

# HIV Status Disclosure and its associated factors among Children on Antiretroviral Therapy in West Shoa Zone, Ethiopia, 2019: A Mixed method cross-sectional study

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## Research

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# Abstract

Background Evidences from previous studies claim that informing children about their HIV status has long term positive implications in the HIV disease management, children's quality of life and ART drug adherence. However, in many parts of the Sub-Saharan African Countries, the HIV status disclosure among children reaches from 0 to 69.2%. Since the issue of disclosure is complex and highly influenced by socio-cultural characters and perception of the community towards HIV disease, it is important to investigate the up to date evidence which will help in designing contextualized approaches for disclosure. The objective of the current study was to assess the HIV status disclosure and its associated factors among children on ART in West Shoa Zone, Ethiopia.

Methods Institutional based quantitative cross-sectional study supplemented by qualitative was conducted from February to April /2019 among 247 caregivers and or their children.

Results The mean age of the children was  $11.11 \pm SD 2.8$ , and 43.6%, (95% CI: 37, 50.9) of the children were fully disclosed. The average age at disclosure was  $11 \pm SD 2.12$ . The main reasons for the disclosure were for drug adherence and better self-care, while underage was the commonest reason for nondisclosure. Compared to the age (10-15) years, the child in the age (6-9) was 97% [AOR: 0.027, 95% CI: 0.003, 0.22,  $P < 0.001$ ] less likely to be disclosed. Female children were 2.7 times more likely to be disclosed compared to males children [AOR: 2.73, 95% CI: 1.24, 6,  $P < 0.013$ ].

Conclusion The current finding reveals that the HIV status disclosure is generally low, and the decision to disclose or not to do so is affected by many factors like child age, and child sex. This will affect directly or indirectly the child drug adherence, treatment outcome and also disease transmission.

## Introduction

Globally, it was estimated that 38.8 million (95% CI 36.7–40.4) people were living with HIV/AIDS by 2015. Of these, more than 66.2% (above 25.7 million) were from Africa, and Children of age less than 15 years contributed about 2.1 million out of the total HIV infected population[1][2].

In Ethiopia, nearly 710, 000 people were living with HIV, of which 62,000 were children of less than 15 years of age. Out of these, only 35% of them were on antiretroviral treatment (ART) by 2016[3].

Notifying the children about their HIV status has a paramount advantage in the long term management of the HIV infection [4]. Studies indicated that if children living with HIV know about their HIV status, they are more likely to adhere to ART and had a positive influence on the children's quality of life [5].

It is also the children's right to get information about their health status. Because of these, World Health Organization (WHO) recommends that children of school age should be told their HIV positive status and their parents HIV positive status; younger children should be told their status and their parents' status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full

disclosure. So, it is recommended to start HIV disclosure at age of 6 and continued in incremental approach up to 12 years so that at the age of 12 the child should fully know his/her status[6][7].

For instance, a case-control study conducted among 309 HIV positive children indicated that quality of life was comparatively high among children with HIV status disclosed compared to those without HIV status disclosure [5].

Even though studies claim that informing children about their HIV status has long term positive implications in HIV disease management, children's quality of life and ART drug adherence, In many parts of the Sub-Saharan African Countries, the HIV status disclosure reaches from 0 to 69.2%[8].For instance, the HIV status disclosure reaches 26% -33% in Kenya [9], 32.6% in Uganda [10], 22.3% in Tanzania[11], 40% in South Africa [12], with the age at disclose reaching from 5 to 15 years[13]. In the Democratic Republic of Congo, nearly 50% of children didn't know their status while 15% partially informed. The full disclosure only reached 3%.[14] In a cross-sectional study among 149 caregivers of 4–17 years old children in South African indicated that only 39.6% with the median age of discloser of 9.3 years, in Ghana only 15 out of 71 of the caregivers disclosed the HIV status of their children to the child[15].

One study conducted in North Gondar, Northern part of Ethiopia revealed that only 39.5% of the children were disclosed [16]. In another study conducted among 177 participants in Hawassa, Southern Ethiopia, the prevalence of the disclosure was 33%[4].

