



HIV positive status disclosure and associated factor among HIV infected children in pediatric ART clinics in Gondar town public health facilities, North West Ethiopia, 2018

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ABSTRACT

Background: Due to the increasing availability of antiretroviral treatment, HIV infected children are living longer which points out the necessity of disclosure. And which is important to support the uptake and adherence to treatment. Disclosure is an important measure to prevent secondary transmission when children are sexually active.

Objective: The aim of this study was to determine the prevalence of HIV positive status disclosure and associated factors among human immune virus-infected children in pediatric antiretroviral treatment clinics in Gondar town public health facilities.

Method: An institution based cross-sectional study was conducted among 449 primary caregivers of children aged 6–15 years in regular follow-up at pediatric ART clinics in Gondar town public health facilities between March 3, 2018, to April 25, 2018. All subjects in the study area were included in the study. Data was collected in 5 pediatric ART clinics in Gondar town by structured questionnaires through face to face interview and supplemented by chart review to obtain some clinical factors. The variables which have an association with disclosure were identified on the basis of AOR, with 95%CI and p-value <0.05. Model fitness was checked using Hosmer and Lemeshow goodness of fit test.

Result: Out of 449 participants, 418 were interviewed with response rate of 93%. The prevalence of HIV positive status disclosure found to be 44%. Age of child >10 years [AOR = 5.88, (95% CI: 3.52, 9.81)], duration on ART [AOR = 2.67 (95% CI: 1.59, 4.51)], place of follow-up [AOR = 2.23 (95% CI: 1.27, 5.01)] and educational status of caregiver [AOR = 3.00 (95% CI: 1.62, 5.56)] were identified variables.

Conclusion: The prevalence of disclosure found to be low. Therefore appropriate measure should be taken to promote disclosure.

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Introduction

Human immune virus/Acquired immune deficiency virus has a devastating impact on both adult and children. According to the UNAIDS report in 2016, 36.7 million people living with HIV. Of all, 2.1 million were children less than 15 years. In addition, 160,000 children become newly infected with HIV and 1 million people died from AIDS related illness in the same year worldwide [1]. Sub Saharan

Africa accounts for 76% AIDS related global morbidity and 75% global mortality [2]. In Ethiopia, 718,500 people were living with HIV, out of this around 398,277 adults and 21,686 children under the age of 15 are taking ARV [3].

Disclosure is one of the greatest psychological challenges that families and health care providers face to decide how and when to disclose HIV positive status to children [4,5]. Due to the increasing availability of antiretroviral treatment, HIV infected children are living longer which point out the necessity of disclosure and it aid adherence to treatment [6]. Caregivers with HIV infected child have difficulty accepting the illness, either their own or their child's, and struggle with whether or not to disclose the diagnosis of HIV infection [3]. Caregivers fear the consequences of disclosing HIV positive status to the children. Disclosure commonly occurred suddenly in response to a crisis, rather than as part of an anticipated and

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planned process [6,7]. As one systemic review showed that prevalence disclosure of HIV positive status varies widely which is ranged from 1.2 to 75.0% as a result of various factors [4]. In Sub Sahara African setting, 50% of caregivers had provided no information to the child about their HIV status [8].

According to EDHS 2011, young people are more likely to have sex before age 15 or age 18 [9]. Likewise in Uganda, a study on preventive service reported that only 37% of children living with HIV [10]. Poor disclosure causes a disastrous effect in children who do not know their HIV-positive status and consequently, children may be less likely to take their medication regularly, which can lead to drug resistance and death [11]. On the other hand, disclosure impacts on clinical outcome and mental health of children living with HIV. A study in Rome on the influence of disclosure of HIV diagnosis on time to disease progression revealed that non-disclosed children were more likely to die and experienced CD4 decline [11]. Furthermore, a study conducted in Nigeria reported that from 19.4% of children with mental health problem 89% were not aware of their HIV status [12]. Disclosure in HIV infected children improved clinical outcomes like viral suppression, adherence, and HIV knowledge [13–15]. In addition, disclosure improves retention in care [16].

