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SCHOOL OF MEDICINE

DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

Practices, perspectives and barriers of HIV disclosure to children and adolescents by Health care workers; in Addis Ababa health facilities, Ethiopia

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Abstract

Introduction

According to 2016 global HIV statistics, in 2016, globally there are an estimated 36.7 million people living with HIV of which 25. 5 million are in sub-Saharan Africa and 1.8 million are children .In Ethiopia, by 2017, there are estimated 722,248 people living with the virus of which 57,132 are children up to the age of 14 years according to the Ethiopian public health institute. Survival of perinatally infected children into adolescence and beyond made disclosure a major challenge for caregivers and healthcare professionals providing service to HIV-infected children. Although disclosure is associated with improved adherence to HAART and attendance to follow up clinics, there are significant numbers of children and adolescents who are receiving treatment without being fully informed about their HIV status because many health care workers fear that disclosure may create distress for the child.

Objectives

The objective of this research was to assess the practices, perspectives and barriers of pediatric HIV disclosure among health care workers in Addis Ababa health facilities, Ethiopia

Methodology

A quantitative cross sectional study design was conducted at health facilities taking care of pediatric HIV patients (both adult and pediatric ART clinics) in Addis Ababa, Ethiopia from June 1, 2017 to July 30, 2017. A structured, standardized and pretested questionnaire was used to asses 138 HCWs during the study period. Data was collected by trained nurses through self-administration. Collected data was edited, coded, entered and analyzed using Statistical package for social science (SPSS) version 20. The results were presented with percentages, frequency tables and figures. Bivariate analysis was done to test the association between pediatric HIV status disclosure by HCPs and different factors of the health care workers. To identify the independent predictors of disclosure to children by HCPs, we did multivariable logistic regression.

Results

A total of 138 HCPs included in the study the majority 96(69.6%) were females and nurses account more than half of the participants 75 (54.3%).More than half of the health care workers 76 (55.1%) had work experience of 5 to 10 years. Though most of HCPs 134(97.1%) believed children will benefit if they are disclosed, more than one third (36.2%) of them have not ever disclosed a child. Training on pediatric HIV disclosure [AOR=6.264; 95%CI: 1.978-19.841, p value =0.001] and availability of guidelines for

disclosure [AOR =8.350; 95%CI: 1.737-40.126, p value =0.001] independently increased the odds of HIV positive status disclosure to children by HCPs.

Conclusion and Recommendations

Unavailability of guidelines at the health facilities and lack of training on pediatric HIV disclosure for HCPs have been found healthcare providers constraints in the process of disclosure.
Improved training and availability of guidelines on pediatric HIV disclosure would alleviate the discrepancies that exist among healthcare providers on this issue.
Key Words: HIV, Disclosure, Health care provider, Disclosure guidelines, Perinatally infected children, Caregivers.

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List of abbreviations

AAU: Addis Ababa University

AHF: AIDS Health care Foundation

AIDS: Acquired Immune Deficiency Syndrome

AOR: Adjusted odd ratio

ART: Anti retroviral therapy

CDC: Center for disease control

COR: Crude odd ratio

CD4: Cluster of differentiation 4

HCP: Health care provider

HCW: Health care worker

HIV: Human immune virus

NGO: Nongovernmental organization

SSA: Sub Saharan Africa

SPSS: Software Statistical package for social science

WHO: World health organization

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1. Introduction

According to 2016 global HIV statistics**,** in 2016, globally there are an estimated 36.7 million people living with HIV of which 25. 5 million are in sub-Saharan Africa and 1.8 million are children .In Ethiopia, by 2017, there are estimated 722,248 people living with the virus of which 57,132 are children up to the age of 14 years according to the Ethiopian public health institute[1]

Survival of perinatally infected children into adolescence and beyond made disclosure a major challenge for caregivers and healthcare professionals providing service to HIV-infected children[2] . HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness and many health care workers fear that such communication may create distress for the child [3]. As a result, there are significant numbers of children and adolescents who are receiving treatment without being fully informed about their HIV status**[2].**

