

Research Article

Disclosure Status and Associated Factors among Children Living With HIV in East Gojjam, Northwest of Ethiopia 2014

Yezihalem Tamir

Debre Markos University, Debre Markos, Ethiopia

Mekonen Aychiluhem

GAMBY College of Medical Sciences, Bahir Dar, Ethiopia

Dube Jara

Department of Public Health, Debre Markos University, Debre Markos, Ethiopia

ABSTRACT

Background: Expanding access to ART is changing the global HIV epidemic in momentous ways. But, one of the greatest psychosocial challenges that parents/ caregivers and health care workers face is the disclosure of HIV-positive status to children living with the virus.

Objective: To assess the magnitude of HIV-positive status disclosure and associated factors among children living with HIV in East Gojjam zone, Northwest of Ethiopia.

Methods: Institutional based cross-sectional study was conducted to collect data from 300 family/caregivers of 6-15 years old children and have follow-up on pediatric ART care and treatment center in East Gojjam Hospitals. The collected data were entered and cleaned using Epi-data 3.1 and exported to SPSS version 16.0 for analysis. Logistic regression model was used to fit data in order to identify factors associated with HIV positive status disclosure.

Result: Of total, 33.3% of the children living with HIV

were disclosed their HIV-positive status. Age of the child, length of stay on ARV drug treatment and responsibility to take drug were significantly associated with disclosure. Those children belong to age group 6-9years were 0.86 times less likely to be disclosed about their HIV status as compared with those children belong to age group 13-15years [(AOR = 0.15; 95% CI = 0.06-0.37)]. Children who were responsible for their ARV drug were 2.68 times more likely to be informed about their HIV status than their counterparts (AOR = 2.68; 95% CI: 1.34-5.37).

Conclusion: The rate of disclosure of HIV positive status to HIV infected children is low. Age, children who are responsible for their ARV drug and who stays for longer duration on ARV drugs were the most important factors. Health care provider emphasis on educating responsibility of children on their ARV drug medication

Keywords: Disclosure, ARV drug and East Gojjam zone

Introduction

People living with HIV (PLWH) account 35.3 million worldwide; of this 32.1 million are adults, 17.7 million are women and 3.3 million Children under 15 years of age in 2012. Almost 90% of all HIV infected children live in sub-Saharan Africa & almost 2% from all in Ethiopia.¹

Expanding access to ant-retroviral therapy (ART) is changing the global HIV epidemic in momentous ways. AIDS-related mortality rates are declining rapidly. ART prevents an estimated 4.2 million deaths in low- and middle-income countries in 2002–2012 and the number of children who are younger than fifteen, receiving ART has increased from 566,000 in 2011 to 630,000 in 2012.²

A survey conducted in many Sub-Saharan Africa Countries indicated that more than half the people estimated to be living with HIV are not aware of their HIV status, but one definition of disclosure refers to a child gaining knowledge of his/her HIV status.^{3,4}

Disclosure is central to debates about HIV, because of its links to confidentiality and privacy as human-rights issues and

its potential role in prevention and also considered a way to “open up” the HIV epidemic. Hence; it is a crucial step toward ending stigma and discrimination against people living with HIV.⁴

With the advent of highly active antiretroviral therapy HIV-infected children are surviving into adulthood. Despite, emerging evidence of the benefits of disclosure, understanding how families and health care providers communicate with children about their health is important to maximize the positive psychosocial and clinical benefits associated with knowing one’s status.^{5,6} However, different research shows that Prevalence of disclosure to children living with HIV is low and also there are many factors that influence it.