The majority of the parents or caregivers of HIV positive children do agree that the status of the child should be disclosed for the child. However, pieces of evidence from different studies indicated that a minority of HIV-infected children in resource-limited settings knew his/her HIV status, reaching from 0–69% [17].

This evidence supports the fact that a significant number of caregivers/parents lack skills or sufficient knowledge of when and how to disclose the child's status[6]. And the majority of the children's parents prefer disclosure by a health professional than themselves. However, a study indicated that due to a lack of clear guidelines on the roles and responsibility of health care providers and standardized training in pediatric HIV disclosure, confusion was noted among health professionals in the process of disclosure [18].

The inability of most caregivers to handle disclosure has defined the three main patterns of Disclosure: complete parental, partial, and non-disclosure. In complete disclosure, the child is told that he/she has HIV and is given disease-specific information; while, in partial disclosure, the child may know that he/she has an illness but he/she has not told specifically that he/she has HIV infection [15].

Evidence from systematic review indicated that prevalence of HIV status disclosure in resource-limited countries was generally low among both children and adolescents, and accompanied by different reasons. The age of the child, fear of stigma in the community if disclosed, whether the child asks about his/her status, and caregivers perception about child ability to understand about the meaning of HIV if

disclosed were common reasons mentioned by parents or caregivers as a reason for not disclosing the status for their children. Additionally, the parents/caregivers' skill gap on how to disclose is also other factors for not disclosing [4][12]. So many parents prefer the age at disclosure should be above 10 and if the child age is 10 and above he/she has 80% more likely to be informed about his/her status (AOR: 8.8, 95% CI: 4.7, 16.5)[15][19].

In the same study, the main reason for disclosing the child status was that the children were not adhering to the ARV drugs [12].

In general, different studies were conducted on the issue under investigation. However, few studies were conducted in Ethiopia specifically in the capital cities of the country where the literacy rate of the people is relatively high. In addition, in previously conducted studies, almost all of the studies were quantitative and it is difficult to fully understand the caregivers and health care providers' experience and perception regarding child status disclosure. Besides, since the issue of disclosure is complex and highly influenced by socio-cultural attitudes of the community towards HIV disease, it is important to investigate the up to date understanding which will help in designing contextualized approaches for disclosure. So, the objective of this study was to assess the HIV status disclosure and associated factors among children on ART at Health institutions in west Shoa Zone, 2019.

## **Methods And Materials**

### **Study area and Design**

This study was conducted in Health Facilities found in West Shoa Zone, Oromia Regional State, Ethiopia. There were eight hospitals and 92 Health centers in west Shoa Zone. Out of these, 24 sites (health centers and Hospitals) were delivering ART services for patients with HIV. According to the data obtained from the CDC branch of the West Shoa Zone Health Department, there were about 9156 HIV positive patients on ART. Out of these, children between 6-15 years were around 556. The number of children who fulfills the inclusion criteria in each ART site ranges from 1 to 218 (West Shoa Health Department, 2018).

The institutional-based cross-sectional study design was used. The study was conducted from February 15- April 15/2019.

By considering the WHO recommendation for the lowest age at which disclosure should be initiated, all HIV positive children age between 6 and 15 on ART for the last six months at the selected hospital or Health centers (Ambo General Hospital, Incini Health Center, Ginchi H/C, Holota H/C) were included in the study.

### **Sample size determination**

To calculate the sample size for this study the following assumptions were considered:

The sample size for the first objective was calculated using the prevalence of HIV status disclosure (P=33%) among children in southern Ethiopia [17], 95% CI and 0.05 degree of precision.

Accordingly, the sample size was 339.

[Due to technical limitations, the formula could not be displayed here. Please see the supplementary files section to access the formula.]

**The sample size for the second Objective:**

The sample size for the second objective was calculated as follows: The power of the study to be 80%, the ratio of exposed to unexposed to be 1:1, 95% CI, % of outcome among exposed and unexposed were taken into account. Accordingly, the following sample size was calculated using open **Epi info version TM7** computer software and the sample size for the second objective was 442(table 1).