American Academy of Pediatrics and WHO strongly recommends a gradual process of giving age appropriate information to HIV infected school-age children by considering the child's cognitive and emotional development [6,17].

Despite recommendations and benefit of disclosure, different studies report a low prevalence of disclosure due to different factors. In our country, there are studies conducted on this regard and disclosure rate is low. As studies in Ethiopia showed that the prevalence of disclosure was 39.5%, 17.4% and 31.5% in Gondar, Addis Ababa, and Bahirdar, respectively [32–34]. And most of the studies were conducted only at a hospital setting. Furthermore, current information on HIV positive status disclosure among children is not known in the area. Therefore, the aim of this study was to determine the prevalence of HIV positive status disclosure and factors among children who have ART treatment follow-up at Gondar Town public health centers facilities Gondar Ethiopia.

Method and materials

Institutional based cross-sectional study was conducted from March 3 to April 25, 2018. The study was conducted at Gondar town public health facilities/health centers which provide pediatric ART service. Gondar is about 750 km far from the Northwest of Addis Ababa, the capital city of Ethiopia. According to the 2015 population projection of major cities in Ethiopia, the total population size of Gondar town was estimated to be 323,900. Currently, Gondar town has one Referral Hospital and eight governments Health Centers. Out of eight health centers, namely Maraki health center, Azezo health center, poly health center, and Teda health center provide ART service. A total of 753 children, less than 15 years are on ART in the town. Out of this 449, hundred children are aged from 6 to 15 years. All HIV positive children aged from 6 to 15 years who are in regular follow-up at pediatric ART clinics in Gondar town public health facilities were source and study populations. The adult accompanying children who are not primary caregivers of a child and who did not know a child's disclosure status, Caregivers of the child whose age is less than 18 years and children who came to the clinic by themselves were excluded from the study.

Sample size determination and sampling procedure

Sample size determination

The sample size was determined by single population proportion formula by considering the following statistical assumptions:

95% confidence level (CI), proportion = 31.5% (from a study conducted in Bahirdar) and 5% of marginal error. The final sample size was 365 with a 10% non-response rate. Since the calculated sample size approximately close to the source population, finally, all the subjects (449 subjects) included in the study.

Operational definition

Disclosure is when caregivers said that the child knows his/her HIV/AIDS diagnosis regardless of who told the child [31,32].

Primary caregiver – A person, who lives with the child, participates in the child's daily care and who knows most about the child's health [16].

Data collection tool and procedure, and analysis

The questionnaires were prepared by reviewing previous studies and carefully adapted to local contexts. Data was collected from 5 pediatric ART clinics by using structured questionnaires through face to face interview and supplemented by chart review. The questionnaire was first prepared in English and then translated to local language Amharic then back to English to ensure consistency. The training was given for data collectors and supervisors before the actual data collection. A pretest was done at Bahir Dar health centers by taking 10% of the population to assess clarity, flow and consistency, and revision was done prior to data collection. Before analysis, the data was cleaned up and cross-checked for completeness and its consistency. After the data have been checked, coded and entered to EPI INFO version 7 and then exported to SPSS version 22 for analysis. Frequencies and proportions were computed for description of the study population in relation to socio-demographic and other relevant variables. Variables with p-value <0.2 in binary logistic regression were entered into multiple logistic regression models. Multiple logistic regressions were used to control the possible effect of confounders. Finally, the variables which have an association with disclosure were identified on the basis of AOR, with 95%CI and p-value ≤0.05. Model fitness was checked using Hosmer and Lemeshow goodness of fit test.

Result

Socio-demographic characteristics of the caregiver

Out of 449 caregivers, 418 were interviewed during the study period with a response rate of 93%. Of them 305 (73%) were females, 203 (48.6%) belonged to the age group 31–40 years. The median age of caregiver was 37 years (IQR = 11 years). Regarding educational level, 163 (39%) of caregivers attended primary school while 121 (28.8%) were illiterate. Concerning residence majority of caregivers 369 (88.3%) was urban residence. In terms of relation with child, 325 (77.8%) of caregivers were biological parents and 316 (75.6%) of caregivers were HIV positive (Table 1).

