



## Health Care Providers Perception and Practice of HIV Disclosure to Sero-Positive Children and Adolescents in a Tertiary Health Facility in Abuja, Nigeria

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### Abstract:

**Background:** Ideally, disclosure of HIV status to infected children and adolescents should involve both health care workers and parents/caregivers. Most studies on disclosure in children have focus mainly on parents/caregivers with little information on health care workers. We conduct this study to evaluate the practice, perception of the healthcare workers in our health facility on disclosure to infected children and adolescents. It is envisaged that such information will help in the design of better strategies on disclosure in our environment.

**Methods:** A cross sectional hospital based study was conducted among health care workers at the special treatment clinic, and heart to heart unit of the University of Abuja Teaching Hospital, Gwagwalada from January to March 2017 for the above objective. A structured questionnaire was used to collect information on disclosure among the healthcare workers, which include among others: their bio-data, knowledge, perception, and practice on disclosure in the two service areas of the hospital.

**Results:** Of the 80 health care workers interviewed, 60(75.0%) were females, 11(13.8%) were doctors, 9(11.3%) nurses, 17(21.3%) monitoring/evaluation/record clerks, and 16(20.0%) were either voluntary counseling and testing counselors or adherence counselors. Their mean age and duration in service in the two areas were 39.70±7.10 and 7.93±4.99 years respectively. Over half 48(60.0%) of the health care workers were unaware of the hospital having guideline on disclosure, 64(80.0%) have not been trained, and 68(85.0%) does not know any key information on disclosure. While all 80(100%) felt that disclosure was a good practice for better adherence, only 16(20.0%) had actually disclosed, with 6(37.5%) not seeking any formal permission from parent/caregivers before disclosing. Ages 8-16 years was recommended by 60(75%) as the appropriate age to disclose, however 28(35.0%) recommended age 14-16 years. Over half of the respondents 58(72.5%) admitted that disclosure should be a shared responsibility between themselves and the caregivers, most however perceive their role as only preparing the parents/caregivers for disclosure, and providing ongoing counseling to both the parents/caregivers and the children and adolescents. Lack of training on disclosure, and none availability of guideline in the health institution were major setback on the ability of the healthcare providers to fully participate in disclosure process.

**Conclusion:** While healthcare providers support the idea of disclosing at mid and late adolescent, their perceived role was that of support and provision of ongoing counseling. Lack of training and none availability of disclosure guideline affects their perceived role. There is need to train and retrain healthcare workers on disclosure guideline, and making such guideline available in the health facilities.

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## Introduction

With successful use of antiretroviral therapy (ART), infected children are now surviving into adolescents and adulthood. Disclosure of human immunodeficiency virus (HIV) sero-status to them becomes a very crucial issue to address. It has remained one of the greatest psychosocial and emotional challenges facing parents/ caregivers and healthcare workers (HCW) of these children. Disclosure is a controversial and emotionally charged issue amongst both the HCWs and parents/caregivers.<sup>1</sup> It involves disclosing to the child about a potentially life threatening, stigmatized and transmissible illness that many parents/caregivers fear that such information may create psychological and emotional distress for the child.<sup>2</sup> HCWs are often challenged by the complicated issues facing HIV-affected families. They are faced without support of definitive evidence-based policies and guidelines on when, how, where, and under what condition(s) infected children should be informed about their own or their caregivers' HIV status.<sup>3</sup> Consequently, many HCWs around the world are uncertain how to counsel clients about the disclosure process. This lack of disclosure ultimately and adversely affects the well-being of the child, including access to paediatric HIV treatment care and support and adherence to ART.<sup>3</sup>

