

ORIGINAL ARTICLE

MAGNITUDE OF DISCLOSURE, AND ASSOCIATED FACTORS ON HIV POSITIVE CHILDREN IN NORTH WEST ETHIOPIA, A MIXED-METHOD

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ABSTRACT

Background: Disclosure of HIV positive status of children is an essential component of HIV care services in the long-term disease management. It is a complex process, and it varies from community to community. Therefore, it is important to understand the disclosure status, determinants, and to explore the reason. Thus, this study aimed to assess disclosure status of children, associated factors, and reasons for not to disclose among caregivers in the Northwest part of Ethiopia.

Methods: A mixed approach with a facility based on cross sectional study for the quantitative component was employed. Similarly, the qualitative component was conducted concurrently with the quantitative one with phenomenological study design. Four hundred children, and 19 caregivers for both the quantitative and qualitative study were enrolled. Data were collected in the Northwest part of Ethiopia, Gondar town from January to June 2019. In the same way, simple random sampling technique was employed to select study participants for quantitative data, and purposive sampling for qualitative ones. In addition, a structured questionnaire, and in-depth interview guide were used to collect the data. Binary and multivariable logistic regression was done to identify associated factors for quantitative data whereas the thematic analysis was used for the qualitative data.

Results: Nearly two-third 262 (65.5%) (95% CI; 61.0-70.0) of the children disclosed their HIV positive status. Age of the child (Adjusted odds ratio AOR=8.05, 3.98-16.27), age of caregiver (AOR= 1.92, 1.07-3.42), duration on ART (AOR=3.24, 1.66-6.32), death of family (AOR=1.99, 1.01-3.92), being trained about disclosure (AOR=4.02, 1.83-8.36) and responsible person for medication of the child (AOR=2.87, 1.43-5.76) were significantly associated to HIV disclosure status. Participants expressed the view that if children had given adequate information about having HIV, they would not only adhere to medication, but they also play an active part in the management of their conditions.

Conclusion: Although WHO guideline on HIV disclosure counselling for children and other global HIV disclosure perspectives recommend that all children starting from six year should be disclosed of their HIV status, the HIV disclosure status of children was low in our study. Age of the child, age of the caregiver, duration on ART, death of family, training about disclosure, and responsible person for the child's medication was independent determinants of the disclosure. Thus, we recommend the establishment of effective strategies to promote disclosure in health facilities.

Keywords: - HIV, Children, Disclosure, Mixed Method, Ethiopia

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INTRODUCTION

The Human Immunodeficiency Virus (HIV) pandemic is one of the most severe public health challenges facing the world since its discovery (1). The World Health Organization/ WHO/ report showed that approximately 3.3 million children younger than 15 years were living with HIV of which 88% were living in Sub-Saharan Africa (2). Sub-Saharan Africa is the home for 76% acquired immune deficiency syndrome /AIDS/- related global morbidity, and 75% global mortality (3). In Ethiopia, 718,500 people were living with HIV of which around 398,277 were adults, and 21,686 children were under the age of 15 who were taking antiretroviral therapy / ARV/ in 2017 (4).

There are many challenges and emerging complex issues that HIV infected children are facing. This disclosure is one of the greatest psychological challenges that families and health care providers face to decide on how and when to disclose HIV positive status to children. Disclosure refers to a child gaining knowledge of his/her HIV positive status (5-7). Disclosure of HIV status remained a major hindrance in the fight against the spread of HIV in sub-Saharan Africa (8).

Several studies have documented that disclosure of HIV diagnosis to infected children has paramount importance in clinical practice as it offers many clinical and psychosocial benefits to improve the quality of life of people who are infected with HIV disease (2, 4, 7, 9-13). The United Nations Educational, Scientific and Cultural Organization /UNESCO's/ reported that the knowledge of children about their disease will enable the children to make safe and healthy life choices about relationships, sex, and reproduction (14). Besides, evidence showed that informing children about their HIV diagnosis can improve adher-

ence to ART thereby increased survival rates, improve personal health maintenance, decrease psychological effects associated with accidental disclosure, and foster HIV prevention within the larger population (15).

As a result, the American academy of pediatrics and WHO strongly recommend the gradual process of giving age-appropriate information to HIV infected school-age children by considering the child's cognitive and emotional development (16, 17). Similarly, the African network for the care of children who are affected by HIV/AIDS (ANECCA) recommends that pediatric HIV disclosure start as early as 5-7 years old (18).

Despite the ANECCA recommendations and benefits of disclosure, different quantitative and qualitative studies reported a low rate of disclosure. The global proportion of HIV disclosure status in children varies greatly. Evidence on disclosure among children showed that only small proportion of children knew their diagnosis that is ranged from 1.2 to 75% (19). Similarly, another systemic review study conducted in a resource-limited setting revealed that the proportion of disclosed children was 0% to 69.2% (20). Moreover, Some cross-sectional studies conducted among caregivers in different African countries reported that the disclosure status was 23.3% in Ghana (14), 29.8 % in Zambia (13), 33% in Namibia (9), 30.9% in Nigeria (21), 65% in Rural Uganda (22), 34% in South Africa (23), 22.3% in Tanzania(24), 64% in Rwanda (25) and in Ethiopia. Furthermore, previous different studies reported that there was between 17.4% and 49.4% (2, 11, 26-29) proportion of disclosure.

Shreds of evidence have also noted that there are several factors which are associated with disclosure. These includes: caregivers related age and education-

al level (27, 30), residence and family size (27, 28), sex (14), occupation, marital status, and caregiver's-child relation(13). Child-related factors like the age of the child, sex, and educational status (1-7, 9, 11-15, 18, 19, 21, 22, 24, 26-29, 31-57) , and age at diagnosis of HIV, duration on ART, WHO clinical stage, history of hospital admission, history of opportunistic infection, and history of other medications were among clinical determinants (26, 28, 44, 57).

