# ORIGINAL ARTICLE PRACTICES, PERSPECTIVES AND BARRIERS OF HIV DISCLOSURE TO CHIL-DREN AND ADOLESCENTS BY HEALTH CARE PROVIDERS; IN ADDIS ABABA HEALTH FACILITIES, ETHIOPIA

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#### ABSTRACT

Survival of prenatally infected children into adolescence and beyond made disclosure a major challenge for caregivers, and healthcare professionals providing service to HIV-infected children. There are significant numbers of children and adolescents who are receiving treatment without being fully informed about their HIV status. This is because many health care workers fear that disclosure may create distress for the child.

**Objectives:** To assess the practices, perspectives, and barriers of pediatric HIV disclosure among health care professional in Addis Ababa health facilities, Ethiopia

**Methodology**: Quantitative cross-sectional study design was conducted at health facilities taking care of pediatric HIV patients in Addis Ababa from 1st June to 30th of July 2017. A structured and pretested questionnaire was used to assess 138 HCWs during the study period. Data was collected by trained nurses. The collected data was analyzed using SPSS version 20. The results were presented with percentages, frequency tables, and figures. Bivariate analysis was done to test the association between pediatric HIV status disclosure by HCPs and different factors of the health care workers. Multivariable logistic regression was used to identify the independent predictors of disclosure to children by HCPs.

**Result**: A total of 138 HCPs included in the study the majority 96(69.6%) were females. Nurses account more than half of the participants 75 (54.3%). Though most HCPs 134(97.1%) believed children will benefit if they are disclosed, more than one third (36.2%) of them have not ever disclosed to a child. Training on pediatric HIV disclosure [AOR=6.264; 95%CI: 1.978-19.841, p-value =0.001] and availability of guidelines for disclosure [AOR =8.350; 95%CI: 1.737-40.126, p-value =0.001] independently increased the odds of HIV positive status disclosure to children by HCPs.

**Conclusion:** Unavailability of guidelines in some of the Health facilities, and lack of training on pediatric HIV disclosure for HCPs have been found to be constraints for disclosure. Improved training and the availability of guidelines on pediatric HIV disclosure would alleviate the discrepancies that exist among healthcare providers on disclosure of HIV status to children.

Keywords: HIV, Disclosure, Guidelines, Health professionals

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#### Background

HIV/AIDS is still a major public health problem globally. In 2018, there were about 770,000 HIV/AIDS deaths, 1.7 million new HIV infections and a total of 37.9 million people were living with HIV infection (1) According to the report by the World Health Organization (WHO) in 2018; In sub-Saharan Africa, 25.6 million people were living with HIV; among them 1.8 million are children<sup>-</sup> (2) According to the Ethiopian public health institute projection by 2019 in Ethiopia, an estimated 669,236 people were living with the virus; of which 44,229 were children up to the age of 14 years (3)

Several reports showed that there is an increased number of survivals of perinatally infected children into adolescence and beyond. This is due to the availability of antiretroviral drugs and relatively better health care (4-5) As a result, disclosure of the HIV status to the children/adolescent becomes a challenge both for the caretakers and health professionals (6-10)

Despite availability of American Academy of Pediatrics (AAP) guidelines since 1999 and WHO guideline in 2011(11 12) disclosure rate in sub-Saharan countries reported rates varied from 11 to 38% (13-17) Both health professionals and parents/caregivers of children and adolescents showed hesitance to disclose the HIV/AIDS status to the children. Fear of HIV stigma, uncertainty about cognitive development of children, local traditions that limit discussion of sexuality, keep family secrets outside the home, lack of emotionally readiness of care takers to disclose, and willingness of healthcare workers to lead the disclosure were the major reason why they are not disclosing the HIV status to their children. <sup>(6,8,10,13-20)</sup>