**Table 1: Sample size calculation using different works of literature as a baseline for study on HIV status disclosure and associated factors among Children on ART in West Shoa Zone, Ethiopia**

Place of the study	%outcome among exposed	% outcome among non exposed	Sample size	Ref.
Tikur Anbessa Hospital, Ethiopia	29.2%	42.3%	442	[20]
Hospitals in Addis Ababa	13%	73.8%	24	[17]

But, since the total study population was 556 (less than 10,000); the population correction formula was applied, and the final sample size was 247.

**Sampling procedure and data collection tools**

Since some health centers had only one case which fulfills the inclusion criteria, we decided to include all health centers with at least 20 and above cases. Accordingly, we selected four Health institutions. The study participants who fulfill the inclusion criteria were selected by simple random sampling technique. The samples for a qualitative study were selected purposively.

**Data Collection Methods and Procedure**

Quantitative data was collected through face to face interview. For data collection, five degree holder nurses (one for each health institution except for Ambo Hospital where it was two) were recruited, and trained for two days on objectives of the study, how to interview the clients, and on how to take the consent from the caregivers or parents. Nine in-depth interviews (IDI) (four with health care providers and five with child caregivers) were conducted. The participants for IDI were purposively selected health care

providers working on ART clinics from all health institutions and child caregivers, whose child was ever disclosed.

## Operational Definitions

**Full disclosure:** Disclosure was considered as “full disclosure” when it involved the caregiver or health care providers or anyone else having disclosed to the child that he or she has HIV specifically. This was determined if the care givers claimed that he/she describes the term HIV in his/her explanation for the child during disclosure process.

**Partial disclosure:** Disclosure is considered “partial” when the illness is described in a way that is consistent with HIV although the term “HIV” is avoided. For insistence: when the child is informed/knows that he/she has chronic health problems but not told specifically that the disease is HIV.

**No disclosure:** When the caregiver reported telling the child nothing about his or her illness.

**Deflected disclosure:** The strategy of deceptive disclosure that caregivers often use, frequently out of concern for the child’s psychological well-being, telling their children only about an unrelated condition (e.g., asthma, cancer), and attributing all medical needs (e.g., appointments, medication) to that less-stigmatized condition[21].

## Data management and analysis

The collected data were checked for completeness, coded, entered into Epi data software version 4.5 statistical packages and exported to SPSS version 20 for statistical analysis. Descriptive statistics such as frequency distribution with percentage was computed. To assess the association between dependent and independent variables, first bi-variate analysis was done. Independent variables those were associated with the dependent variable at  $P\text{-value} < 0.25$  were included in the Multiple Logistic regression analysis. With an odd ratio of 95% CI, the level of statistical significance was declared at  $P\text{-value} < 0.05$ .

The in-depth interview was tape-recorded and transcribed. The qualitative data analysis was done through a thematic analysis approach. The patterns of experiences were derived from the transcripts, either from direct quotes or through paraphrasing common ideas. Data from all the transcripts relating to the classified patterns were identified and placed under the relevant theme where it complements the quantitative findings.

## STROBE compliance

This study is reported in compliance with the STROBE guidelines[26].

## Results

Socio-demographic characteristics’ of the children and their caregivers

A total of 236 participants were interviewed. Out of the interviewed participants, 129(54.7%) were the child's caregivers, 61(25.8%) were both caregivers and children, and 46(19.5%) were only children. One hundred thirty-five (57.2%) of the caregivers were biological mothers. More than half (53%) of the children were males, and the majority of the children (95%) had started their education which reaches from the level of the nursery to junior primary school. The mean age of the children was  $11.11 \pm SD2.8$ . The majority (73.2%) of the children were in the age between 10 and 15. Eighty-three (35.2%) of the children were the first child for the family. Nearly 2/3 of the children were from urban residency. Thirty-eight (10.2%) of the children were orphan i.e. lost either their mothers or fathers or both. Out of them, twenty-four (10.2%) lost their fathers and mothers, 10(4.2%) lost their mothers and 4(1.7%) lost their fathers. One hundred twenty-five (53%) of the caregivers were in union (married), and 71(30.1%) can't read and write. The caregivers' mean age was  $36.4 \pm 8.2$  (table-2).