In the same way, different studies have also noted barriers to disclosure such as emotional unpreparedness for disclosure, fear of stigma, disclosure being treated as a once off event rather than as a process, and caregivers' lack of skills or knowledge to facilitate disclosure (11, 28, 37, 58). Besides, repeated questions by the child, a need to improve medication adherence, practicing safe sexual behaviour, disease progress, and children's need to know the nature of their disease (38, 44, 59) were the usual reasons to caregivers to disclose children's HIV status. Most caregivers believe that the child is too young to understand the illness (18, 21, 32, 60) , fear of negative consequences, stigma/social rejection, caregivers' knowledge on disclosure, guidance, and fear of a child's reaction were in contrary reason to not disclose to children's care giver. (2, 7, 21, 27, 44, 57).

Many HIV positive children entered to their adolescence age without knowing about their illness which can have significant implications for health treatment, adherence, emotional well - being, and prevention of the spread of HIV. If this non-disclosure allowed to continue, it would have negative ramifications for the entire nation, and it challenges the plan to end HIV epidemics by 2030. This is because non-disclosure will lead to non-adherent, and consequently poor treatment outcomes such as treatment failures, increased drug resistance strains, increased viral load, and associated risk of HIV transmission to the general

population. Understanding the diverse associated factors of disclosure, and exploring the reasons for non-disclosure across different settings is crucial in the management of HIV infected children. Therefore, it is imperative to study the magnitude and determinants of disclosure and reasons for non-disclosure.

METHOD

Study design, setting, and population: A mixed approach with a facility based on cross sectional study for the quantitative component was conducted. The qualitative component was conducted concurrently with the quantitative one, and it has phenomenological study design. Data were collected in the Northwest part of Ethiopia, Gondar town from January to June 2019. Gondar is located 750 km far from Addis Ababa, the capital city of, Ethiopia to the Northwest direction. Currently, the town has one comprehensive specialized hospital, and eight government health centres. Out of the eight government health centres, six health centres, and the available one hospital give paediatric ART services. There were a total of 736 children whose age ranged from 6 up to 18 years on ART in the study area. The source of population for this study was all HIV infected children while the study population was children on regular follow up in paediatric ART clinics.

Sample size determination: The sample size was determined using single population proportion formula by considering the following statistical assumptions: 95% confidence level, which is proportional with a study conducted in Bale South East Ethiopia (28.5%) (2) and a 5% margin of error. Thus, the sample size was 344, and when it considered determinants of disclosure, was calculated using EPI info -provided 400 including a 10% non-response rate. Accordingly, 400 were taken the sample size for the quantitative study.

The sample size for the qualitative study was determined based on the saturation level. Nineteen Interviews were conducted. Case managers, and HIV counsellors who were working in selected paediatric ART clinics during data collection as well as caregivers who came with their children were selected purposively for In-depth Interviews.

Data collection method and procedures: Data were collected from four health centres, and from one comprehensive specialized referral hospital using structured questionnaires, and face to face interviews of the caregivers, and they were supplemented by chart review. In addition, ten trained Bachelor of Science / BSc/ nurses were involved in the data collection under close supervision. Furthermore, every study participant was introduced briefly about the purpose of the study. Besides, the participants' name and any identifier were not used to ensure the confidentiality of the participants' profile. The questionnaire was prepared in English and then translated to Amharic then back to English to ensure consistency. Similarly, audio recorder was used as well as in-depth interview was conducted, translated, and transcribed.

Variables

Dependant variable: disclosure status

The independent variables were categorized as child socio-demographic characteristics including: age, sex, educational status, support from any organization, caregivers, marital status, occupation, educational level, residence, family size, caregiver-child relationship. Likewise, clinical factors of a child including: age at diagnosis time of HIV, history of opportunistic infection, duration on ART, WHO clinical stage, history of hospitalization, history of other medications used, Clinical factors of a caregiver: - HIV status of a caregiver, duration on ART, caregiver disclosure status, support from the health care provider were also considered.

Operational Definition

Disclosure: It was dichotomized as yes when caregivers asked child whether or not that the child knows his/her HIV/AIDS diagnosis regardless of who told the child, and it was no when children are not informed(27, 28).

A **"caregiver"** was defined as someone who is responsible for the well-being of the child and who brought the child to the clinic at the same time who was knowledgeable about the child's HIV care behaviours(57)

Data processing and analysis: The data were entered into EPI INFO version 7, and then, it was exported to SPSS version 21 for cleaning, coding, and analysis. Descriptive analysis was carried out using text, tables, and graphs. In the same way, binary logistic regression analysis was used to identify factors associated with HIV positive disclosure status. Similarly, variables with a p-value of < 0.2 in the binary logistic regression were entered into multiple logistic regression models. Likewise, model fitness was checked by using Hosmer and Lemeshow goodness of a fit test ($p=0.51$). Finally, variables with p-value of ≤ 0.05 at 95% CI with its AOR were considered as having a statistically significant association with disclosure status.

Regarding qualitative data, recorded interviews were transcribed verbatim, and they were translated by the principal investigator. Transcripts were read line-by-line. Representative quotes covering the range of data were selected to illustrate the themes. Transcripts were analysed using the principles of thematic analysis by Atlas ti version 7 software. Themes were identified within each transcript, and then they were compared. Themes were clustered, and subordinate themes were grouped under main category headings and illustrative quotes were again selected for each theme.

RESULT

Socio-demographic & clinical factors of the caregiver:

This study included 400 participants with a response rate of 100%. Among 19 care givers, (83.3%) were females and 57.0% of them were below 38 years of

age. Concerning the educational level of care giver's, 42.3% of the respondents have not attended formal education while 9.8% have college diploma and above. The majority of the caregivers 94.3% were urban dwellers. Finally, about eighty-seven (21.8%) of care-givers took training about disclosure (**Table 1**).

Table 1: Socio-demographic characteristics & Clinical factors of care givers of a mixed-method study of disclosure on HIV positive children in the Northwest part of Ethiopia, 2019.