Although studies regarding health care professionals (HCP) in respect to disclosure of HIV/AIDS status were few, the available reports showed that majority of HCP believe in the benefit of disclosure but most of them did not want to take the lead for disclosing the positive sero- status to the children and adolescent. Facing the negative emotional reactions from children, parental refusal to disclose to the child, and lack of paediatric HIV disclosure training were mentioned as reasons for not disclosing the HIV positive status to them. (21-25)

In Ethiopia, many studies conducted on disclosure to HIV-infected children have focused on the experiences of caregivers. (15,16,17). The perspectives and practices of health care providers (HCPs) regarding pediatric HIV disclosure have not been adequately investigated. Therefore, this study was conducted to assess the HCP perspectives and associated factors on HIV sero-status disclosure to children living with the virus in Addis Ababa, Ethiopia.

#### Methodology

## Study Design and Period

A quantitative cross sectional study design was conducted from 1st of June to 30 th of July 2017.

#### **Study Area**

The study was conducted at ART clinics in seven public Hospitals (three teaching and four referral hospitals) and 30 health centers in Addis Ababa, Ethiopia. These health facilities were the major referral centers for HIV care in Addis Ababa, Ethiopia.

# Source and study Population

All HCPs taking care of pediatric HIV patients in public health institutions in Addis Ababa, Ethiopia

#### **Study population**

All HCPs taking care of pediatric HIV patients in the selected public health institutions in Addis Ababa, Ethiopia.

**Inclusion Criteria**: HCPs taking care of pediatric HIV patients in the selected government health institutions and willing to participate were included.

**Exclusion criteria**: HCPs who were on leave at the time of data collection

#### **Sample Size Determination**

The sample size was estimated based on an assumption that proportion of HCPs disclosing children with HIV is 50% (P) because we don't know the proportion, taking 5% margin of error and 95% confidence level of certainty, the actual sample size for the study was determined using single population proportion formula

 $n = Z^2 1 - \alpha/2 (P)(P-1)/d2 = 384$ 

Assumptions Z=1.96, p=50 %( because we

don't know the proportion), w=0.05. The estimated sample size based on the above assumption is 384. Since the source population is less than 10000, population correction formula is applied.

#### na = nr/1 + (nr-1)/n

Where na = the adjusted sample size, nr = the original required sample size (384) and N = total population (200). This reduces the sample size required to 131. By taking additional 5% contingency for non-response rate, the total sample size calculated was 131+5 % \*131=131+7=138

#### **Sampling procedure**

There were ninety health centers in the city; out of which only thirty-nine were delivering services to HIV infected children. Among them, thirty health centers were randomly selected and included in the study. There were only seven hospitals providing health care and ART to HIV infected children in the city, and all of them were included in the study. After selecting the health institutions based on the above criteria, all HCPs who were giving care to HIV infected children in the selected health facilities at the time of data collection were included in the study. Allocation of the final sample size to health centers and hospitals was made based on their proportion of HCPs, and lottery method was used to identify the final study participants (Figure One)



Figure 1. Schematic Sampling Procedure

#### Data collection tools and procedures

Data were collected using structured and standardized questionnaires by trained Nurses supervised by the principal investigator. The questionnaires were adapted from different studies considering the local situation of the study area <sup>(21-25)</sup>.

## Data processing and analysis

Data were initially cleaned, entered and analyzed using SPSS version 20. Descriptive statistics was used to dependent and independent variables. Bivariate and multivariate analysis were also used to check for association between dependent and independent variables. A 95% confidence interval, Odds ratio and P value were also used to check for association between dependent and independent variables. P value less than 0.05 was considered as statistically significant. Frequency table and association table were used to present the summarized data.

Ethical Consideration: Research approved by the Pediatrics department research and publication committee and Institutional Review Board of the college of health sciences, Addis Ababa University. An authorization to conduct the study was obtained from Addis Ababa health bureau. Written consent was taken and confidentiality of the participants was kept during the study.