In sub-Saharan Africa, the prevalence of disclosure to children living with HIV is low this was between 1.7 % and 28%.⁵⁻¹⁰ In Ethiopia, the disclosure rate of children was low which is between 16% -39% and also have different factors that affect the disclosure status.¹¹⁻¹³

New medical innovations and increasing availability of antiretroviral therapy have improved the health and longevity

of PLWH's. With increased survival, one of the greatest psychosocial challenges that parents/ caregivers and health care workers of HIV-infected children face is the disclosure of HIV-positive status to children living with HIV.² Disclosure needs to make decisions about what, when, to whom, and how much to disclose.^{14,15}

HIV/AIDS disclosure becomes more significant because of the multiple benefits for the children and their caregivers.¹⁶ Disclosure is related to good or improved adherence to ART medications and influences children's participation in healthcare decision-making. It also enables children to understand HIV infection and make sense of their disease-related experiences as well as the importance of adherence.¹⁷ Different studies show that disclosure is associated with higher self-esteem, fewer symptoms of depression, improved adherence and higher CD4 counts, seek social support and have improved coping skills.^{18,19}

Disclosure is crucial to long-term disease management; however disclosing HIV infection is a challenging task because of potential stigma, blame, shame and fear associated with HIV infection.²⁰ Studies indicated the high rates of delayed disclosure or non-disclosure among HIV-positive children yet how and when caregivers and healthcare professionals disclose to children are not well-characterized and the number of children that know their status is generally thought to be low.^{21,22} Recent data from Ethiopia show that HIV disclosure rates remain low (39 %) and very little is known about when, why, and how caregivers disclose children living with HIV.¹¹

Despite the growing evidence of the benefits of disclosure and the increasing population of children and adolescents on ART, HIV disclosure to infected children continues to be delayed until older childhood and beyond. In Ethiopia, disclosure to HIV infected children is described as one of the main challenges for parents and health care workers, particularly for parents having younger children and disclosure rates remain still low. As far as investigator knowledge despite the importance of disclosure, relevant studies are not yet done in the study area. Therefore, this study was conducted to assess the prevalence of HIV sero-status disclosure and associated factors among Children infected with HIV in East Gojjam zone.

The findings of this study will give a highlight on factors which influence to disclose and the finding it will also be used as source document for further studies.

Methods and Materials

Study area and setting: The study was conducted from March 19 to April 21st at two hospital of East Gojjam zone which is located in the Northwest of the capital city of Ethiopia. The zone has two hospitals (Debre Markos Referral Hospital and Shegaw Mota Hospital), 100 health centers, 402 health posts and different NGO. Debre Markos Referral Hospital is far from Addis Ababa at a distance of 299kms and 265kms to the capital city of Amhara Nation Regional state Bahir Dar and Shegaw Mota Hospital located about 370 Km from Addis Ababa, 120 Km to the capital of Amhara Nation Regional state Bahir Dar and 210 Km from Debre Markos the capital of East Gojjam zone. Debre Markos Referral Hospital established in 1964 and start ART service in 2004 G.C. and the total number of client since ART service started are 8725, from this 446 are between 5-15

years and 232 are age 6-15 and currently on follow up. Shegaw Mota Hospital established in 1999 and start ART service in 2005 G.C The total number of client enrolled in the care since ART service start is 3767 and 2372 of them start ART and 1234 are currently on follow up. And 225 of the total enrolled in the care and currently on follow up are pediatrics age from 6-15 years.

Study design and Population: Institutional based cross-sectional study was conducted using quantitative data collection method. Source populations were all HIV positive children age 6-15 years who have follow-up at pediatric ART and care center at East Gojjam hospitals (Debre Markos referral and Shegaw Mota). Study population were all HIV-positive children age 6-15 years who have follow-up in pediatric ART and care center at two Hospital Debre Markos Referral Hospital and Shegaw Mota Hospital during the study period who at least fulfill inclusion criteria. All caregivers of the children who diagnosed before 6 month and on follow up visit at pediatric ART units of the two hospitals were included in the study. All caregivers of the children those who cannot communicate/seriously ill at the time data collection were excluded from the study.