Socio-demographic and clinical characteristics of HIV positive children

Out of 418 children aged 6–15, more than half of children 233 (55.7%) age were greater than 10 years and half of the children 212 (50.7%) were males. The mean age of children was 10.8 (SD = 2.52) years. Majority of children 388 (92.8%) were started education.

About two hundred thirty (55%) of them were duration on ART between 6–10 years. The median age at diagnosis was 3 yrs and (IQR = 4) years. Majority of children 339 (81.1%) attended their follow-up at the hospital. About 347 (83%) children had a history

Table 1
Socio-demographic characteristics of care giver of HIV positive children who attend ART clinic in Gondar town public health facilities, North West Ethiopia, 2018.

Variables	Frequency	Percent	
Age	<+30	82	19.6
	31–40	203	48.6
	41–50	78	18.7
	51–60	36	8.6
	>+61	19	4.5
Sex	Male	113	27
	Female	305	73
Residence	Urban	369	88.3
	Rural	49	11.7
	Illiterate	121	28.8
Educational status	Can read and write	53	12.7
	Primary education	163	39
	Secondary and above	81	19.4
Marital status	Married	198	47.4
	Unmarried	220	52.6
	Farmer	36	8.6
Occupation	Employed	88	21.1
	Unemployed	294	70.1
Family size	<3	143	34.2
	>+3	275	65.8
Relation with child	Biological parents	325	77.8
	Non biological	93	22.2
HIV status	Positive	316	75.6
	Negative	98	23.4

Table 2
Socio-demographic and clinical characteristics of the child who attends ART follow-up at Gondar town public health facilities, North West Ethiopia, 2018.

Variables	Frequency	Percent	
Age of child	<10 years	185	44.3
	≥10 years	233	55.7
Sex	Male	212	50.7
	Female	206	49.3
Educational level	Not started	30	7.1
	Started	388	92.8
Age at diagnosis	<5	326	78
	≥5	92	22
	1–5	160	38.3
Duration on ART	6–10	230	55
	11–15	28	6.7
	Health center	79	18.9
Place of follow-up	Hospital	339	81.1
	Stage I	169	40.4
	Stage II	120	28.7
WHO clinical staging	Stage III	112	26.8
	Stage IV	17	4.1
	Yes	347	83
History medication other than ART	No	71	17
	Yes	334	79.9
History of opportunistic infection	No	84	20.1
	Yes	167	40
History of hospitalization	No	251	60
	Yes	174	41.6
Support from any organization	No	244	58.4
	Yes	190	45.5
Death of family members	No	228	54.5

of taking medication other than ART and 334 (79.9%) had history of opportunistic infection. Out of the total of children, 169 (40.4%) children had WHO clinical staging I disease and 167 (40%) children had a history of hospitalization (Table 2).

Disclosure status of HIV positive children

In this study, 184 (44%) of children living with HIV knew their HIV status. The mean age at disclosure was 9.4 (SD=2) years. Among this 184 children's, majority of children 120 (70.7%) were disclosed by their biological parents, 25 (13.6%) by their grandparents, 20 (10.8%) by health professionals, relatives 8 (4.3%) and

others (0.5%). The common reasons for disclosure reported by caregivers were due to repeated question of the child 132 (61.1%), because the child thought to be matured to understand the illness 36 (16.7%), to prepare the child to take medication 24 (11.1%), fear of accidental disclosure 13 (6%) and 11 (5.1%) others. On the other hand, common reasons for not disclosing were because the child is too young and fear that the child's inability to keep secret 143 (42.3%) and 86 (25.4%), respectively. For children's who did not disclose, caregivers told other reasons to visit a clinic like TB 32 (13.7%), cardiac follow-up 60 (25.6%), for appointment 100 (42.7%), to prevent illness 34 (14.5%) and 8 (3.4%) others. All of caregiver's of children who were not disclosed had a plan to disclose HIV status of their children. In addition, all caregivers believe that disclosing HIV positive status to the children have an advantage. Majority of caregivers believed that 342 (81.8%) biological parent should be responsible to disclose HIV status of the children. About (40.7%) of caregivers of children who were not disclosed believed that the preferred age to disclose a child should be 10–14 years.