#### Results

#### Socio demographic characteristics

Out of 138 HCPs included in the study the majority were females, 96(69.6%). Nurses account for more than half of the study participants, 75(54.3%). More than half of them

76 (55.1%) had service experience of 5 to 10 years. Most of the study participants were working in health centers, 80 (57.9%). (Table 1)

Table 1. Socio der	nographic charact	eristics of health	care providers in A	Addis Ababa,	Ethiopia,
October, 2	2017. (N=138)				

Variable	Category	Frequency	Percentage
Age (in years)	21 – 29	81	58.7
	30 - 58	57	41.3
Sex	Female	96	69.6
	Male	42	30.4
Professional qualification	Nurse	75	54.3
	Health officer	48	34.8
	General practitioner	12	8.7
	Resident	3	2.2
Work place	Hospital	58	42.1
	Health center	80	57.9

# Healthcare providers' attitude and practice about pediatric HIV disclosure

Most of HCPs ,134 (97.1%), believed that children will benefit if they are disclosed and 65.7% have disclosed a child at least once as compared to none from those who said disclosure is not important [OR = 2.913; 95% CI: 2.306-3.682; p value: 0.016]. The benefits of disclosure stated were: to protect others from being infected (adolescents), for children to understand the disease (HIV), it is their right and for medication adherence. Among the participants, 37% of them think disclosure is not timely in their set up. The barriers for untimely disclosure were: lack of training on disclosure, lack of guidelines on disclosure, lack of parents'/caregivers' readiness and parental refusal.

Almost all HCPs (99.3%) believe parents/ caregivers require help from HCPs in disclosing to their children in the form of offering psychological support, providing practical guidelines and medical information as well as preparing children for disclosure. The practice of health care workers in disclosing to HIV infected children. Significant numbers of HCPs 50(36.2%) haven't ever disclosed a child. The barriers

stated by the participants were presented on table 2.

Table 2. Barriers of HCPs for not disclosing children in Addis Ababa health facilities, Ethiopia, (N=50)

Barriers of disclosure	Frequency*	Percentage*
lack of guidelines on disclosure counseling	26	52.0
lack of training on disclosure counseling	21	62.0
	51	02.0
lack of caregivers readiness and ability to disclose children	40	80.0
lack of knowledge when and how to disclose	33	66.0
fear the child will react negatively to his parents	8	16.0
Others (Preferred if parent disclose, parental refusal)	3	6.0

\* one participant mentioned more than one choice as a barrier

The attitude and practice of HCPs affected the probability of disclosing the HIV status to children and adolescents. Counseling parents/ caregivers to facilitate disclosure [OR = 3.762; 95%CI: 1.503-9.414; p value: 0.01], benefits believing disclosure children [OR=2.913; 95%CI: 2.306-3.682); p value: 0.016] and thinking health facility is a better place for disclosure than home [OR=4.706; 95%CI: 1.841-12.032; p value: 0.001] increased the odds of disclosure to children. The entry points for disclosure stated were: when patients have poor drug adherence, when patients have poor clinical attendance, when patients begin persistently asking questions why they are taking drugs.

The challenges reported by HCPs during and after disclosing a child were disappearance from follow up, negative emotional reaction and parental refusal.

# Appropriate setting for pediatric HIV disclosure.

Concerning the right age of disclosure about half of participants 67 (48.6%) said the child should be told between 11 and 14 years, 29 (21%) said between 8 and 10 years, 20 (14.5%) said between 5 and 7 years, 18(13%) said between 15 and 18 years and 4(2.9%) said between 3 and 4 years. The results showed that almost two third 85 (61.6%) stated an older age above 10 years as the right age to tell children about their HIV status. Most of the HCPs ,111 (80.4%), think disclosure is a shared responsibility for both HCPs and parents/caregivers, while 22 (16.0%) thought the caregivers are the appropriate people to disclose to children and only 5 (3.6%) said that HCPs should initiate discloWhen it comes to the best place for HIV disclosure to children, most of HCPs 114 (82.6%) believe a health facility is the best place to disclose children and these HCPs have disclosed children better (70.2 %) than those who said home as the best place (33.2%) [OR = 4.706; 95%CI: 1.841-12.032; p value: 0.001] (See table 3). They stated that disclosing at a health facility will benefit children as they will obtain reliable answers for their questions and concerns.