Disclosure of HIV diagnosis is not an isolated event but rather a step in the process of adjustment by a child, the caretakers and the community to an illness and the life challenges that it poses. Factors associated with HIV sero status non-disclosure have been explored, with corresponding explanatory theories proposed, since the early 1990s[4]. In the literature, the proportion of disclosed children varies from nation to nation, but in general ,Child's age and perceived ability to understand the meaning of HIV infection, education level of the parent, openness about parental HIV status, and beliefs about children's capacities have been found to be related to disclosure**[5].**

The socio-cultural profile in the developing world is different, and the rate of HIV status disclosure is not precisely known in this setting. To target educational interventions, a range of possible predictors to disclosure should be identified. Furthermore, while adherence to antiretroviral therapy (ART) is widely recognized as an important goal, and the social context has significant influence on adherence, there is little understanding of the impact of disclosure on ART adherence on the child's functioning in society and school[6].

While guidelines on disclosure of HIV status among adults have received considerable attention[3] until the recent guidelines developed by the World Health Organization[7] there were no such guidelines for assisting HCWs to support caregivers to make decisions about disclosure to HIV infected children in resource limited settings[8]

While many caregivers are reluctant to inform their HIV-infected children about their status[9],One of the major barriers to disclosure is that caregivers, particularly from resource-limited settings, lack knowledge, skills, and guidance on how to approach disclosure to HIV-infected children [10-12]. Thus, caregivers need considerable support from HCWs during the process of disclosure to children, as expressed by some of the caregivers from sub-Saharan Africa [13].It has been reiterated by HCWs that, where

caregivers lacked knowledge and skills to disclose, health services should adopt a disclosure program that would allow them to support caregivers to disclose to HIV-infected children[14]. Furthermore, it has been shown that caregivers who discuss disclosure with HCWs are more likely to disclose HIV status to their children [15, 16].

Interventions to facilitate disclosure to HIV-infected children should incorporate the experiences and views of caregivers, HCWs, and infected children. Some experts argue that to fully understand disclosure to HIV-infected children, it is essential to understand the perspectives of all HCWs involved in the disclosure process but there are limited studies on the perspectives and practices of HCWs on disclosure to HIV-infected children almost in all sub-Saharan countries.

The purpose of the study is to assess perspectives of health care workers about disclosure to HIV-infected children, to describe the role of health care workers in disclosure of HIV infected children and to determine the barriers of pediatric HIV disclosure facing HCWs in governmental health facilities found in Addis Ababa, Ethiopia.

1.1 Statement of the problem

Different studies show that disclosure is associated with higher self-esteem, fewer symptoms of depression, improved adherence , higher CD_4 counts, seek social support and have improved coping skills[17].

The American Academy of Pediatrics published disclosure guidelines in 1994 to promote disclosure to HIV-infected children. The World Health Organization recommends that health services need to provide strategies that will allow HCWs to support caregivers to disclose to their HIV infected children by the age of 12 years[7]. However, in many developing countries, health care workers (HCWs) still lack the support of policies and guidelines on when and how children should be informed about their HIV status(7).

Despite the above recommendations, the prevalence of disclosure varies widely, a 2007 review reported disclosure rates from 10% to 75% among several studies from North America and Europe[3].In sub-Saharan Africa, the prevalence of disclosure to children living with HIV is low this was between 1.7 % and 28%[18]. In Ethiopia, the disclosure rate of children was low which is between 16% -39% and also have different factors that affect the disclosure status [6, 19, 20].

Although many studies conducted on disclosure to HIV-infected children have focused on the experiences of caregivers, the perspectives and practices of HCWs regarding pediatric HIV disclosure have not been adequately investigated.

Recent data from a situational analysis for pediatric HIV/AIDS care in Ethiopia show that HCWs are still constrained by inadequate knowledge about pediatric HIV care as well as lack of knowledge of pediatric counseling [21].Therefore, this study will be conducted to assess the HCW perspectives and associated factors on HIV sero status disclosure for children living with the virus among HCW in Addis Ababa, Ethiopia.