### HIV and ART status of the Children and Caregivers

The caregivers were asked whether their child knows why he/she was taking the drug. If the caregivers said yes for this question, the question "what did you tell him/her?" followed with three options was asked. The options were i) I told him that he has HIV in his blood or ii) I told him/her that he/she has a chronic disease in his body but did not mention the term HIV in explanation or iii) the third option was open for the respondents. Accordingly, out of the total 236 participants interviewed, 103[43.6%, 95% CI: 37, 50.9] of the children were fully disclosed (told that they had HIV in their blood), 32(13.5%) were partially disclosed (told that they had some germs in their blood which is not curable, but the term HIV was not mentioned).

The average age at disclosure was  $11 \pm SD2.12$ . Only one child was fully disclosed at the age of less than 10 years. The caregivers' preferred mean age to disclose was  $12.26 \pm 2.3SD$  with (min = 6 and Max = 18). The median age of children since they have started ART was 8.35 years. Ninety-four (92.15%) of the disclosure was done after the child had started ART, while the others were disclosed pre ART drugs. One hundred three (43.5%) of the children were in 3rd stage, 82(34.6%) were in the first stage and 42(17.7%) of the children were in the second stage of WHO HIV classification Table (3). The majority of the children, (92%) took the TB prophylaxis drug. About 170 of the caregivers were HIV positive and 167 of them were taking ART drugs. From the HIV positive caregivers, 164 disclosed their HIV status to either family members or someone else. Twenty-two (9.3%) of the caregivers reported that their child missed a drug in the last two weeks. Forgetfulness was the commonest reason for missing ART drug followed by child refusal.

### Reasons for disclosing or not disclosing the child

The commonest reasons explained for the children as of why they were taking the drug were: as the child has disease like TB, intestinal parasitosis, anemia among others was mentioned by the majority of the caregivers. Some of the caregivers also mentioned that they told their child as if she/he was taking the candy. The caregivers were asked why they decided to disclose the child status, and the commonest reason they mentioned were: if the child knows his/her status he/she will take her drug as ordered by the

physician, and also he/she will take care of her/his health i.e. the child will take responsibility in caring for his/her self so that she/he will live better lives in the future. Some caregivers also mentioned they disclosed the child's status to ease child confusion and tension since the child repeatedly asks them why she/he is taking the drug.

Those caregivers who didn't disclose mentioned since the child was not mature enough, she/he doesn't understand the discussion about HIV. Some of the caregivers mentioned that it is better not to disclose because not thinking about HIV will avoid child psychological disturbance and in turn avoid child death. Some others also reported the child doesn't keep secret as a reason for not disclosing yet.

Ninety-seven (41.1%), 77(32.6%), and 40(16.6%) of the caregivers reported that the disclosure should be done by joint caregivers and health professionals, only by caregivers and only by health professionals respectively.

#### Factors Associated with the child HIV status disclosure

To assess the factors associated with the child status disclosure, bivariate analysis was done first. Variables which were associated with the dependent variable at  $p\text{-value} \leq 0.25$  were selected and included in multiple logistic regressions analysis (Table 4). The model fitness was checked by Hosmer and Lemeshow Test ( $p\text{-value} = 0.54$ ) and it was fitted. Accordingly, three of the variables, child age, child sex and caregivers level of education were significantly associated with the child status disclosure. Compared to the adolescence (10–15) age, the children in the pre-adolescence age were 97% [AOR: 0.027, 95% CI: .003, 0.22,  $P < 0.001$ ] less likely to be disclosed. Females children were 2.7 times more likely to be disclosed compared to males children [AOR: 2.73, 95% CI: 1.24, 6,  $P < 0.013$ ] (Table-4).