Increase adherence to treatment with reduced risk of death is one of the major health benefits of disclosure. Other benefits include: higher self-esteem, fewer symptoms of depression, higher CD4, better ability to seek for social support, improved coping skills, and practice of safer sex to prevent secondary transmission.<sup>4-9</sup> There is little evidence of psychological or emotional harm; however stigmatization remains a major barrier, and often delays the decision to

disclosure.<sup>10,11</sup> As a result of this, significant numbers of children and adolescents in most developing nations of the world on ART are not fully informed about their HIV status.<sup>10,11</sup> The American Academy of Pediatrics (AAP) recommended counselling to the caregivers to be provided by healthcare providers, it should be on-going process, individualized putting into consideration the child's cognitive ability, and developmental stage.<sup>5</sup> Its recommendation also insisted that adolescents should know their HIV status, and be fully informed in order to appreciate the consequences of their health including sexual behaviours and issues around their treatment.<sup>5</sup> However, in many developing countries, HCWs still lack the support of policies and guidelines on when and how to start counseling of parents/caregivers of infected children about their HIV status or their caregivers' HIV status.<sup>2,12-16</sup> Guideline was developed by the WHO<sup>2</sup> for assisting HCWs to support caregivers on disclosure in resource-limited settings, however such valuable information are usually not available in many health care facilities in such areas. Nigerian national guidelines on paediatric HIV and AIDs treatment also recommends early commencement of disclosure and to be done overtime,<sup>17</sup> such practice is also not routinely done. HIV disclosure rate in high prevalence regions need to be evaluated and improved upon drastically in order to reduce the risk of acquiring new infections, improve adherence to ARTs, and practice of safe sexual behaviors.<sup>8,9,10,18</sup> Unfortunately, limited body of work exists on the prevalence and practice of disclosure by HCWs in sub-Saharan Africa (SSA).<sup>15</sup> Most studies on disclosure have focused on parents/caregiver with little information on HCWs. HCWs in the sub-region are either not trained or unaware of existent of guideline in their various health facilities. The aim of this study is therefore to determine the HCWs knowledge,

perception, and practice on disclosure to infected children adolescents in our health facility. Such information as envisaged will be relevant in the development of culture sensitive counseling strategies to improve our disclosure rate.

## Methods

The study was cross sectional hospital based study conducted in the two service areas where HIV infected/exposed children and adults are tested, treated, monitored/evaluated, and followed up (special treatment clinic, and heart to heart unit) of the university of Abuja teaching hospital (UATH) from January to March 2017. Special treatment clinic (STC) is an out-patient clinical service area where HIV infected/exposed children (paediatric special treatment clinic) and adults (adult special treatment clinic) were followed up for treatment, care and monitoring. Heart to heart unit (HTHU) is an arm of STC, and a unit of the mental health department of the hospital for voluntary counseling and testing (VCT). STC has many consulting rooms for the doctors, nurses, adherence counselors. Record clerks, pharmacists, home based care, laboratory technicians, treatment support specialists, nutritionists, monitoring and evaluation unit, cleaners and other services (security, gardeners) were also at their disposal on week days (Monday-Friday, from 7.30 am to 4 pm). HTHU has voluntary counseling counselors, psychologists, laboratory scientist, volunteers, and other supporting staff also at their disposal on week days and same time. UATH is a 350 bed capacity referral hospital, sub-serving the people of Federal Capital Territory (FCT) Abuja and five neighbouring states. Is one of the first centers to start offering free HIV/AIDS services in the country, through the President Emergency Plan for AIDs Relief (PEPFAR) since 2005 and Federal Government of Nigeria (FGN).

The subjects were HCWs providing clinical, non-clinical, and counseling services to HIV infected/exposed children and adults at the STC and HTHU of the hospital. Inclusion criteria are clinical and non-clinical staff working at the STC and HHTU of the hospital who accepted to be interviewed. Excluded from the study were those health workers unwilling to participate in the study. A structured questionnaire was used to collect the following information from the HCWs which included:

the type of services provided in the clinic/unit, the duration of such services, their sex, age, knowledge about disclosure guideline in the facility, their perception about disclosure, appropriate age to commence disclosure, how many parents/caregivers they have assisted with disclosure, the ideal age for disclosure, who else to be disclosed to, whether they have received training on disclosure counseling, and the availability of disclosure guidelines in the health facility.

Ethics clearance was obtained from the Ethics Committee of the health institution before the commencement of the study. Data analysis was conducted using SPSS version 21.0 that produced frequencies, percentages, means, and standard deviations.