1.2 Significant of the study

Though no data found in our country on the healthcare workers perspectives, from researches conducted on experiences of caregivers on disclosure to HIV-infected children ,the rate of pediatric HIV disclosure is low worldwide and significantly low in sub-Saharan Africa including our country Ethiopia. This has significant negative impact on drug adherence, HIV transmission to others particularly from adolescents and overall health for children living with the virus. To avoid these problems it is wise to know what the practices and perspectives of HCWs looks like and what barriers they are facing for not disclosing children with HIV. After the paper is finalized; it will open the path to, at least address major barriers which are delaying pediatric HIV disclosure from the HCWs aspect. In addition, it will help to have a domestic data, assists policy makers on identification of the problems on this regard and to bring solutions. Moreover, this study will be used as a base line data inviting researchers for further studies related to health care workers perspectives on pediatric HIV disclosure to this nation.

2. Literature review

According to the CDC report there were 2.6 million children living with HIV around the world at the end of 2015, the majority in Africa, where AIDS remains the leading cause of death among adolescents. Recent data indicate that the top 10 ranking of HIV/AIDS cases by country is populated by countries in SSA [22]. In 2015, SSA contributed to 70% of new cases globally[22].

Majority of new HIV infection cases occur in low and middle income countries that lack properly defined guidelines or resources to equip HCPs[23]. HIV disclosure may be one of the critical links between new infections and the sustained high prevalence in SSA[9, 14]. Inadequate health-care provider (HCP) training in HIV disclosure and testing services appear to contribute to new cases. Unfortunately, limited body of work exists on the prevalence and practice of disclosure by HCPs in SSA[24] .

Over the last 15 years, there has been a 35% decrease in global HIV infections and a 58% decrease among children, yet more than 54% of children currently infected may be unaware they have the disease[7, 25].

Studies in resource rich countries showed disclosure rates to children range widely from 10 to 77% [26, 27]. This variability is consistent with studies in resource limited countries that had available disclosure rates (Ghana, Kenya, and Ethiopia) reported rates that varied from 11 to 38% [14, 20, 28]

One systemic review on Perspectives and Practice of HIV Disclosure to Children and Adolescents by Health Care Providers and Caregivers in sub-Saharan Africa [29] explored perspectives on disclosure types, prevalence, facilitators, timing, process, persons best to disclose, disclosure setting, barriers, and outcomes of disclosure and results are as follows:

- Prevalence of HIV disclosure estimated at 30.9% among infected children and 68.1% among infected adolescents.
- Major facilitators for caregivers in initiating disclosure was knowledge of availability of ART therapy , view of disclosure as the right of the child , persistent inquiries by the HIV positive child or adolescent, presence of chronic illness in the child or a family member.
- The age for disclosure varied widely among the studies and ranged from 5 to 15 years.
- Majority of the studies that explored “persons best to disclose” favored disclosure by caregivers with support from HCPs.
- On disclosure setting, the health facility setting was preferred by HCPs because this provided an avenue for caregiver support during the disclosure process, and

also gave adolescents the opportunity to obtain reliable answers to questions and interact with peers at the health facility.

- Barriers to disclosure by HCPs or caregivers included the fear of HIV stigma, uncertainty about cognitive development of children, and local traditions that limit discussion of sexuality.
- Some studies described benefits from the disclosure process, and this included improved ART adherence and mental health of affected individuals, opportunity to cope with the illness, and the associated stigma.

A study conducted in South Africa showed that the prevalence of disclosure was 40% and the mean age of disclosure was 9.3 years. Reasons for disclosure included that the child was not adhering to treatment (*n* = 59; 39%); the child was consistently asking questions about the treatment and nature of the disease (*n* = 59; 39%). Reasons for non-disclosure were that the child was too young (*n* = 90; 72%); the child would tell others about diagnosis (*n* = 90; 21.1%); the child would be socially rejected (*n* = 90; 18.6%); fear of negative consequences for the child (*n* = 90; 13.3%); and caregivers do not know how to tell or approach disclosure (*n* = 90; 8.9%)[11]

A care giver based study done in Nigeria showed twenty (16.4%) of the children aged 9 to 17 years (13.3±2.4 years) had been disclosed .Commonest reason for non-disclosure was child being sad (29.5%), blaming the parents (18.0%), not understanding the import of the diagnosis (9.8%) and 6.6% feared child disclosing to others. Sixty-seven (54.9%) of the caregivers who did not disclose said they would do so after 10 years of age.[30]