Variable	category	Frequency	Percent
Age in year	<38	228	57.0
	≥38	172	43.0
Sex	Female	333	83.2
	Male	67	16.8
Educational level	Non formal education	169	42.2
	1-8 grade	98	24.5
	9-12 grade	94	23.5
	College & above	39	9.8
Religion	Christian	377	94.3
	Muslim	23	5.8
Residency	Urban	377	94.2
	Rural	23	5.8
Occupation	Private	328	82.0
	Government Employer	72	18.0
Marital Status	Married	190	47.5
	Unmarried	210	52.5
Family Size	<4	264	66.0
	≥ 4	136	34.0
Relationship	First degree relatives	345	86.2
	Second degree relatives	55	13.8
HIV status of the care giver	Positive	282	70.5
	Negative	118	29.5
Care giver disclosure status	Yes	291	72.7
	No	109	27.3
Support from the HCP	Yes	301	75.3
	No	99	24.7
Duration on ART of the care giver	< 2 year	168	59.6
	≥ 2 year	114	40.4
Number of families living with HIV	<2	256	64.0
	≥2	144	36.0
Attended disclosure training	Yes	87	21.8
	No	313	78.2
Care giver Start ART	Yes	312	78.0
	No	88	22.0
Responsible Person for a child's medication	Yes	153	38.3
	No	247	61.8

Socio-demographic & Clinical factors of the child:

Out of 400 children, 206 (51.5%) were less than 12 years, and 219 (54.8%) of them were females. In addition, the majority of the children, 364 (91.0%) had started education. Besides, more than half, 224 (56.0%) of the children had taken ART for less than 6 years, and the majority of them, 363 (90.8%) were living with their parents.

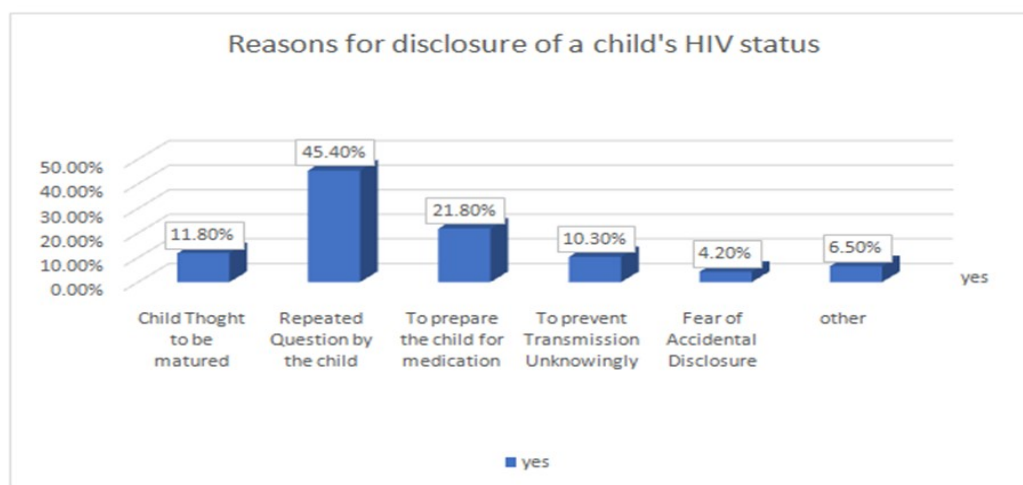
Furthermore, about one fifth, 77 (19.3%) of the children had a history of taking medications in addition to ART, and 118 (29.5%) had a history of opportunistic infections. In the same way, out of the total children, 381 (95.3%) had WHO clinical stage I disease, and 143 (35.8%) had a history of hospitalization. In addition, 122 (30.5%) of caregivers had a family death history (**Table 2**).

Table 2: Socio-demographic characteristics & Clinical factors of HIV positive children of a mixed-method study of disclosure in the Northwest part of Ethiopia, 2019.

Variable	Category	Frequency	Percent
Age in years	<12	206	51.5
	≥12	194	48.5
Sex	Male	181	45.3
	Female	219	54.8
Educational level	Non educated	36	9.0
	Educated	364	91.0
Organizational Support	Yes	110	27.5
	No	290	72.5
Death of Family	Yes	122	30.5
	No	278	69.5
Age at diagnosis of HIV	<4 year	208	52.0
	≥4 year	192	48.0
Duration on ART of the Child	<6 Year	224	56.0
	≥6 Year	176	44.0
WHO clinical stage	Stage 1	381	95.3
	Stage 2	19	4.8
History of Opportunistic Infection	Yes	118	29.5
	No	282	70.5
History of Hospital Admission	Yes	143	35.8
	No	257	64.3
Number of Hospitalization	< 2	380	95
	≥ 2	20	5
medications used other than HIV	Yes	77	19.3
	No	323	80.8
Drug Adherence	Good	360	90.0
	Fair	40	10.0
With Whom the child is currently Living	Parents	363	90.8
	Relatives	37	9.3
Responsible person for medications of the child	Yes	153	38.3
	No	247	61.8
Place of Follow up	Health Center	90	22.5
	Hospital	310	77.5
Malnutrition Status	Yes	25	6.3
	No	375	93.8
How a child knows his/her status	Spontaneous	17	6.49
	Process	245	93.5

Proportion of disclosure and reasons for disclosure of a child’s HIV status: Among 19 caregivers, nearly two-third, 262 (65.5%) (95% CI; 61.0-70.0) of them had disclosed the HIV status for the children.

The most prominent reason for the child’s HIV disclosure is repeated questions by the child which accounted for 45.4% (**Figure 1**).



*Other: - child has reached puberty/started talking about sex.

Figure 1: caregiver’s reason for disclosing their children’s HIV positive status

Factors associated with HIV positive disclosure status: After controlling the confounders, six variables namely; the age of the caregivers, age of the child, duration on ART, death of family, training, and responsible person for the medication of the child were found to be significantly associated with the disclosure status at 95% CI with the corresponding AOR.

Children whose ages were greater than or equal to 12 years were at 8 (AOR=8.05, 95% CI: 3.98-16.26) times greater to the disclosure compared to children’s whose age were less than 12 years.