## Results

There were 20 (25%) males, and 60 (75%) females HCWs giving a m:f ratio of 1:3 in STC and HTHU. Their mean age, and duration of service in the two service areas were  $39.70 \pm 7.10$  and  $7.93 \pm 4.99$  years respectively. Monitoring/evaluation and record clerks constitute 17(21.3%) of the work force, VCT & adherence counselors were 16(20.0%), while doctors (13.8%), nurses (11.3%), and pharmacists (6.3%) were the other staff. 40(55.0%) of the working staff were in the adult section of the clinic, 15(35.0%) were in the paediatric section, while 8(10.0%) were working in HHTU (Table 1).

With respect to whether the hospital has a guideline on HIV disclosure, 48 (60.0%) of the HCWs were not aware of any hospital guideline. On the issue of training on the guideline, it was found that 64(80.0%) has received no training, and 68(85.0%) do not know any key information on disclosure. On the ideal age for disclosure, 75% of the respondents suggested ages 8-16 years, while 28(35.0%) recommended 14-16 years. On the best way to disclosure, 60(75.0%) of the HCWs suggested that disclosure should be complete but a gradual process. Though all the HCWs 80(100%) agreed that it is good to disclosure to children and adolescents of their HIV status, 48(60%) said so for better adherence to medication, 14(7.5%) respectively said for the child to be taken his/her drugs, and for protecting him/herself (Table 2).

Table 1. Characteristics of the Health Workers (n=80)

Variables	Mean ±SD	Total (%)
<b>Age (years)</b>	39.70±7.10	-
<b>Duration of working in STC and HTHU</b>	7.93±4.99	-
<b>Sex</b>	-	
Male	-	20 (25.0)
Female	-	60 (75.0)
<b>Carder of staff</b>	-	
Doctors	-	11(13.8)
Nurses & community health extension workers	-	9(11.3)
Pharmacists	-	5(6.3)
Administrative & account clerk	-	4(5.0)
Volunteers/networking staff	-	6(7.5)
Monitoring/evaluation, record clerks	-	17(21.3)
Home based staff	-	7(8.8)
VCT & adherence counselors	-	16(20.0)
Laboratory scientists & technicians	-	4(5.0)
Treatment support specialists	-	5(6.3)
Nutritionists	-	4(5.0)
Cleaners & security staff	-	5(6.3)
<b>Place of work</b>		
ASTC	-	40(55.0)
PSTC	-	15(35.0)
HTHU		8(10.0)

*ASTC: Adult special treatment clinic, PSTC: Paediatric special treatment clinic, HTHU: Heart to heart unit, VCT: Voluntary counseling and testing*

Table 2. Health Workers Knowledge about Disclosure to HIV Infected Children and Adolescents

Variables	Total (%)
<b>Does the hospital have a guideline on disclosure of HIV to children?</b>	
Yes	32(40.0)
No	16(20.0)
I don't know	32(40.0)
<b>Have you been trained on disclosure guideline?</b>	
Yes	16(20.0)
No	64(80.0)
<b>What is the key information on the guideline?</b>	
I don't know	68(85.0)
Supportive role of health workers	8(10.0)
Child to be ready for medication	2(2.5)
Parents/caregiver need to give consent for disclosure	2(2.5)
<b>Should the child be told about his/her HIV Status?</b>	
Yes	76(95.0)
No	4(5.0)
<b>At what age should the child be told about his/her HIV status?</b>	
5-7 years	0(0.0)
8-10 years	14(17.5)
11-13 years	22(27.5)
14-16 years	28(35.0)
17- >18 years	16(20.0)
<b>What is the better way for disclosure?</b>	
Complete at once	6(7.5)
Complete gradual	60(75.0)
Partial	14(17.5)
<b>Is it important to disclose?</b>	
Yes	80(100.0)
No	0(0.0)
<b>Why is important to disclose?</b>	
To protect him/herself	14(17.5)
For better adherence	48(60.0)
For the child to take his/her drugs	14(17.5)
To avoid spreading the disease	4(5.0)
<b>Have you disclosed or supported parents/ caregiver to disclose?</b>	
Yes	16(20.0)
No	64(80.0)
<b>Did you obtain permission before the disclosure? (n-16)</b>	
Yes	10(62.5)
No	6(37.5)