Factors associated with HIV positive status disclosure

In bi-variable analysis, eight factors were associated with HIV positive status disclosure of children but after controlling confounding in multivariable logistic regression place of follow-up, duration on ART, the age of child and educational status of caregiver were significantly associated with disclosure (Table 3).

Discussion

This study tried to determine the prevalence of disclosure and associated factors among children aged 6–15 years. The study revealed that, 44% (95% CI, 39%–49%) of HIV positive children knew their serostatus. The finding of this study is in line with the previous study which was conducted in north Gondar hospitals (39.5%) so far and in India (41.4%) [20,33]. The possible justification of this similarity with this study might be similar to the socioeconomic and cultural conditions of the participants. The study which was conducted in India might be highly similar to with age groups of this study.

But the finding of this study, higher as compared to other studies which were conducted in Bahir Dar, Addis Ababa, Kenya, Tanzania, Nigeria, and South Africa 31.5%, 17.4%, 11.1%, 22.3%, 29%, and 34%, respectively [25,28–30,32,33]. The possible explanation for the study conducted in Bahir Dar and Addis Ababa might be due to the difference of awareness about the benefit of disclosure. In addition, most of the caregivers in the current study that they attended only primary education. For the study in Kenya, HIV positive status disclosure in children measured based on both caregivers and children report. As opposed to the current study which was based on the only caregivers report which might have an effect on prevalence. The possible justification for the study which was studied in South Africa might have age group difference which was 4–17 years. Since the study includes young children, the families may believe that the child is young to understand the illness. For other studies, there might be socio-cultural and health service variations.

However, lower as compared to studies conducted in North America, Canada, Uganda, and Rwanda, which was 10%–75%, 56%, and 64%, respectively [18,23,26]. This could be due to socio-cultural difference, good child-parent interaction and the presence of better health care service that promote disclosure. The possible explanation for the study was conducted in Uganda is that the study includes elderly children aged 5–18 years who have a greater possibility to be disclosed. They are matured and eager to ask questions frequently to know about their illness, as a result, the caregivers

Table 3
Bivariable and multivariable logistic regression analysis of factors associated with HIV positive status disclosure Gondar town public health facilities, Northwest Ethiopia, 2018.

Variables		Disclosure status		COR (95%CI)	P-value	AOR (95%CI)
		Yes	No			
Marital status	Married	78	120	0.699 (0.474–1.031)	0.71	0.627 (0.389–1.011)
	Unmarried	106	114	1		
Residence	Urban	171	198	2.392 (1.228–4.657)	0.10	1.441 (0.620–3.349)
	Rural	13	36	1		
	Illiterate	31	90	1		
Educational status of caregiver	Can read and write	22	31	0.476 (0.261–0.869)	0.16	2.163 (0.958–4.880)
	Primary education	97	66	0.981 (0.486–1.980)		
	Secondary and above	34	47	2.032 (1.183–3.489)		
Educational status of child	Not started	6	24	1	0.009	1.280 (0.379–4.324)
	Started	178	210	0.295 (0.118–0.738)		
	Stage1	88	81	1.222 (0.450–3.319)		
WHO clinical staging	Stage2	61	59	1.163 (0.421–3.217)	0.771	1.284 (0.399–4.127)
	Stage3	27	85	0.357 (0.126–1.017)		
	Stage4	8	9	1		
Place of follow-up	Health center	18	61	1	0.000	2.230 (1.277–5.012)*
	Hospital	166	173	0.308 (0.174–0.542)		
Age of the child	<10	35	150	1	0.000	5.884 (3.528–9.813)*
	≥10	149	84	0.132 (0.083–0.207)		
Duration on ART	1–5	45	115	1	0.000	2.678 (1.591–4.510)*
	6–10	121	109	0.217 (0.093–0.507)		
	11–15	18	10	0.617 (0.273–1.394)		

Key * stands for significant variables.

may disclose to children. And for the study which was conducted in Rwanda, it might be due to variation in the study setting.