Caregivers whose ages were greater than or equal to 38 years were 2 (AOR=1.92, 95% CI: 1.07-3.42) times greater probability of disclosing the child’s status compared to caregivers whose age was less than 38 years old .

Those children who stayed on ART for greater than or equal to 6 years were at 3.2 (AOR=3.24, 95% CI: 1.66-6.32) times more odds of disclosure compared to children whose stay on ART was less than 6 years Children who have a history of family death have 2 (AOR=1.98, 95% CI: 1.01-3.92) times more probability of disclosure as compared to children who have no family death history.

Children who have a responsible person for their medications were 3 (AOR=2.87, 95% CI: 1.43-5.76) times greater odds of more disclosure as compared to children who have no responsible person for their medications.

Caregivers who took training about disclosure were 4 (AOR=4.02, 95% CI: 1.93-8.36) times greater chance of disclosing a child’s status as compared to caregivers who don’t take training about disclosure. (**Table 3**).

Table 3: Multivariable binary logistic regression analysis results about disclosure status of HIV positive children in the Northwest part of Ethiopia, 2019.

Variable Name	Child HIV disclosure status		COR (95% CI)	AOR (95%CI)
	Non disclosed	disclosed		
Age of the care giver				
<38	102	126	1	1
≥38	36	136	3.06(1.95-4.80)	1.91(1.07-3.42) *
Age of the child				
<12	122	84	1	1
≥12	16	178	16.15(9.03-28.9)	8.05(3.98-16.26) *
Marital Status				
Married	73	117	0.72(0.47-1.08)	0.74(0.41-1.34)
Unmarried	65	145	1	1
Child's Educational Status				
Non educated	17	19	1	1
Educated	121	243	1.79(0.90-3.58)	1.13(0.46-2.76)
Residency				
Urban	127	250	1.80(0.77-4.20)	1.12(0.39-3.26)
Rural	11	12	1	1
Death of family				
Yes	31	91	1.84(1.14-2.95)	1.98(1.005-3.92) *
No	107	171	1	1
Care giver Start ART				
Yes	117	195	0.52(0.30-0.89)	1.05(0.41-2.73)
No	21	67	1	1
Responsible person for Medication of a child				
Yes	17	136	7.68(4.37-13.48)	2.87(1.43-5.75) *
No	121	126	1	1
Training for a care giver about disclosure				
Yes	17	70	2.59(1.45-4.62)	4.02(1.93-8.34) *
No	121	192	1	1
Duration on ART of the child				
< 6 year	104	120	1	1
≥ 6 year	34	142	3.62(2.29-5.72)	3.24(1.65-6.32) *
Child's Age at Diagnosis of HIV				
< 4 year	89	119	2.18(1.43-3.34)	1.16(0.84-3.12)
≥ 4 year	49	143	1	1
Current caregiver				
Parents	133	230	1	1
Relatives	5	32	3.7(1.40-9.72)	4.39(0.99-19.36)
Relationship of Care giver				
1 ST degree relative	125	220	0.54(0.28-1.05)	2.01(0.53-7.54)
2 ND degree relative	13	42	1	1
Family Size				
< 4	89	119	0.71(0.45-1.10)	1.10(0.57-2.12)
≥ 4	49	143	1	1

Reasons for disclosure or non disclosure: Three main themes were emerged from the qualitative data. These are: reasons for non-disclosure, reasons of the caregivers to come to the child to the health institution and benefit of disclosure.

Reasons for non-disclosure: Participants who were living with HIV infected children reported that they faced being discriminated by the community. Besides, some participants who shared experiences of children who were living with HIV were given nicknames and not allowed to play with other kids in the school. In addition, caregivers mentioned their reasons for not disclosing to the child in several ways as follows:

<<Her friends said, 'We do not go with you, because you are so sick.' They stigmatized her in the kebele, and then I told her, 'you do not have to give attention to what they say. You would rather listen to me and avoid them as friends'>> / biological mother of 10 – year, non-disclosed child//

<<I have one neighbour and she told said to my child, 'I don't drink and ate with you, and I do not use your property/material/. Even I don't drink a cup of water that you touch.' After this event, I did not send my child to my Neighbours. Besides, in the village, they said ton my child, 'you have HIV/AIDS. You are so sick.' So, I said to my child no matter it is not known by your forehead>>/ biological mother of 11- year non-disclosed child/.

<< Why you didn't tell me early? Ohh, why you did not abort me? Why you did birth to me? Ohh, am sorry I don't want to be birth>>/ case manager of 12 - year disclosed child/

<<I don't disclose her status because she may die as soon as she heard her HIV status because she may shock, and she may take aggressive action on herself. Also, she may develop psychological trauma.>>/ biological mother of 12- year non-disclosed child/.

Reasons for caregivers to bring the children who don't know their HIV status to the health institution: << Sick. Since she is sick especially she has ear pain. I tell her to have to go to the health centre to get medication for her ear pain and for her heart pain>>/ biological mother of 12 -year non-disclosed child/

<<I come to the clinic with my child by saying we have an appointment. Our medication appointment is reached>>/biological mother of 8 years non-disclosed child/.

Benefit of disclosure

For medication adherence: Most of the study participants have the view that disclosing the diagnosis would provide HIV-infected children with a reason to take daily medications. Thus, they believed that it would impact positively on medication adherence.

One participant stated, - <<since I told her, she always comes to attend the psychosocial meeting of the hospital. So, now her cognitive ability is developed, and she takes her medication appropriately>> / case manager of 10 – year disclosed child/

For empowering children to take responsibility for their health:

Study participants expressed their view that if children were given adequate information about having HIV, they would not only adhere to medication, they would also play an active part in the management of their conditions such as: reminding parents of allergies, the timing of medications, and timing of reviews. This view was exemplified in this quote: <<Previously she was not volunteer to come to the hospital. Now, she is a volunteer. Once upon a time when I had been sick, she said to me, 'my mother your medication time is reached so please take it.' Even she said to me when the medication box voices, she said, 'my mother, please do not voice the box what are you doing my mother?' She asked me.>> /biological mother of 8 years disclosed child/

For responsible adolescent sexual behaviour: Adolescence is considered generally as a stage in life that is characterized by experimentation in sexual and other areas. Most respondents indicated that irresponsible sexual behaviour by infected children at this stage could have direct consequences on viral transmission. An important way of dealing with this, according to most respondents, was to make infected adolescents awarded of their HIV status.