# Factors associated with pediatric HIV disclosure

Bivariate regression was done to assess the HCPs characteristics which increased their probability of disclosing the HIV status of children and adolescents (see table 3). Bivariate regression to assess the HCPs characteristics which increased their probability of disclosing the HIV status of Children and adolescents showed that: Counseling parent/ caregivers to facilitate disclosure, thinking a health facility is a better place for disclosure than home, having isolated room for disclosure, and working at health centers have increased the odds of pediatric HIV disclosure to children. HCPs aged 21-29 years were 55% less likely to disclose HIV status to children compared to those aged 30-58 years (Table 3).

Taking training on pediatric HIV disclosure [AOR=6.264; 95%CI: 1.978-19.841, p value: 0.001] and availability of guidelines for disclosure [AOR =8.350; 95%CI: 1.737-40.126, p value: 0.001] increased the odds of HIV status disclosure to children and adolescents by HCPs in the multivariable analysis (Table 3)

Variable	category	Disclosed		Crude OR	Adjusted OR	
Age of HCP	21-29	58	23	0.441(0.27-0.896)**	0.478(0.176-1.370)	
	30-58	30	27	1	1	
Sex	Female	59	37	1	1	
	Male	29	13	0.715(0.33-1.548)	2.175(0.658-7.193)	
Workplace	Hospital	26	32	1	1	
	Health cen-	62	18	4.239(2.029-8.859)*	0.318(0.051-1.994)	
	ter					
Disclosure bene-	yes	88	46	2.913(2.306-3.682)**		
fits the child						
	No	0	4	1	1	
Disclosure is	yes	66	21	4.143(1.976-8.687)*	0.565(0.109-2.942)	
timely in set up	No	22	29	1	1	
Parent counseled	yes	79	35	3.762(1.503-9.414)**	1.013(0.239-4.289)	
about disclosure	No	9	15	1	1	
Better place for	Clinical set	80	34	4.706(1.841-12.032)	3.612(0.814-16.022)	
disclosure	up			*		
	Home	8	16	1	1	
Disclosure guide	yes	85	23	33.3(9.262-59.5)	8.350(1.737-40.126)*	
available	No	3	27	1	1	
Got training on	yes	75	12	18.3(17.606-43.883)	6.264( 1.97-19.841)*	
disclosure						
	No	13	38	1	1	
Have isolated	yes	44	14	2.571(1.226-5.419)**	1.176(0.367-3.765)	
room for disclo-	No	44	36	1	1	

Table 3Association of selected HCPs variables with disclosure of HIV status to children<br/>among HCPs, Addis Ababa/Ethiopia

OR = odds ratio, N=number

\*p<= 0.001

\*\* P<0.05

^ Adjusted only for significant variables in the bivariate analysis

### Discussion

The survival of prenatally HIV infected children to adolescents and adulthood increased significantly due to introduction of HAART and associated better medical care. (4,5) As a result, disclosure of HIV positive status becomes a difficult task for parents and Health professionals. (6-10) There are several published studies looking into the barriers of disclosures of parents/guardians. Most of the publications in sub-Saharan countries pointed to lesser active involvement of Health Care Professionals in the disclosure process (15,16,19,22). Thus this cross-sectional study examined the practices, perspectives and barriers of HIV disclosure to children and adolescents by Health Care Professionals, in Addis Ababa health facilities, Ethiopia.

In our study, most of the study participants were females between the ages of 21-29 years. Concerning professional mix, most of them were nurses who were stationed at health centers.