This table reveals the following: Of the 80 HCWs interviewed on the timing of disclosure, 68 (85.0%) suggested when the child is mature enough to understand the implications of his/her status, 10(12.5%) during teenage and puberty, the remaining 2(2.5%) did not specify any time. On the HCWs perceptions about telling the children and adolescents about their HIV status, the most common cited reasons were: For the child to be taken his/her drugs 32(40.0%), the child to be responsible for their medications 18(22.5%), and for them to live a healthier life 12(15.0%). With regard to who should disclose the HIV status to infected children and adolescents, 58(72.5%) of HCWs were of the opinion that disclosure should be shared responsibility between them and parents/caregivers, 18(22.5%) advocated disclosure by only parents/caregivers, while 4 (5.0%) favored disclosure to be done by only the HCWs. The reasons cited by the 18 HCWs who suggested that parents/caregivers should take the lead on disclosure include: Because the parents/caregivers know the right age and time to disclose the child 8(44.4%), the child trusts them better than the HCWs 4(22.2%), while 3 (16.7%) said the parents/caregivers can cope with the child emotional support after disclosure. On the contrary, the 4 HCWs who suggested that is better for them to take the lead in disclosure said so because they the HCWs are more skillfulness 2(50.0%), they can also provide ongoing counseling 2(25.0%). From the HCWs perspective on why parents/caregivers delay telling their children and adolescents about their HIV status, the most cited reason(s) were: stigma 32(40.0%), afraid the child will tell others 28(17.5%), fear of hurting the child 8(10%). When the HCWs were asked to identify their roles in disclosing to HIV status to infected children, the most mentioned roles was supporting parents/caregivers to disclose 32(40.0%), providing ongoing counseling to caregivers for manage disclosure 17(21.3%), providing health education for the children to take care of themselves 15(18.8%), and provide information about the importance of disclosure to assist caregivers 10 (12.5%). On what type of support is needed by HCWs to facilitate disclosure to infected children/adolescents, 36 (40.0%) said they needed workshops and training on disclosure, 24 (30.0%) requires in service education and training on disclosure, 14(17.5%) mentioned provision

of guideline on disclosure (Table 3) .

## Discussion

In this study, it was the opinion of all the HCWs that all positive children and adolescent should be informed of their status. Majority however taught that such information should be done when the child is mature enough to understand the implication of him/her knowing his/her status. The WHO guidelines on disclosure of HIV status to positive children recommends school age period.<sup>2</sup> At this school age, children should be told of their HIV-positive status, and the younger ones informed in stepwise manner taken into consideration their cognitive development and emotional maturity. This was to be in preparation for full disclosure at a latter age. Sariah et al<sup>15</sup> in their experiences with disclosure of HIV-positive status to the infected children from the perspectives of HCWs in Tanzania pointed out that disclosure can be a very complex and confusing process to HCWs, but however noted that their national guideline recommended disclosure process to begin as early as 4–6 years of age. In another disclosure study from South Africa by Madiba and Mokgatle,<sup>16</sup> the authors noted that over half of their HCWs suggested an older age (above 10 years, range 11–18 years). This findings appeared similar to what was obtained in the present study were 8-16 years was suggested by 75% of HCWs as ideal age to disclose HIV status to infected children and adolescents. The South African study believe that at the age above 10 years most children will be mature enough, or they may become sexually active and risk reinfection with a different strain of the virus. Similar reason was also given in the present study were the HCWs equally believe that at older age (8-16years) children will be mature enough to understand the implication(s) of being HIV positive, and may also have started indulging in sexual activities with risk of not only infecting others but also reinfecting themselves with resistance strain of the virus. This current trend of disclosing to infected children at a relatively older age of 12 years and above compared to earlier suggested 6 years appeared more culturally accepted in South Africa, and other resource limited settings.<sup>14,16</sup> Data from this study and from others underprivileged communities suggest age of disclosure to be a subjective process to be influenced by community taking into consideration

Table 3. Content analysis of the responses to disclosure of HIV status of infected children and adolescents by health workers.