For instance, one of the participants explained that, << Ya, a child of 15-years old searches peer friends for sexual friendship. So, if you told in this age, he may suicide himself so disclosing early is the best one for me. But if you disclose at the age of nine or ten years, the child lives with his parents, and asks them for the future of his life. Generally, I recommend that let us tell to the child according to their cognitive skill how they accept the status. Now a day's children are so fast, they see period/ye wor abeba/ at the age of eleven, so it is better to disclose them early I think so>>/ biological mother of 10 - year non disclosed child/

DISCUSSION

This study tried to determine the proportion of disclosure, and associated factors on children aged 6 - 18 years old. The study revealed that (65.5%) (CI= 61.0-70.0) of HIV positive children knew their HIV status.

This finding was in line with a study in Rwanda (64%) and Uganda (65%) (22, 37). This might be due to majority of care givers attended psychosocial support groups and received support from the health care provider during the study period.

In addition , the finding of this study was greater compared to other studies conducted in Bahir Dar (31.5%) (28), Addis Ababa (16.3%) (31), and South

east Ethiopia (28.5%) (2). The probable reason for the higher prevalence of disclosure in our study could be due to a inclusion of large number of older school-aged children in the study. Evidence showed that the school-aged children who are on education are highly collated with increased awareness towards disclosure of HIV status (24, 44). This has been supported by our findings where the proportion of school-age children in our study was 48.5% whereas the proportion of school-age children in Addis Ababa, Ethiopia was 22.6 %. Specifically, the studies conducted in Bahir Dar and Bale included children aged 10-14 years old with 51.9%, and 54.5 % respectively. Time difference between the studies could be another possible reason for the observed difference. For instance, the study in Addis Ababa and Bahir Dar, Ethiopia was conducted in 2012 and 2013, respectively. As time passes, awareness is created, and different stakeholders work on areas to improve the disclosure status.

However this finding was greater as compared to studies conducted in Nigeria (30.9%) (18) ,Namibia (33%) (9) , Zambia (29.8%) (13) , Ghana (23.3%) (14) , Tanzania (22.3%) (24), South Africa (34%) (42) and Kenya (26%) (57). It can be due to differences in the period and increased awareness of the benefit of the disclosure of caregivers. Moreover, in this study, first degree relatives were the main caregivers in the sample. So, they are highly forced to disclose their child's status, and it is known that first degree relatives are more likely to disclose their children and orphans (13, 14)

According to our study, age of the child, age of the caregiver, death of family, duration on ART, responsible person for the child's medication, and training were associated factors of disclosure status of HIV positive children.

The odds of being disclosed of HIV positive status with a child whose age was greater than or equal to

12 years was 8 times as compared to children whose age was less than 12 years. Similarly, findings in other African countries reported that children were more likely to know their HIV diagnosis result when they are older. Also, it is supported by a qualitative study done in Tanzania and Ghana (36, 51). A qualitative component of this same study further lends support to this finding reporting that most caregivers considered children below the age of 12 years as being incapable of understanding their illness. Moreover, this might be the caregivers' belief that the child is immature to understand the illness. In addition, this could be due to older children's repeatedly asking to know the reason why they are taking medication. Furthermore, a majority of older children were also in school, and they may have had a chance to learn about HIV.

The odds of disclosure of HIV positive statuses among children who were taking ART medication, and who were greater than or equal to 6 years were 3 times more disclosed compared to their counterparts. This finding was consistent with studies conducted in Bahirdar and Bale Ethiopia, Ghana, and Uganda (2, 28, 47, 61). This could be children who stay on ART for a longer period has regular clinic visits, and they contact health care professionals regularly. As a result, caregivers and children get on-going counselling which helps to facilitate disclosure. Another possible justification could be children who stay on ART for long period makes children ask why they are taking medication while they are well. This may lead to decreased adherence. Therefore the care giver's last option becomes disclosing HIV status to the child. In addition, when the children stay on ART for a long time, they might have a chance to ask questions about the medications that they are taking. The children might ask why they take the medication while they seem healthy. This is also supported by the qualitative component of our study.

This study also found that the death of the family is significantly associated with disclosure. Disclosure among children who have a history of family death was 2 times more likely to disclose as compared to children who have not family death history. This finding is similar to a study conducted in Zambia (13). This could be when a family of the child lost the child raised questions to the present caregiver. Moreover, the majority of HIV infected children acquired the virus from their families. Since disclosure often leads to family secrets that lead to the child to be disclosed.

The age of the caregiver was also another independent determinant factor for disclosure. The odds of to disclose the child's HIV status among caregivers whose age was greater than or equal to 38 years was 2 times than the counterpart. This was similar to a study conducted in South Africa (27, 41). This could be as the age of the caregiver increased, understanding of the benefit of disclosure also increased. So, their disclosure ability may be increased.

The odds of disclosure to the child among caregivers who took training about disclosure were 4 times greater to disclose as compared to caregivers who do not take training about disclosure. It was supported by a qualitative study done in Tanzania (51). The possible justification was training can help caregivers to grasp the bigger picture. When they know more, they are more confident, and thus have greater morale to disclose or may enhance their readiness to disclose. Moreover, improved training on paediatric HIV disclosure would alleviate the discrepancies that exist among caregivers whose responsibility is to disclose the HIV infected child.