Sample size and Sampling technique: The required sample size was calculated using single population proportion formula by taking 39% proportion of HIV positive status disclosure from study conducted in Gondar, 5% margin of error and 95% CI. By adding 10% non response rate, the final sample size was 401.¹¹ Only 457 children age 6-15 years were currently on follow-up in pediatric ART and care center at two hospitals. Investigators took all 300 children on care follow up who fulfilled inclusion criteria without considering the calculated sample.

Therefore, all the Caregivers of children between 6–15 years who have been on follow up in pediatric ART and care center at Debre Markos referral hospital and Shegaw Mota hospital waited for consultation and medication for their children during the study period based on inclusion criteria were included.

Variables and Measurement: The dependent variable of the study was HIV positive status disclosure and the independent variables were Socio demographic factor (age, sex, educational status), Clinical factor (clinical stage, on ART, Duration of ART start, responsible for medication) and Caregiver/family factor (Ethnicity, Religion, educational status, family/caregiver type/ relation, family/caregiver HIV status, biological family status (death or alive), caregiver/family disclosure status e.t.c...). Caretaker -A person, who lives with the child, participates in the child's daily care and who knows most about the child's health. They may either biological parents or guardians acting as surrogate parents to the child. Disclosure- when the caregiver said that the child knows his/her HIV diagnosis.⁶ Non-disclosure- When the caregiver said that the child does not know his/her infection or where the caregiver is unsure if the child knew his/her status.⁶

Data collection Methods: The data were collected from caregivers of the children through face to face interview technique using a structured questionnaire. Four clinical nurse data collectors and two supervisors of a public health profession were participated. Each and every client was introduced briefly about the purpose of the study and confidentiality of information was maintained. To ensured quality of data questionnaire

translation to local language (Amharic) and pre-test were made. One day training was given for data collectors and supervisors by the principal investigators on the objectives of the study, methods of data collection and how to obtain informed consent. They were also be familiarized with tool of data collection. Brief introduction was given to study subjects before and during the collection process. The supervisors and principal investigators were performed immediate supervision on a daily basis. The overall data collection process was controlled by the principal investigators. Questionnaire was checked for completeness immediately after each day's collection. Data were entered in Epi data version 3.1 computer programs to minimize data entry error.

Data processing and analysis: The collected data were entered using Epi-data 3.1 and exported to SPSS version 16.0 for further analysis. Frequencies and proportions were computed for description of the study population in relation to socio-demographic and other relevant variables. Logistic regression was used to fit data in order to identify factors associated with HIV positive status disclosure. All explanatory variables that were associated with the outcome variable in bivariate analysis with p-value of 0.20 or less were included in the initial logistic models of multivariable analysis. The crude and adjusted odds ratio together with their corresponding 95% confidence intervals was computed. A P-value < 0.05 was considered to declare a result as statistically significant in this study.

Ethical approval and clearance was obtained from College of Medicine and Health Sciences of Debre Markos University ethical review committee. And also Permission was taken from the concerned bodies of East Gojjam Zonal Health Department, Debre Markos referral hospital and Shegaw Mota hospital. Study subjects were informed about the purpose of the study and verbal informed consent was taken. In addition they were assured their full right to discontinue or refuse to participate in the study. For their confidentiality, names were not recorded and their privacy also maintained.

Result

Socio demographic characteristics of caretakers of children

A total of 300 caretakers were interviewed. Of these, 255 (85%) of them were female, 136 (45.8%) of them were belong to age group of 25-34 years, 291 (97%) of them were Amhara in ethnicity, 269 (89.7%) were followers orthodox Christian, 255 (85%) of them were urban residents. About half (48.3%) of the caretakers had a monthly income of 1000-1999 Ethiopian Birr and 132 (44%) were private workers and 192 (64%) of the caregivers were biological parents of the children. Regarding the educational status of care giver 122(40.7%) of them were unable to read and write. (Table 1)