Table 2

The socio-demographic characteristics of the children on ART and their caregivers in West Shoa Zone, Ethiopia, 2019

<b>Variables</b>	<b>Frequency (%)</b>
Child age	
6–9	62(26.3)
10–15	174(73.7)
Child sex	
Male	125(53.0)
Female	111(47.0)
Educational status	
not started education	12(5.1)
Kindergarten	17(7.2)
Elementary	139(58.9)
junior primary	68(28.8)
Birth order	
First	83(35.2)
Second	63(26.7)
Third	47(19.9)
Fourth	18(7.6)
Fifth	25(10.6)
Residency	
Urban	141(59.7)
Rural	95(40.3)
Child-care giver relationship	
Father	46(19.5)
Mother	135(57.2)
Siblings	14(5.9)
Other(grandmother/father)	18(7.6)

<b>Variables</b>	<b>Frequency (%)</b>
is child orphan	
Yes	38(16.1)
No	198(83.9)
Caregivers education	
Has no formal education	71(30.1)
Elementary(1–4)	32(13.6)
Junior Elementary(5–8)	48(20.3)
High school and above	54(22.9)

Table-3- child and caregivers HIV and ART status and related matters in West Shoa Zone, Ethiopia, 2019

<b>Variables</b>	<b>Frequency (%)</b>
Disclosure status	
Disclosed	103(43.6)
Not disclosed	134(56.8)
Who made the disclosure	
Mother	26(25.5)
Father	14(13.7)
other family members	21(20.6)
health professional	33(32.3)
Other(from friends/by himself)	8(7.8)
Who do you think should disclose the child HIV status	
Caregivers	77(36.0)
joint of caregivers and health professional	97(45.3)
health professional	40(18.7)
Do you think disclosure is important	
Yes	150(70.1)
No	64(29.9)
WHO disease stage	
1	82(34.9)
2	42(17.9)
3	103(43.8)
4	8(3.4)
Who disclosed	
Mother	25(24.0)
Father	14(13.5)
other family members	8(7.7)
health professional	33(31.7)
heard from friends	3(2.9)
Joint disclosure	21(20.2)

Table 4

binary and multiple logistic regression analysis results on factors associated with HIV status disclosure among 6–15 years old children in West Shoa Zone, Oromia, 2019.

Variables	Disclosure status		Crude OR With 95% CI	Adjusted OR With 95% CI	p-value
	Disclosed	Not disclosed			
Child age					
6–9	1	61	0.01(0.002, .085)	.027(.003,0.22)	P < .001
10–15	102	72	Ref		
Child sex					
Male	42	83	Ref		
Female	60	51	2.4(1.42, 4.1)	2.73(1.24, 6)	0.013
Educational status					
Not started	2	27	Ref		
elementary	47	92	6.8(1.5, 30)	1.58(0.22, 10.9)	0.64
Junior primary	54	14	52(11, 245)	13.2(1.6, 109)	0.02
Birth order					
first	37	46	0.87(.35, 2.13)	.482(.13, 1.81)	.280
second	27	36	0.86(0.34, 2.19)	.747(.179, .11)	.688
third	21	26	0.87(0.33, 2.31)	.756(.17, 3.31)	.710
fourth	5	13	0.42(0.11, 1.5)	.323(.05, 1.99)	.224
Fifth	12	13	Ref		
Residency					
urban	68	73	0.63(0.37, 1.1)	1.43(.61,3.35)	0.41
rural	34	61	Ref		
Is the child orphan					
Yes	17	21	1.05(0.52, 2.12)	1.55(.53, 4.52)	0.42
No	85	113	Ref		
Caregivers education <sup>41</sup>					
no formal education	30	41	Ref		

Variables	Disclosure status		Crude OR With 95% CI	Adjusted OR With 95% CI	p-value
	Disclosed	Not disclosed			
Elementary(1–4)	10	22	0.62(.25, 1.5)	.40(.118, 1.38)	.148
(5–8)	28	20	1.9(.91, 4)	1.78(0.63, 5)	.275
≥ High school	14	40	0.48(0.22, 1)	.23(0.07, 0.7)	.010

### Findings from the qualitative study

Four nurses (3 females and one male) working on ART at different health institutions and five child caregivers (three mothers and two fathers) who have ever disclosed their child status were interviewed. All of them agree on the importance of HIV status disclosure and believe it should be done when the child is mature enough to understanding the discussion about HIV. However, the age that the participants thought as maturing age varies. Some of the participants said maturity age is 10, others 12 and above.