Another significant variable was assigned responsible person for the child's medication. The odds of disclosure of HIV positive status among children having a responsible person for their medication

were 3 times greater than their counterparts. This was supported by a mixed study conducted in Kenya (38). The possible reason is that if the child has a responsible person for his/her medication, takes medications appropriately. As a result, the child asks why he takes this medication regularly, and the responsible body may be in forced to disclose his/her status. In addition, most HIV-infected children acquire their infection through vertical transmission, and HIV-infected parents can feel guilt and fear that the child will lose respect for the parent following disclosure. Disclosure to the child can also result in simultaneous disclosure of parental status and may unveil other family secrets. Therefore, HIV-infected parents are faced with issues that make disclosure emotional and challenging. However, if there is a responsible person, this issue may not happen.

This study revealed four themes which are associated with paediatric HIV disclosure status. The most common reasons of non-disclosure reported by caregivers in this study include: child is too young, fear of inability of the child to keep secret, fear of negative emotional and psychological consequences, and stigma. These were in line with a systemic review study that includes most of the resource-limited settings including Ethiopia and a qualitative study done in Zambia (20, 46). In addition, it was also in line with a study conducted in Addis Ababa and South Africa (31),(44). The participants also mentioned that the child could not understand the information, and they may disclose it to other people. This was in line with a study conducted in Bale, Ethiopia (2).

The most frequent reason for disclosure was a child was consistently asking questions about the reasons why he/she was taking medication. It was consistent with some studies conducted previously in different countries such as in South Africa, Zambia, Nigeria, and Bale, Ethiopia (2, 21, 44, 46).

The study found that caregivers who had disclosed in this study reported seeing some benefits in doing so. After knowing their HIV diagnosis, children displayed good adherence practices to their ART medication, and their overall acceptance of living with HIV. Some of the caregivers reported that their children started their ART medication with minimal supervision while others reported that they had less difficulty in persuading their children to go for a medical check-up. Knowing more about the disease assisted children to know more about their illness, the effects of missing doses, and acceptance of their HIV diagnosis. This finding was consistent with a study conducted in Ghana (62).

Studies showed that communication of caregivers with their infected children was characterized by deceit, and the use of false names to describe their illness. In this study, caregivers who had not disclosed told their children inaccurate information about their illness. Providing deceptive information is a strategy used when caregivers feel unprepared for full disclosure. This was parallel with a qualitative study conducted in Botswana (45).

Another major barrier to the disclosure of HIV status was the stigma which is associated with the illness. They have of the view that in their communities, HIV is seen as a sickness caused by the supernatural powers as a result of either punishment or breaking communal taboos. Once people get to know of your HIV status, you are labelled, and people will not be willing to interact with you. This will affect people's participation in community activities. In order to avoid these negative attributions and labelling, caregivers decide not to disclose the status to the children. This was in line with a study conducted in Ghana (36) and a qualitative study conducted in Botswana (45).

Limitation: This study has a limitation. Since dis-

closure was determined based on the caregiver's report, the study may be suffered by a social desirability bias. Besides, there may be recall bias that might have affected this study.

CONCLUSION

Although WHO guideline on HIV disclosure counseling for children and other global HIV disclosure perspectives recommend that all children starting from six year should be disclosed of their HIV status, the HIV disclosure status of children was low in our study. Age of the child, age of the caregiver, duration on ART, death of family, training, and responsible person for the child's medication was significantly associated with disclosure. The caregivers have explored multi-factorial reasons for disclosure of HIV status of a child. It is better to plan interventions and strategies to improve disclosure of HIV status to children in health Institutions.

List of abbreviation

AIDS - Acquired Immune Deficiency Syndrome

ART - Antiretroviral Therapy

COD- crude odds ratio

FMOH – Federal Ministry of Health, HCP- Health Care Provider

HIV - Human Immune Virus, **IDI** – In-depth Interview

UNAIDS-United Nation Program on Human Immune Virus/Acquired Immune Deficiency Virus

WHO - World Health Organization, **HAART**-Highly active antiretroviral therapy

Ethics approval and consent to participate: A formal letter was taken from the University of Gondar, College of medicine and health sciences, Institute of Public Health. The Ethical letter-number permitted to do this research was Ref no./IPH/120/06/2011 written on the date of 26/06/2019. Oral consent was obtained before the participants interviewed from each individual.

Authors contribution: ZAY selected the title, developed the proposal, analysed the data, and prepared the manuscript. GD wrote the methods of the manuscript, participated in the data quality follow up and analysis wrote, and approves the manuscript. MWM and AE have commented the proposal, developed, edited the manuscript. AA has participated in the proposal writing, data analysis, check the data quality, and approve the manuscript. All the authors have participated in approving the manuscript.

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REFERENCE

1. Aderomilehin O, Hanciles-Amu A, Ozoya OO. Perspectives and practice of HIV disclosure to children and adolescents by health-care providers and caregivers in sub-Saharan Africa: a systematic review. *Frontiers in public health*. 2016;4:166.
2. Lencha B, Ameya G, Minda Z, Lamessa F, Darega J. Human immunodeficiency virus infection disclosure status to infected school aged children and associated factors in bale zone, Southeast Ethiopia: cross sectional study. *BMC pediatrics*. 2018;18(1):356.
3. Wang H, Wolock TM, Carter A, Nguyen G, Kyu HH, Gakidou E, et al. Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2015: the Global Burden