Socio demographic characteristics of HIV positive children

From the 300 children ages 6-15 (mean = 9.78 standard deviation [SD] = 2.705] years), 140 (46.7%) children were belongs to 6-9 years of age, 155 (51.7%) were boys and 61(20.3%) had grade 5 and above, 192 (64%) of them lives with their biological family, 174 (58%) had biological mother alive and 160 (76.7%) had biological father alive.(Table 2)

Clinical characteristics of children and caregivers

From 300 children half of them had follow up every month (51.5%), Two hundred one (67%) participants were currently on HAART, among these 113 (56.3%) of them are responsible for their drugs and majority of them were committed to take the drug and 90 (44.8%) duration of ARV drug were \leq 24 months regarding about care giver 202 (67.3%) of them were HIV positive.(Table 3)

Disclosure status of HIV positive children and caretakers

Of 300, 100 (33.3%) of the children living with HIV were disclosed their HIV-positive status. Sixty-four (64%) children were disclosed by their biological parents. The reasons for disclosure as mentioned by caregivers were "needs long term medical follow up and repeated question from the children" (92% and 81%) respectively. Participants mentioned reasons for not disclosing the child about his/her HIV-positive status majority of them believe that the child is too young (lack of maturity) (93.5%) and fear of discrimination (64.5%). All of the caregivers believed that disclosing the HIV-positive status to the child have an advantage.

Regarding the challenge during disclosing time 41% of the care givers reported that faced the challenge and two third of the caregivers are still suffered because of not disclosing to their HIV positive children and 85% of HIV positive care takers disclosed their status to at least to some one but only 27% of the children knew about their family status. (Table 4)

Factors Associated with HIV-Positive Status Disclosure

In bivariate analysis, 11 factors were associated with disclosure of HIV status the children. These factors were age of the child, length of stay on ARV drug treatment, children who are responsible for their drug, sex, educational status, ART start or not, number of visit to the ART unite of the hospital and loss of family member, care taker educational status, relation of care taker (biological or non biological), and HIV status of the care taker. After controlling for the effects of other variables in the multivariate logistic regression analysis only three variables were significantly associated with disclosure (age of the child, length of stay on ARV and responsible for medication).

Age of children showed statistically significant association with disclosure status. Those children belong to age group 6-9years were 0.86 times less likely to be disclosed about their HIV status as compared with those children belong to age group 13-15years [(AOR = 0.15; 95% CI = 0.06-0.37)] and those children belong to age group 10-12years were 0.37 times less likely to be disclosed about their HIV status as compared with those children belong to age group 13-15years [(AOR = 0.37; 95% CI = 0.16-0.86)]. Length of stay on ARV drug treatment was found to have statistically significant association with disclosure status. Those children who are on ARV drug for less than equal 24 months were 0.81 times less likely to be disclosed about their HIV status as compared with those children who are on ARV drug for more than 48 months [(AOR = 0.19; 95% CI: 0.05-0.70)], and children who were responsible for their ARV drug was also found to be associated with disclosure status. Children who were responsible for their ARV drug were statistically significant more likely to be informed about their

Table 1: Socio demographic characteristics of caretakers of HIV positive children attending their follow up in east Gojjam hospitals, Northwest Ethiopia, 2014.

Variables	Frequency	Percent
Sex of caretaker		
Male	45	15.0
Female	255	85.0
Age group of caretaker		
15-24	5	1.7
25-34	136	45.8
35-44	116	38.7
45-54	31	10.3
55-75	12	4.0
Religion of care taker		
Orthodox	269	89.7
Muslim	31	10.3
Ethnicity		
Amhara	291	97.0
Tigre	9	3.0
Residence		
Urban	255	85.0
Rural	45	15.0
Marital status		
Single	68	22.7
Married	117	39.0
Divorced	44	14.7
Widowed	71	23.3
Educational status		
Unable to read and write	122	40.7
Able to read and write	43	14.3
Primary school (1-8)	53	17.7
Secondary school (9-12)	70	23.0
Diploma and above	12	4.0
Occupational status		
Public servant	31	10.3
Government organization	61	20.3
Private	132	44.0
Farmer	36	12.0
Housewife	40	13.3
Monthly family income		
<1000	126	42.0
1000≤2000	145	48.3
>2000	29	9.1

HIV status than their counterparts (AOR = 2.68; 95% CI: 1.34-5.37).