“I think children should know their status. But, the disclosure should be based on their maturity and ability to understand what we are going to discuss with them. From my experience, it is better if disclosed at 12 or 13. But,, some children are very active and fast even at 9 years. In such a case, the disclosure is also possible... Currently, we are facing many challenges concerning the child viral load. Children are discontinuing their drug and their viral load becomes higher when they come to the health center here. So, to overcome the challenges of drug adherence, I think disclosure is the solution if they are matured. Many children are entering into the fire age, and by this age, they will have opposite-sex friends. Knowing their status is better for them, so that they will prevent themselves and others from disease transmission”.

In addition, if the child is disclosed at an early age they will more likely to refuse to take the drug and they become hopeless. One of the participants described the consequences of early disclosure as follows.

“If the child disclosure is done before maturity, the child will discontinue the drug or not adhere to it. The child will disturb the family. Since she/he acquired the disease from his/her mother, he/she will angry with his/her mother saying I acquired this curse from you which I haven’t done. The child becomes hopeless, and he/she will discontinue the drug and then finally come to us by developing Opportunistic Infection.”

Both health professionals and caregivers had a different perception of who should disclose child status. Some of the health professionals responded that it is better determined by caregivers as who should disclose it to the child.

“Some caregivers say we will disclose it. But, for me, it is better if the disclosure is by joint caregiver and health professional. Because, it is difficult for the caregiver alone to disclose, and the health professional can use their scientific knowledge to make the children understand.”

One of the child caregivers also responded the same idea with the above as follows.

“For me, since the health professionals have more detail knowledge about the disease and the drug, the issue about the disease is better told by the health profession. We, the caregiver will inform about our status, as we are taking the drug and sharing our life experience with the child. So, it is better if done jointly, and some part by health professional and some part by the family/caregivers”.

Both caregivers and health professionals were asked their experience on how of the disclosure process. Even though their process of disclosure varies, their common sense was that all of them were trying to disclosing the child with the most possible system of calming and stabilizing the child. One of the caregivers (father) portrayed his experience as follows.

“To disclose the child status, first I started from myself. I said, my daughter; I am a patient person, infected with HIV disease. Currently, as you are seeing me, I am taking this drug. I am doing my daily activities. Nothing is different for me from my pre-disease condition. You are also infected with this disease. The disease was transmitted to you from your mother while you were in the womb. Now, you can continue your education, you can live as any other healthy person and when your success in your education, you will help me in the future”.

Children experience different feelings during disclosure. The commonest experiences mentioned were described as follows.

“They will anger to their mother, they will cry, some of the children will refuse to take their drug in the first week, and become depressed. But, if they get support from their care givers, they become stable after a week. Even though it is rare, those children in the age of 15 and above may sometimes engage in revenging others. They will try to infect other people by concealing their status. Both male and female will engage in unsafe sex.”

The other disclosure process mentioned by one of the health professions was what he explained as peer disclosure, which they used rarely.

“.....Rarely, we also use peer disclosure. In this disclosure, children/adolescents of nearly on same age are collected together....Their numbers may reach up to forty. Then, the disclosure will be done at the collection moment. Those already disclosed children will introduce themselves as they are HIV positive... saying I am X, I am living with HIV for the last 15 years, now I am grade eight. So, being HIV positive doesn't prohibit you from your future goal... different individuals will share their experience there. Those not disclosed will know themselves there, and will develop hope. They will develop hope by seeing those people who were introducing themselves as a model.”