- of Disease Study 2015. *The lancet HIV*. 2016;3(8):e361-e87.
4. Odiachi A. The impact of disclosure on health and related outcomes in human immunodeficiency virus-infected children: a literature review. *Frontiers in public health*. 2017;5:231.
 5. Arrivé E, Dicko F, Amghar H, Aka AE, Dior H, Bouah B, et al. HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PLoS One*. 2012;7(3):e33690.
 6. Boon-Yasidhi V, Naiwatanakul T, Chocephai-bulkit K, Lolekha R, Leowsrisook P, Chot-pitayasunond T, et al. Effect of HIV diagnosis disclosure on psychosocial outcomes in Thai children with perinatal HIV infection. *International journal of STD & AIDS*. 2016;27(4):288-95.
 7. Namukwaya S, Papparini S, Seeley J, Bernays S. "how Do We start? and how Will They react?" Disclosing to Young People with Perinatally acquired hiV in Uganda. *Frontiers in public health*. 2017;5:343.
 8. Atuyambe LM, Ssegujja E, Ssali S, Tumwine C, Nekesa N, Nannungi A, et al. HIV/AIDS status disclosure increases support, behavioural change and, HIV prevention in the long term: a case for an Urban Clinic, Kampala, Uganda. *BMC Health Services Research*. 2014;14(1):276.
 9. Beima-Sofie KM, Brandt L, Hamunime N, Shepard M, Uusiku J, John-Stewart GC, et al. Pediatric HIV disclosure intervention improves knowledge and clinical outcomes in HIV-infected children in Namibia. *Journal of acquired immune deficiency syndromes (1999)*. 2017;75(1):18.
 10. Kodyalamoole NK, Badiger S, Kiran NU, Dodderi SK, Rewari B. Pattern of paediatric HIV status disclosure in coastal Karnataka. *The Indian journal of medical research*. 2018;147(5):501.
 11. Mengesha MM, Dessie Y, Roba AA. Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia: a health facility-based cross-sectional study. *BMJ open*. 2018;8(8):e019554.
 12. Naigino R, Makumbi F, Mukose A, Buregyeya E, Arinaitwe J, Musinguzi J, et al. HIV status disclosure and associated outcomes among pregnant women enrolled in antiretroviral therapy in Uganda: a mixed methods study. *Reproductive health*. 2017;14(1):107.
 13. Tsuzuki S, Ishikawa N, Miyamoto H, Dube C, Kayama N, Watala J, et al. Disclosure to HIV-seropositive children in rural Zambia. *BMC pediatrics*. 2018;18(1):272.
 14. Hayfron-Benjamin A, Obiri-Yeboah D, Ayisi-Addo S, Siakwa PM, Mupepi S. HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana. *BMC pediatrics*. 2018;18(1):365.
 15. Watermeyer J. 'Are we allowed to disclose?': a healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expectations*. 2015;18(4):590-600.
 16. American Academy of pediatrics .Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*. 1999;103(1):164-6.
 17. World Health Organization . Guideline on HIV disclosure counselling for children up to 12 years of age. 2011.
 18. Ubesie A, Iloh K, Emodi I, Ibeziako N, Obumneme-Anyim I, Iloh O, et al. HIV status disclosure rate and reasons for non-disclosure among infected children and adolescents in Enugu, southeast Nigeria. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 2016;13(1):136-41.
 19. Pinzón-Iregui MC, Beck-Sagué CM, Malow RM. Disclosure of their HIV status to infected chil-

- dren: a review of the literature. *Journal of Tropical Pediatrics*. 2012;59(2):84-9.
20. Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society*. 2013;16(1).
 21. Odiachi A, Abegunde D. Prevalence and predictors of pediatric disclosure among HIV-infected Nigerian children on treatment. *AIDS care*. 2016;28(8):1046-51.
 22. Staff PO. Correction: Caregivers' Attitudes towards HIV Testing and Disclosure of HIV Status to At-Risk Children in Rural Uganda. *PLoS one*. 2016;11(4):e0154169.
 23. Madida S, Mahloko J, Mokwena K. Prevalence And Factors Associated With Disclosure Of HIV Diagnosis To Infected Children Receiving Antiretroviral Treatment In Public Health Care Facilities In Gauteng ,South Africa. 2013;1(1):35.
 24. Mumburi LP, Hamel BC, Philemon RN, Kapan-da GN, Msuya LJ. Factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre in Moshi, Tanzania. *The Pan African Medical Journal*. 2014;18.
 25. Ingabire S, Mutesa L. Factors determining disclosure by parents among children living with hiv/aids attending the center of excellence in Kigali University Teaching Hospital.. *Rwanda medical journal*; 2014.
 26. Biadgilign S, Deribew A, Amberbir A, Escudero HR, Deribe K. Factors associated with HIV/AIDS diagnostic disclosure to HIV infected children receiving HAART: a multi-center study in Addis Ababa, Ethiopia. *PLoS One*. 2011;6(3):e17572.
 27. Negese D, Addis K, Awoke A, Birhanu Z, Muluye D, Yifru S, et al. HIV-positive status disclosure and associated factors among children in North Gondar, Northwest Ethiopia. *Isrn aids*. 2012;2012.
 28. Alemu A, Berhanu B, Emishaw S. Challenges of Caregivers to Disclose Their Children's HIV Positive Status Receiving Highly Active Antiretroviral Therapy at Pediatric Antiretroviral Therapy Clinics in Bahir Dar, North West Ethiopia. *Journal of AIDS & Clinical Research*. 2013;4(253).
 29. Tadesse BT, Foster BA, Berhan Y. Cross sectional characterization of factors associated with pediatric HIV status disclosure in southern Ethiopia. *PLoS One*. 2015;10(7):e0132691.
 30. Bhattacharya M, Dubey AP, Sharma M. Patterns of Diagnosis Disclosure and its Correlates in HIV-Infected North Indian Children. *Jornal of tropical pediatrics*. 2011; 57(10).
 31. Abebe W, Teferra S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. *AIDS care*. 2012;24(9):1097-102.
 32. Atwiine B, Kiwanuka J, Musinguzi N, Atwine D, Haberer JE. Understanding the role of age in HIV disclosure rates and patterns for HIV-infected children in southwestern Uganda. *AIDS care*. 2015;27(4):424-30.
 33. Britto C, Mehta K, Thomas R, Shet A. Prevalence and correlates of HIV disclosure among children and adolescents in low-and middle-income countries: a systematic review. *Journal of developmental and behavioral pediatrics: JDBP*. 2016;37(6):496.
 34. Das A, Detels R, Javanbakht M, Panda S. Issues around childhood disclosure of HIV status—findings from a qualitative study in West Bengal, India. *Child: care, health and development*. 2016;42(4):553-64.