Discussion

In this study, HIV positive status disclosure and associated factors among children were assessed. The study showed that, 33.3% of HIV-positive children were disclosed their sero-status. This finding is comparable with other study conducted in Gondar which was reported a disclosure rate of 39.5%.¹¹ This might be due to similar proportion of children who were living with their biological parents, children attended their primary school and also due to the study period.

However the proportion is very low as compared to studies done in high-income countries in which the disclosure rate

ranges from 57 to 100%.²³⁻²⁵ The lower prevalence of disclosure in the present study might be due to parents perceived that the child's age is too young and fear of stigma and discrimination.

But this study finding was higher as compared to study done in Democratic republic of Congo, Poland, Addis Abeba and Ghana which were 3%, 16%, 17% and 21% respectively.^{5,6,12,26} High disclosure rate in this study the reason might be all of the caregivers believed that disclosing the HIV-positive status to the child have an advantage and children have to disclosed their status in order to have long term medical follow up and additionally, this study assessed disclosure status among children 6–15 years of age, but the study conducted in Addis Ababa includes all pediatric age groups.

Table 2: Socio demographic characteristics of HIV positive children attending in East Gojjam hospital ART unit, Northwest Ethiopia, 2014.

Variable	Frequency	Percent
Sex	155	51.7
Male	145	48.3
Female		
Age group	140	46.7
6-9	98	32.7
10-12	62	20.7
13-15		
Educational status	58	19.3
Unable to read and write	22	7.3
K.G	159	53.0
1-4	61	20.3
5 and above		
Family type	192	64.0
Biological	108	36.0
Non biological		
Mother alive	174	58.0
Yes	126	42.0
No		
Father alive	230	76.7
Yes	70	23.3
No		

Table 3: Clinical characteristics of children and caregivers in East Gojjam Zone, Northwest Ethiopia, 2014.

Variable	Frequency	Percent
No of visit	155	51.7
Every month	68	22.7
Every two month	56	18.7
Every three months	21	7.0
As necessary		
Art start	201	67.0
Yes	99	33.0
No		
Duration of ART	90	44.8
≤24 month	88	43.8
25-48 month	23	11.4
>48 month		
Responsible for ART	113	56.3
Yes	88	43.7
No		
Care taker HIV status	202	67.3
Yes	98	32.7
No		

Table 4: Disclosure status of HIV positive children and caretakers attending East Gojjam hospital ART unit, Northwest Ethiopia, 2014

Variable	Frequency	Percent
Disclosure status		
Yes	100	33.3
No	200	66.7

Information Given Biological family		
Yes		
No	64	64.0
Relatives		
Yes	41	41.0
No	59	59.0
Health professionals		
Yes	55	55.0
No	13	13.0
Informally		
Yes	87	87.0
No		
Reason for disclosing		
Repeated question		
Yes		
No	81	81.0
Right to know		
Yes	52	52.0
No	48	48.0
Needs medical treatment for long time		
Yes	8	8.0
No	55	55.0
Grow up in age and maturity		
Yes	55	55.0
No	45	45.0
I believe that he/she has to know		
Yes		
No		
Challenge during disclosing		
Yes	41	41.0
No	59	59.0
Use of disclosing		
Yes	100	100.0
No	0	0.0
Reason for not disclosing		
Discrimination		
Yes		
No	129	64.5
Lack of maturity		
Yes	71	35.5
No	187	93.5
Yes	13	6.5
Current health I good		
Yes	102	51.0
No	98	49.0
Yes	79	39.5
Not asked by the child		
Yes	121	60.5
No	78	39.0
Yes	122	61.0
Guilty filling		
Yes		
No		
Challenge of not knowing		
Yes	127	63.5
No	73	36.5
Care taker disclosure status		
Yes	172	85.1
No	30	14.9
Child know about care taker HIV status		
Yes	55	27.2
No	147	72.8

Table 5: multivariate analyses of variables associated with HIV positive status disclosure among HIV positive children in East Gojjam Hospitals ART unit. Northwest Ethiopia, 2014.

