of their increasing maturity and independence. It is more difficult to keep secrets from children as they become more inquisitive with age and education. Caregivers also believe that the older child would understand the nature of the diagnosis and the need to keep it secret from others and thus avoid being stigmatized. This may have informed the World Health Organization (WHO) guidelines which recommended that children of school age should be informed of their HIV-positive status while younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure at an older age [9]

The majority of caregivers who are yet to disclose agreed that HIV status should be disclosed to children much later on, from the teenage age (13 years and above) as they believe that at that age, the child is more mature to understand and would not share the information with others and would not suffer negative emotional consequences. This finding was similar to the report from India [12], Ethiopia [20] and South Africa [15] which showed that majority of the caregivers wanted disclosure to take place during the mid-teen age (14-18 years). This decision may have implications for sexual health and other risky behavior in the adolescence.

Having more than one positive child, longer duration of diagnosis and refusing to take antiretroviral drugs also influenced disclosure. This may be related to the caregiver's desire for the child or adolescent to maintain adherence to their treatment regimen and thus stay healthy and significantly less likely to experience disease progression and death.

Other factors that may influence the decision to disclose include: caregivers wanting their child to improve or maintain a certain level of adherence, the caregiver's level of knowledge of HIV disclosure, and the child or adolescent's status on ART [21-23]

Disclosure was more in children who have been on ART for over 24 months. This may be because the child may have started to enquire why he is taking medications or may have started to refuse ARVs which may have forced the caregivers who understand the implications of non-adherence to disclose in an effort to improve drug adherence. This finding was also supported by other studies. [4,24] The child's quest to know why he or she is constantly taking medication or falling sick or going to the clinic was the commonest reason why some caregivers opted to disclose the HIV status to the child.

Disclosure was found to be beneficial to both the caregivers and the children. The major positive impact of disclosure on the children (as reported by caregivers) were better adherence to ARVs, improved motivation to take ARVs as well as more determined to survive, better self esteem and improved social interaction. This was similar to the findings in studies by Gyamfi et al [15] Vreeman et al [4] and Ferris et al [26] who also reported the main benefits of disclosure to include improved medication adherence and healthier, more responsible adolescent sexual behavior.

Other merits of disclosure on the child observed by other workers include better control of their healthcare and medications, better communication, increased opportunities to access adherence support and other forms of psychosocial support from family members and peers as well as develop coping strategies to conceal the medicines and the disease [27,28]

The WHO Disclosure Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (2011) provides strong evidence that disclosure is central to the overall well-being of the child and adolescent. These guidelines confirm the psychological and emotional benefits of disclosure to HIV-positive children and adolescents, dispelling concerns that disclosure may cause harm [Ref 9].

Because disclosure of an HIV status may lead to stigmatization and discrimination, it may have some potential negative effects like depression, sadness, anger, rebellion, parental blame (for vertically infected children), worry and fear of death. [29] The major negative impact on the child reported by the care givers were depression in 38.5% and child scared and cried the whole day in 34.6%. Parents who are distressed perceive more distress in their children than the child may actually be experiencing, thus, children's self-reports about feelings of distress may be more reliable than the caregivers' reports.

The majority of the caregivers who have disclosed felt relieved as there was no longer any need to maintain secrecy and are able to openly discuss the condition with the child or adolescent. It also gave them a feeling of reconciliation or acceptance by the child. Lipson [30] also reported that parents who have disclosed the status to their child experience less depression compared with those who did not. A large number of those who have not disclosed on the other hand felt guilty, were depressed, afraid and anxious that the child may eventually find out the cause of the illness.

**Conclusions:** Despite recommendations by WHO, HIV status disclosure to children is quite low in sub-Saharan Africa especially among the preadolescents. This is as a result of multiple factors such as parents'/caregivers' assertion that the children are young and cannot withstand the psychological impact of diagnosis and fear of the child disclosing status to others, Disclosure impacts positively in terms of improved psychosocial feelings of both caregiver and child as well as improved adherence to medication. Disclosure is a process and is an important step towards long-term disease management and necessary for the transition from pediatric care into adult care settings. It is thus crucial to the continuum of HIV care. While it can be extremely difficult to disclose information about HIV to children, it is better to tell the children as early as possible, especially once they start asking questions.

## **RECOMMENDATION**

Health care providers should actively discuss with caregivers of HIV-infected children how to give age appropriate disclosure as this may enable the parents/caregivers have more skills in handling disclosure to their children. Disclosure strategies addressing caregiver concerns are also urgently needed. All adolescents should know of their HIV status because not only is it their right to know their diagnosis, but it provides them with an opportunity to assume responsibility for their own healthcare and well-being and prevent inadvertent transmission of HIV through risky behaviours.

**Limitation:** The information given by caregivers during disclosure was not stated. Good adherence was not corroborated with viral load/CD4 count. The psychological impact on the child was as reported by the caregiver and may not be a true representative of how the child

actually reacted to the disclosure. In this study, disclosure was based on the subjective reporting of the caregivers and consequently might therefore not reflect the child's perception.

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