35. Ekstrand ML, Heylen E, Mehta K, Sanjeeva G, Shet A. Disclosure of HIV Status to Infected Children in South India: Perspectives of Caregivers. *Journal of tropical pediatrics*. 2017.
36. Gyamfi E, Okyere P, Enoch A, Appiah-Brempong E. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC international health and human rights*. 2017;17(1):8.
37. Ingabire S, Mutesa L. Factors determining disclosure by parents among children living with HIV/AIDS attending the Center of Excellence in Kigali University Teaching Hospital. *Rwanda Medical Journal*. 2014;71(2):5-11.
38. John-Stewart GC, Wariua G, Beima-Sofie KM, Richardson BA, Farquhar C, Maleche-Obimbo E, et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. *AIDS care*. 2013;25(9):1067-76.
39. Kalembo FW, Kendall GE, Ali M, Chimwaza AF. Healthcare workers' perspectives and practices regarding the disclosure of HIV status to children in Malawi: a cross-sectional study. *BMC health services research*. 2018;18(1):540.
40. Krauss BJ, Letteney S, Okoro CN. Why tell children: A synthesis of the global literature on reasons for disclosing or not disclosing an HIV diagnosis to children 12 and under. *Frontiers in public health*. 2016;4:181.
41. Madiba S. Patterns of HIV diagnosis disclosure to infected children and family members: data from a paediatric antiretroviral program in South Africa. *World Journal of AIDS*. 2012;2(03):212.
42. Madiba S, Mahloko J, Mokwena K. Prevalence and factors associated with disclosure of HIV diagnosis to infected children receiving antiretroviral treatment in public health care facilities in Gauteng, South Africa. *Journal of Clinical Research in HIV Aids and Prevention*. 2013;1(2):13.
43. Madiba S, Mokgatle M. Health care workers' perspectives about disclosure to HIV-infected children; cross-sectional survey of health facilities in Gauteng and Mpumalanga provinces, South Africa. *PeerJ*. 2015;3:e893.
44. Mahloko JM, Madiba S. Disclosing HIV diagnosis to children in Odi district, South Africa: reasons for disclosure and non-disclosure. *African journal of primary health care & family medicine*. 2012;4(1).
45. Motshome P, Madiba S. Perceptions, reasons and experiences of disclosing HIV diagnosis to infected children in Kweneng District, Botswana. *International Journal of Health Sciences and Research*. 2014;4(2):129-39.
46. Mweemba M, Musheke MM, Michelo C, Halwiindi H, Mweemba O, Zulu JM. "When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. *BMC public health*. 2015;15(1):1028.
47. Namasopo-Oleja SM, Bagenda D, Ekirapa-Kiracho E. Factors affecting disclosure of serostatus to children attending Jinja Hospital Paediatric HIV clinic, Uganda. *African health sciences*. 2015;15(2):344-51.
48. Organization WH. Guideline on HIV disclosure counselling for children up to 12 years of age. 2011.
49. Osingada CP, Okuga M, Nabirye RC, Sewankambo NK, Nakanjako D. Prevalence, barriers and factors associated with parental disclosure of their HIV positive status to children: a cross-sectional study in an urban clinic in Kampala, Uganda. *BMC public health*. 2016;16(1):547.
50. Punpanich W, Lolekha R, Chokephaibulkit K, Naiwatanakul T, Leowsrisook P, Boon-Yasidhi

- V. Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand. *International journal of STD & AIDS*. 2014;25(13):929-35.
51. Sariah A, Rugemalila J, Somba M, Minja A, Makuchilo M, Tarimo E, et al. "Experiences with disclosure of HIV-positive status to the infected child": Perspectives of healthcare providers in Dar es Salaam, Tanzania. *BMC public health*. 2016;16(1):1083.
52. Turissini ML, Nyandiko WM, Ayaya SO, Marete I, Mwangi A, Chemboi V, et al. The prevalence of disclosure of HIV status to HIV-infected children in Western Kenya. *Journal of the Pediatric Infectious Diseases Society*. 2013;2(2):136-43.
53. Vaz LM, Maman S, Eng E, Barbarin OA, Tshikandu T, Behets F. Patterns of disclosure of HIV status to infected children in a sub-Saharan African setting. *Journal of developmental and behavioral pediatrics: JDBP*. 2011;32(4):307.
54. Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society*. 2013;16(1):18466.
55. Vreeman RC, Nyandiko WM, Ayaya SO, Walumbe EG, Marrero DG, Inui TS. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS patient care and STDs*. 2010;24(10):639-49.
56. Vreeman RC, Scanlon ML, Marete I, Mwangi A, Inui TS, McAteer CI, et al. Characteristics of HIV-infected adolescents enrolled in a disclosure intervention trial in western Kenya. *AIDS care*. 2015;27(sup1):6-17.
57. Vreeman RC, Scanlon ML, Mwangi A, Turissini M, Ayaya SO, Tenge C, et al. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. *PLoS One*. 2014;9(1):e86616.
58. Murnane PM, Sigamoney S-L, Pinillos F, Shiao S, Strehlau R, Patel F, et al. Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status. *AIDS care*. 2017;29(3):378-86.
59. Bhatia A, Ruducha J, Semrau K, Mann C, Lunstead J, Kumar P, et al. DISCLOSURE OF CHILDREN'S HIVSTATUS IN FOUR HIGH PREVALENCE STATES IN INDIA. 2012.
60. C.Vreeman R, Michael.L.Scanlon, Marete I, Mwangi A, Inui TS, McAteer C, et al. Characteristics of HIV infected adolescents enrolled in a disclosure intervention trial in western Kenya. *AIDS Care - Psychological and socio medical aspects of AIDS/HIV*. 2015;27:6 - 17.
61. Kallem S, Renner L, Ghebremichael M, Paintsil E. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS and Behavior*. 2011;15(6):1121-7.
62. Gyamfi E, Okyere P, Appiah-Brempong E, Adjei RO, Mensah KA. Benefits of disclosure of HIV status to infected children and adolescents: perceptions of caregivers and health care providers. *Journal of the Association of Nurses in AIDS Care*. 2015;26(6):770-80.