## **Discussion**

In this study, we assess the magnitude of HIV status disclosure, the process of disclosure and what factors were influencing the disclosure. Accordingly, 43% of the children were fully disclosed. This

relatively higher finding could be attributed to the fact that the majority (73%) of our study children were aged greater than 10 years. However, only 65% of those children aged greater or equal to 12 years were disclosed; which is lower than the ideally expected (should be 100%) number since the majority of the children were in the age considered to be mature age for disclosure. This finding is similar with the finding from a study in South Africa(40%), in Eastern part of Ethiopia(49%), in Gondar town(44%), North Gondar(39%) of Ethiopia[22][16][23][24]. However, it is greater than the studies conducted in Hawassa, the southern part of Ethiopia, and in Tanzania [17][25]. The difference could be due to the difference in sample size. The one study conducted in Hawassa was among 177 children while the current study was among 236. In addition, disclosure is a complex process which is influenced by socio-cultural factors like fear of stigma. So, the difference in the socio-culture of the previous and current study could also be the possible reason for this difference. In addition, the issue of drug nonadherence among children is getting attention among the scientific community which is influencing the disclosure process.

The mean age at disclosure was 11 years and this age was nearly similar to the age assumed to be the maturing age and preferred by the majority of the caregivers. The rate of disclosure increases with age. Only a single child of age less than 10 was disclosed. About 40%, 35%, and 30% of the children age 10 and above, or 11 and above or 12 and above were not disclosed yet respectively. The finding from the qualitative data also justifies this result.

“I think children should know their status. But, the disclosure should be based on their maturity and ability to understand what we are going to discuss with them. From my experience, it is better if fully disclosed at 12 or 13 years. But sometimes, some children are very active and fast even at 9 years. In such a case, the disclosure could be possible.”(ART nurse from Holota Health Center).

“The most challenging part in disclosure is convincing the family. They don't want to disclose. I do have an experience of 16 years old. I have tried to convince the father to disclose. But, he refused..... Our culture is also difficult. Most of the time, our community doesn't want to share sensitive things with their children. Here, the family says, don't disclose my child's status; I will do it at home. But, they don't do it. This means they want to hide it.”(ART nurse from Ambo Hospital)

The same finding was reported previously in the study in Eastern and North-East part of Ethiopia [16][22].

Almost all of the caregivers agreed that child status disclosure is important. The commonly mentioned advantages of the disclosure were: drug adherence after disclosure, for better self-care and to ease child confusion and tension since the child repeatedly asks the caregivers why she/he is taking the drug. Underage was the commonest reason for not disclosing the child. The result from the caregiver's in-depth interview is also consistent with the above quantitative finding.

“Currently, we are facing many challenges concerning the child viral load. Children are discontinuing their drug and their viral load becomes higher when they come to the health center here. So, to overcome the challenges of drug adherence, I think disclosure is the solution if they are matured. Many children are

entering into the fire age, and by this age, they will have opposite-sex friends. So, knowing their status is better for them, so that they will prevent themselves and others from disease transmission”.

Similar findings were reported in many studies conducted in Africa and Asian Countries [24][17][23][18][22][20].

This finding is different from the finding reported in one study conducted in Addis Ababa among orphanage and community children in which disclosure was mainly follows family death and it was un planned [9].

Those undisclosed children were told deception by their caregivers about their status and why they were taking the drug. But, partial disclosure is recommended when the child age is considered to be not matured enough. Failure to do so during an early age will make disclosure difficult at a later age.

The female children were more likely to be disclosed than their male counterparts. Even though we didn't get another study supporting this finding, the following justification was forwarded in qualitative findings.

“It is easy to tell the female children about their status than males. This is due to many reasons such as most of the time female children keep secret. Female child don't expose our mystery to other people if she is told the issue is secret and also females are eager to know things than males and ask repeatedly” (mothers of 11 years old female child)

“I think, female disclosure is also related to violence. I do have an experience on this. One mother told me as she disclosed her daughter at 9 years. I asked her why she disclosed it at this age. She said, my daughter may experience sexual abuse, and for whatever she may face, she better know and keeps herself.”(ART nurse from Ambo Hospital)

Many challenges were hindering both caregivers and health care providers from disclosing the children's HIV status. Factor such as the age of child i.e. not being mature enough, fear of stigma and fear of psychological disturbance if disclosed were commonly mentioned. This finding is almost similar to many of the studies conducted previously. But, what is unique in this study is the barriers claimed by the health professionals. Almost all of the IDI participants raised the issue of family/caregivers' resistance, lack of training on disclosure issues, shortage of time, and space.