Variables	Disclosure status		COR (CI=95%)	AOR (CI=95%)	P value
	Yes	No			
Age					
6-9	16	124	0.05 (0.02-0.20)	0.16 (0.06-0.37)	0.001
10-12	38	60	0.22 (0.11-0.44)	0.37 (0.16-0.86)	
13-15	46	16	1.000	1.000	
Length of stay on ART					
≤ 24 month	27	63	0.09 (0.03-0.29)	0.19 (0.05-0.70)	0.013
1-48 Month	50	38	0.28 (0.09-0.88)	0.40 (0.11-1.42)	
>48 month	19	4	1.000	1.000	
Responsible for ART					
Yes	73	40	5.16 (2.80-9.51)	2.68 (1.34-5.37)	0.005
No	23	65	1.000	1.000	

In the present study, age was identified as a factor for disclosure and most caregivers preferred to delay disclosure up to older ages, this finding is being consistent with previous findings in addis Ababa, Gonder, Ghana and Nigeria and This could be due to the caregivers' belief that, child is too young to know their status, fear of stigma and discrimination and. at early age, the child is lacking the emotional and cognitive maturity needed to understand the disease and its implications.^{6,11,27-30} Children younger than 10 years were less likely to be disclosed than those older than 10 years. The child's theory of cognitive understanding of illness is also in favor of this finding. Accordingly, the age from 9 to 10 years and older is considered to be the best time for HIV-infected children to know about their sickness as at this age children can understand about the complex causes of illness and its consequences.²⁸

In this study, children who were responsible for taking their ARV medication were more likely to know their status. This finding was consistent with other study done in Ghana.⁶ This is due to disclosure has an effect on drug adherence and it is possible that after disclosure, children took charge of their illness and medication leading to improved adherence.

Also in this study, children who were stayed longer than 48 months in ARV drugs are more likely to disclose. This result is similar with other study conducted in Ghana the reason might be children who were stayed longer have more regular contact with health care professionals as a function of the clinical follow-up. During these regular visits counseled by health provider, may get information informally from the hospital environment and children ask repeated question to parents "why I take this pills for long duration" and care givers may inform to them. As a limitation since the study is cross-sectional, the associations observed may not be causal. And is difficult to assess adherence to treatment, we could not include it in the analysis.

In conclusion: The rate of disclosure of HIV-positive status to HIV infected children is low in this study. But all the care givers of the children believed on benefit of disclosing the status of children. Age, children who are responsible for their ARV drug and who stays for longer duration on ARV drugs were the most important factors that affect disclosure of HIV positive status to HIV infected children. Based on the findings of the

study the following recommendations were forwarded.

- Health workers should adequately address disclosure issues and provide health education on the importance of disclosure to care givers.
- Health care provider should emphasis on educating responsibility of children on their ARV drug medication
- Further study should be done to explore drug adherence and disclosure status.

AUTHORS' CONTRIBUTION

Yezihalem Tamir wrote the proposal, participated in data collection, analyzed the data, and drafted the paper. Dube Jara and Mekonen Aychiluhem (Dr) approved the proposal with some revisions, participated in data collection, analysis, and improved the subsequent drafts. Dube Jara also prepared the manuscript for publication. All authors revised subsequent drafts of the paper.

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ADDRESS FOR CORRESPONDENCE

Dube Jara, Debre Markos University, Lecturer of Epidemiology and Biostatistics in college of Medicine and Health science Department of Public Health, O.Box: 269 Debre Markos, Ethiopia, E-mail: jaradube@yahoo.com