<b>Variables</b>	<b>Total (%)</b>
<b>What is the right time to disclose?</b>	
At teenage age	4(5.0)
At puberty	6(7.5)
When the child will understand	46(57.5)
When the child is mature enough	22(27.5)
All of the above?	2(2.5)
<b>What is health workers perception about telling HIV status to infected children</b>	
For the child to take his/her drugs	32(40.0)
So that they will be responsible for their medications	18(22.5)
For them to understand the disease	6(7.5)
To know why they are taking medication regularly	10(12.5)
So that they can live a healthy life	12(15.0)
They have the right to know	2(2.5)
<b>Who should inform the child about his/her status?</b>	
Parents/caregivers	18(22.5)
Health workers	4(5.0)
Both	58(72.5)
<b>Why should parents/caregivers take the lead in disclosure? (18)</b>	
Parents/caregivers are close to the child	2(11.1)
Child trusts them	4(22.2)
Parents/caregivers knows the right age and time to disclose	8(44.4)
They are always there to help and support the child	1(5.6)
They can cope with the emotional support for the child	3(16.7)
<b>Why should health workers take the lead in the disclosure?(4)</b>	
Because they are more qualified and more skillful	2(50.0)
They will provide ongoing support	1(25.0)
They will provide ongoing counseling	1(25.0)
<b>What is health workers understanding why parents/caregivers delay disclosure?</b>	
Fear of hurting the child	8(10.0)
Child not yet of age	4(5.0)
Afraid of stigma	32(40.0)
Afraid of parental guilt	4(5.0)
Parents/caregivers don't know how to start	0(0.0)
Afraid child will tell others	28(17.5)
Other reasons	8(10.0)

<b>What is the role of parents/caregivers in disclosure?</b>	
Support the child	20(25.0)
Provide health education for the child	2(2.5)
Provide ongoing counseling	12(15.0)
Ensures after disclosure child understands HIV and treatment	2(2.5)
Provide ART and ensures child adheres to their drugs	18(22.5)
Provides information about importance of disclosure	2(2.5)
Facilitates initiation of disclosure	14(17.5)
Prepares the child for disclosure	4(5.0)
Assist health workers to disclosure	6(7.5)
<b>What is the role of health workers in disclosing to HIV-infected children</b>	
Support the caregiver through the disclosure process	32(40.0)
Provide health education to children to take care of themselves	15(18.8)
Provide ongoing counseling to caregivers to manage disclosure	17(21.3)
Provide information about the importance of disclosure to assist caregivers	10(12.5)
Monitor the reaction of the child after disclosure	2(2.5)
Encourage and assist parents/caregivers to disclose	4(5.0)
<b>What support is needed by the health workers to facilitate disclosure to a child?</b>	
In service education and training on disclosure	24(30.0)
Workshops and training on disclosure	36(45.0)
Provision of guideline on disclosure	14(17.5)
Counseling to be able to deal with HIV infected children	6(7.5)

the social contexts of disclosure of which HIV-related stigma, discrimination, secrecy, and fear of death plays a very crucial role.<sup>3,8,19</sup>

Lack of training on disclosure and non-availability of the guideline in our health institution contributed substantially to the lack of knowledge and less involvement of HCWs on disclosure in this study. This was reflected in the data obtained where 48 (60.0%) of the HCW said either the hospital does not have a guideline or they are not aware of any guideline in the health institution. In addition, over 85.0% of them do not know any key information on disclosure. According to WHO,<sup>2</sup> essential elements to be added in the training for HCWs in paediatric HIV disclosure should include: the use of culturally appropriate and available resources, use of appropriate communication skills for children of different ages, providing