“.....If I plan to disclose a child status, first I will lock the door. You need to take time for and silent environment to discuss disclosure. But, here, we visit up to 40–50 clients per day. The environment is crowded; the patients will wait for us. And the number of professionals here is few and even out of the three ART professionals here, only me, who took the training. In addition to our daily duties, sometimes we are ordered to do some management activities. So, these factors are hindering us to fully practice the issue of disclosure in our hospital.”

Limitation of the study

We didn't include disclosed children as part of qualitative data collection because of fearing discussing may cause psychological disturbance or unnecessary reaction. Since this data was collected during service rendering for the clients in the ART clinic, there could be a probability of false reports in favor of what the health care providers were advising. Due to the nature of the study design, the association doesn't mean causative.

## **Conclusion And Recommendations**

In the current study, even though the majority of the children were aged greater or equal to 10, an age interval considered being maturity age by the caregivers, the prevalence of children's HIV status disclosure was found to be low and it was affected by factors such as child age, child sex, fear of child psychological disturbance after disclosure, and fear of stigma.

The child age was the most significant factor affecting the disclosure status. Accordingly, disclosure at the two extreme ages i.e. age less than 10 or age greater than 14 was perceived by both caregivers and health professionals to have a negative consequence on either the child or child's family

In addition, lack of sufficient training about disclosure i.e. when, where and how, by whom should it be done, shortage of time, inconvenience of place for discussion about the disclosure were factors identified affecting disclosure from the health care providers perspective.

The challenges from caregivers' side plus gaps from care providers' side, in general, are contributing to this low level of the disclosure. This will affect directly or indirectly the child drug adherence, treatment outcome and also disease transmission.

Since disclosure is a complex process, multi-faceted and needs the collaboration of caregivers and health care providers, there should be clear and detail guidelines on when to start, how, where and who should do what in the disclosure process. The guideline should address issues like the culture of the society, means of managing the concern of family after disclosure which includes stigma, and child psychological disturbances i.e. culturally contextualized guidelines.

Updating health care providers' knowledge and skills, and working on caregivers' attitude is needed to manage disclosure and challenges following it. Health care providers are also highly urged to emphasize discussing the issue of disclosure with caregivers. In addition, health institutions managers should consider facilitating space and other challenges hindering the disclosure process in their plan.

## **List Of Abbreviations**

AOR- adjusted odds ratio

ART-antiretroviral treatment

CDC-communicable disease control

CI-Confidence Interval

H/C-Health Center

-in-depth interview

SD-standard deviation

## Declarations

### Ethical considerations

Ethical clearance was obtained from the ethical review committee of the College of Medicine and Health Sciences, Ambo University, Ethiopia. During the fieldwork, the objectives of the study was clearly explained for the study participants, the confidentiality of the data to be collected and the right not to participate was also assured. The written consent was taken from the caregivers after they read/the consent form was read for them. The participants were asked to confirm their participation in the study by signing the consent form.

### Consent for publication

Not applicable

### Availability of data and material

All data generated or analyzed during this study were included in this published article and its supplementary information files are also included as supplementary data with this submission.

### Competing interests

The authors declare that they have no competing interests in this section.**Funding**

Ambo University has covered the costs of data collectors and supervisors per diem. The funded organization has no role in designing the study, data collection, or manuscript preparation.

### Authors' contributions

**SAS** developed the proposal, analyzed data, and the major contributor of the manuscript.

**WWM** had participated in data collection supervision, read the study throughout the progression of study, starting from proposal development to data analysis.

**AA:** has participated in the designing, data collection and manuscript preparation.

All authors read and approved the final manuscript.**Acknowledgment**

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**MT** had participated in data collection supervision, read the study throughout the progression of the study, starting from proposal development to final manuscript writing.

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