In this study, almost all of the participants (97.1%) believe that knowing positive serostatus benefits HIV-infected children in their overall medical care and survival. Participants mentioned better medication adherence, understanding of the disease (HIV) and protecting others from being infected as a benefit of disclosure. Despite this only 2/3 of the health care professionals disclosed the HIV positive status of the child. Lack of training and appropriate setting for disclosure were among the common reasons reported for hindrance of pediatric HIV disclosure in this study and literatures from sub Saharan countries (13,18,22 -24)

Concerning pediatric HIV disclosure practice, nurses and health officers working at health centers (77.5%) disclosed more than the general practioners and resident physicians working in the hospital (44.8%). This could be due to the readily availability of HIV trainings and other supports at health centers compared to the hospitals due to national task of decentralization of HIV services (25). Moreover, HCPs with higher service years (5-10 years) had disclosed HIV to children than those with lesser service years (<5 years). A study in Malawi indicates that HCPs who had worked in a clinic for less than 2 years were three times more likely never to disclose the HIV status of a child. (21)

Regarding age of pediatric HIV disclosure, half of the healthcare professionals,85 (61.8%), suggested age above 10 years as the right age of disclosure, which is comparable to several other sub-Saharan African studies (19,20,24) The WHO guideline and the AAP recommends school age children 6-12yrs should be informed about their HIV positive status (11,12). According to a systemic review done in sub-Saharan Africa on Perspectives and Practice of HIV disclosure to Children and Adolescents by Health-Care Providers and Caregivers; Majority of HCPs preferred full disclosure of HIV diagnosis to children at a younger age between 6-15 years (24). The plausible reason for this is children above ten years of age are mature enough to understand HIV transmission and how to protect others from HIV infection.

In our study, the majority of the HCP (80.4%) prefer the health facility as the best place for disclosure. They consider that disclosure has to be a shared responsibility of both the parents/caretakers and HCPs. They believe parents/caregivers need their assistance to disclose children. The HCPs see their role in this regard as that of offering psychological support, provision of medical information, providing practical guidelines and preparing children for disclosure, rather than disclosing the seropositive status directly to the child. These roles are similar to what have been reported by Madiba etal and others (9,15,19,20,22,26)

On other hand several studies from lowincome countries indicated that parents/ caregivers should take the lead in disclosure because they believe the caregiver knows when the child is ready for disclosure and also able to follow the change they make after disclosure (9,10,19,21-,23)

In this study, although the majority (97.1%) of the HCPs thought that disclosure should be made to the child; more than a third (36.2%) of them haven't ever disclosed a child. This finding clearly showed that HCPs belief alone is not adequate to facilitate disclosure of HIV positive status to children and adolescents.

The lack of guidelines in the facility, and lack of training on how to disclose HIV positive status in children, lack of parents'/ guardians' readiness, refusal of parents and fear that the child will react negatively towards parents were reasons given by HCPs on why they were reluctant to disclose the HIV status for a child. This is similar to reports from other sub-Saharan African countries. (8,20,2324,26)

In our study, HCPs who have guidelines in their health institutions were eight times more likely disclose HIV status to children compared to those who don't have guidelines. This finding is comparable to several studies done in sub-Saharan Africa <sup>(20-24,26,).</sup>

### Limitation

The limitation of our study is that it employed a quantitative approach to collect data, and the barriers for disclosure from the HCPs perspective couldn't be explored in depth. For effective interventions, knowing the entry points, benefits and barriers of disclosure given by the HCPs in depth is crucial.

#### Conclusion

Pediatric HIV disclosure in Ethiopian health settings is suboptimal. Provision of appropriate pediatric HIV disclosure trainings and availing the guidelines in all Health facilities giving the HIV care are recommended for smooth chronic care of such children.

# **Conflict of interest**

The authors have no conflict of interest to declare.

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