information on HIV treatment and care to parents/caregivers/children, preparing parents/caregivers for both short and long-term emotional reactions of the children following disclosure, developing a plan for the child/parent/caregiver to disclose to others, preparing parents/caregivers to answer questions that will arise over time after disclosure, choose staff member(s) or others with whom to discuss the issues, prepare parents/caregivers to engage in life-planning with children, and reduction of stigma. Rujumba et al<sup>12</sup> in their situational analysis of pediatric HIV/AIDS care in Ethiopia noted that HCWs are still constrained by inadequate knowledge about pediatric HIV care and pediatric counselling. Fair and Walker<sup>13</sup> also argued that fully understanding of disclosure to HIV-infection in children was essential for HCWs involvement in the disclosure process. One of the major concerns of HCWs in many studies from resource limited settings was the



lack of formal guidelines and training on child counseling to guide on how to support caregivers to disclose to children.<sup>12-16,20</sup> The recently published WHO disclosure guidelines for children have not yet been adopted and utilized by HCWs in many health facilities across sub-Saharan countries. HCWs in these areas are hardly ever trained in pediatric HIV and in disclosure counselling to children, and hence lacked skills to assist caregivers to disclose.<sup>12-16,20</sup> Training workshops on childhood disclosure will not only improve HCWs skills and knowledge on disclosure, but will also increase their confidence in assisting parents/caregivers to disclose as well as support infected children to understand the disease.<sup>1,7, 12, 20</sup>

Over 70.0% of HCWs in this study were of the opinion that disclosure to positive children should be a shared responsibility of the both HCWs and parents/caregivers, because parents/ caregivers need the assistance of HCWs to disclose to their children as they see disclosure as difficult task for them to do alone. However, 18(22.5%) argued that parents/caregiver should take the lead in the process of disclosure because the children trusts the them better, and they know the right age and time to disclose. Only 4(5%) were of the opinion that HCWs should take the lead in disclosure in this study. All these findings in the present study appeared closely similar to what Madiba and Mokgatlé<sup>16</sup> observed in their study where 87(42.7%) of their HCWs were of the opinion that disclosure should be a shared responsibility, 99(48.5%) argued that only the parents/caregivers should lead in the disclose process, while 18(8.8%) said is the responsibility of HCWs to lead and initiate disclosure. Other studies,<sup>7,14,16, 21,22</sup> however viewed telling the children about their status as the responsibility of the parents/caregivers, because of the reasons: their close relationship with child, they are better placed to monitor the child's reaction to the disclosure, the child trusts them better, they knows the right age to disclose, they will support the child to adhere to the prescribed treatment plan, they will support the child to cope with disclosure, and child will be comforted by them. Few<sup>14,23</sup> however were the opinion that disclosure should be responsibility of HCWs alone because HCWs are better skilled to prepare the children psychologically before disclosure, and are in position to deal with negative

reactions from disclosure.

HCWs see their role in disclosure as supportive to parents/caregivers, providing health education to children, and provide ongoing counseling to parents/caregivers to manage disclosure in this study. This is in keeping with current findings from a study in Kenya,<sup>17</sup> in South Africa,<sup>12</sup> and Zimbabwe<sup>19</sup> were HCWs documented similar supportive role, ongoing counseling, and health education as their major role. The main reasons for delay disclosure by parents/caregiver from HCWs perspective in this study were fear of stigma (40.0%), fear of telling others (17.5%), and fear of hurting the child (10.0%). Similar barriers to disclose by parents/caregivers as reported by HCWs include: parents' fear of being blamed by their children, parents feeling guilty and fear that the child will tell others,<sup>24,25</sup> child being too young and cannot keep secret,<sup>20</sup> and social stigma surrounding the HIV diagnosis.<sup>25</sup> Other studies<sup>3,14,20,26,27</sup> however reported different reasons which include: fear of the child crying, fear of being very sad, fear of the child run away, and fear of him or herself losing hope. Some parents/guardians resorted to deception as a way of coping with questions from their children until they deems they are ready.<sup>28</sup>

## Conclusion

Healthcare workers support disclosure of HIV sero-status to infected children and adolescents at mid and late adolescent. They perceive their role as mainly supportive and provision of ongoing counseling to parents/caregivers/children. However lack of training and none availability of disclosure guideline in the health facility hinders these perceived roles, hence training and provision of guideline tailored toward culture-sensitive approach will be a better approach.

## Conflict of interest

None

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