In this study, age of the child, place of follow-up, duration on ART and educational status of the caregivers were identified as significant factors. The odds of being disclosed of HIV positive status with age greater than 10 years were 5.9 times higher as compared to children lesser than 10 years age children. This study is consistent with the study that was conducted in Gondar, South Africa, Nigeria, and Uganda [26,31,33]. This might be due to the caregivers believed that the child is matured to understand the illness. And also they may have less dread about the child leaking of the family's secret.

The odds of disclosure of HIV positive status among children who are taking ART medication 6–10 years were 2.7 times more likely as compared to their counterparts. This finding is consistent with studies which were conducted in Bahir Dar and Ghana [32,34]. This could be children stay on ART for a longer period has visited regularly at the clinic. They contact with health care professionals regularly, as a result, the caregivers and the children get ongoing counseling which helps to facilitate disclosure. Another possible justification could be children stay on ART for a long period no longer develops symptoms. And this direct to the children to ask why they are taking medication while they are well. This may lead to decreased adherence; therefore, the caregivers last option become disclosing HIV status to the child.

This study also found that the educational level of caregivers significantly associated with disclosure. Disclosure among children whose caregivers' had primary education was 3 times more likely disclosed as compared to illiterate caregivers. This finding is similar to a study that was conducted in India [20]. This could be increased in awareness about the benefit of disclosure and knowledge about how to disclose by acquiring information through different ways.

Place of follow-up is also another factor that was significantly associated with disclosure. Those children who attended the follow-up at the hospital were 2.2 times more likely disclosed as compared to the health center. This finding consistent with a study conducted in Addis Ababa which showed that the children who referred from hospitals were more likely to be disclosed as compared to health center [30]. This might be due to the presence of more knowledgeable and qualified professionals who assist in disclosure through counseling.

The mean age at disclosure in this study 9.4 (SD=2) and this is in line with studies which were previously conducted in India, Uganda, and Thailand [19,20,26]. This could be possible at the age of cognitive development of illness begins.

The most common reasons for non-disclosure were reported by the caregivers. In this study, the child is too young, fear of inability the child to keep secret, fear of negative emotional and psychological consequences and stigma which was in line with a systemic review that include most of the resource limiting settings includes Ethiopia [21].

Limitation and strength of the study

Since the disclosure of HIV, positive status is based on caregivers report, there might be a possibility that those children who were not disclosed may be falsely reported as disclosed. This study was done on children's who have ART follow-up at governmental health centers and it makes different from previous studies which were done at hospital setup.

Conclusion

The Prevalence of disclosure in this study found to be low. Age of child greater than 10 years, duration on ART 6–10 years, place of follow-up and educational level of the caregiver was significantly associated with disclosure. The care provider should give age-appropriate counseling, by considering the educational level of the caregiver, offer social support and work together with caregivers on the progressions of disclosing children's HIV status. Government and other stakeholders should strengthen and continue their support for the caregivers on the care of children. Further research, like qualitative, may better explore the factors which are not addressed through this quantitative research.

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Competing interests

None declared.

Ethical approval

A formal letter was obtained after the approval of the proposal by the ethical review Committee of School of Nursing on behalf of the Institutional Review Board of the University of Gondar. Written informed consent was obtained before participants interviewed from each individual. The interview was conducted in a private room to ensure privacy. Caregivers were informed that participating in the study was voluntary and refusal to participate will not compromise the medical care that their children received from the clinic. The name or any other identifying information was not recorded on the questionnaires and all recorded information was kept strictly and in a safe place. All collected information was used only for the study purpose.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.jiph.2019.05.018>.

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