One Study in Uganda disclosure rates in 56% of the children. Factors associated with disclosure of sero-status to a child were age of child, child being on antiretroviral therapy and child attending psychosocial support group. There were no appropriate guidelines on disclosure and only half of health providers had training on disclosure of HIV sero status to children[24]

Study in Kenya Prevalence of disclosure was 26% and varied significantly by age; while 62% of 14 year olds knew their status, only 42% of 11 year olds and 21% of 8 year olds knew. In multivariate regression, older age, taking antiretroviral drugs , and caregiver-reported depression symptoms were significantly associated with knowing one's status. Treatment site was associated with disclosure for children attending one of the rural clinics compared to the urban clinic[25]

A study in southern Ethiopia , most caregivers, 137 (77.8%) stated that disclosure of HIV status to children is important and should be done. However, disclosure had only been made to 59 (33.3%) of the participants. Child age more than 10 years , duration of HIV diagnosis of 5 years or more , taking a zidovudin (AZT) based regimen, length of treatment of caregivers of more than 14 years, disclosure of caregiver's HIV status to

children and/or others, and the child's inquiry about their condition predicted HIV positive status disclosure[6].

In one Multi Center Study in Addis Ababa, Ethiopia, A total of 390 children/caretaker pairs were included in the Study and HIV/AIDS status was known by (17.4%) children, (46.2%) respondents said that the child should be told about his/her HIV/AIDS status when he/she is older than 14 years of age[31].

When we look specifically at the HCWs perspectives on pediatric HIV disclosure there are few researches done , of which one was done in south Africa [2],which involve 206 HCWs. Of these, 140 (68.2%) were nurses, 44 (21.5%) were lay counselors, and 4 (2%) were doctors. The majority (*n* = 183, 89.3%) felt that disclosure benefits. Over half (*n* = 93, 51.4%) recommended 11–18 years as the appropriate age to disclose. Half (*n* = 99, 48.5%) said that caregivers should take the lead to disclose, 87 (42.7%) said that disclosure is a shared responsibility of caregivers and HCWs, and 18 (8.8%) said HCWs should lead disclosure. The lack of guidelines and training on disclosure counseling for children affects their ability to fully participate in disclosure to children.

3. Objectives

3.1 General objective

To assess the practices and perspectives of health care workers on pediatric HIV disclosure in Addis Ababa health facilities, Ethiopia

3.2 Specific objective

1. To asses perspectives of health care workers on disclosure to HIV infected children
2. To find out the practice of health care workers on disclosure to HIV infected children
3. To describe the role of health care workers in disclosure of HIV infected children
4. To identify the barriers of pediatric HIV disclosure facing HCWs

4. Methodology

4.1 Study Design and Period

A quantitative cross sectional study design was conducted from June 1, 2017 to July 30, 2017

4.2 Study Area

The study was conducted at ART clinics in seven public Hospitals (three teaching and four referral hospitals) and 30 health centers in Addis Ababa, Ethiopia.

4.3 Source Population

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

4.4 Study population

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

4.5 Inclusion Criteria: HCWs taking care of pediatric HIV patients in the selected government health institutions in Addis Ababa, Ethiopia

4.6 Exclusion criteria: HCWs who were on leave at the time of data collection

4.7 Sample Size Determination

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

$$n = \frac{Z^2_{1-\alpha/2}(p)(1-p)}{d^2}$$

Assumptions Z=1.96, p=50 %(because we don't know the proportion), w=0.05.The estimated sample size based on the above assumption is 384. Since the source population is less than 10000, population correction formula is applied.

$$n_a = \frac{n_r}{1 + \frac{(n_r - 1)}{N}}$$

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

4.8 sampling procedure

There are a total of ninety health centers in the city; out of which only thirty nine of them are delivering services to HIV infected children. Thirty health centers were randomly selected and included in the study. There are fourteen public hospitals in the city out of which only seven of them are providing health care and ART to HIV infected children and all of the hospitals were included. After selecting the health institutions based on the above criteria, all HCWs who are giving care to HIV infected children in the selected health facilities at the time of data collection were included in the study.

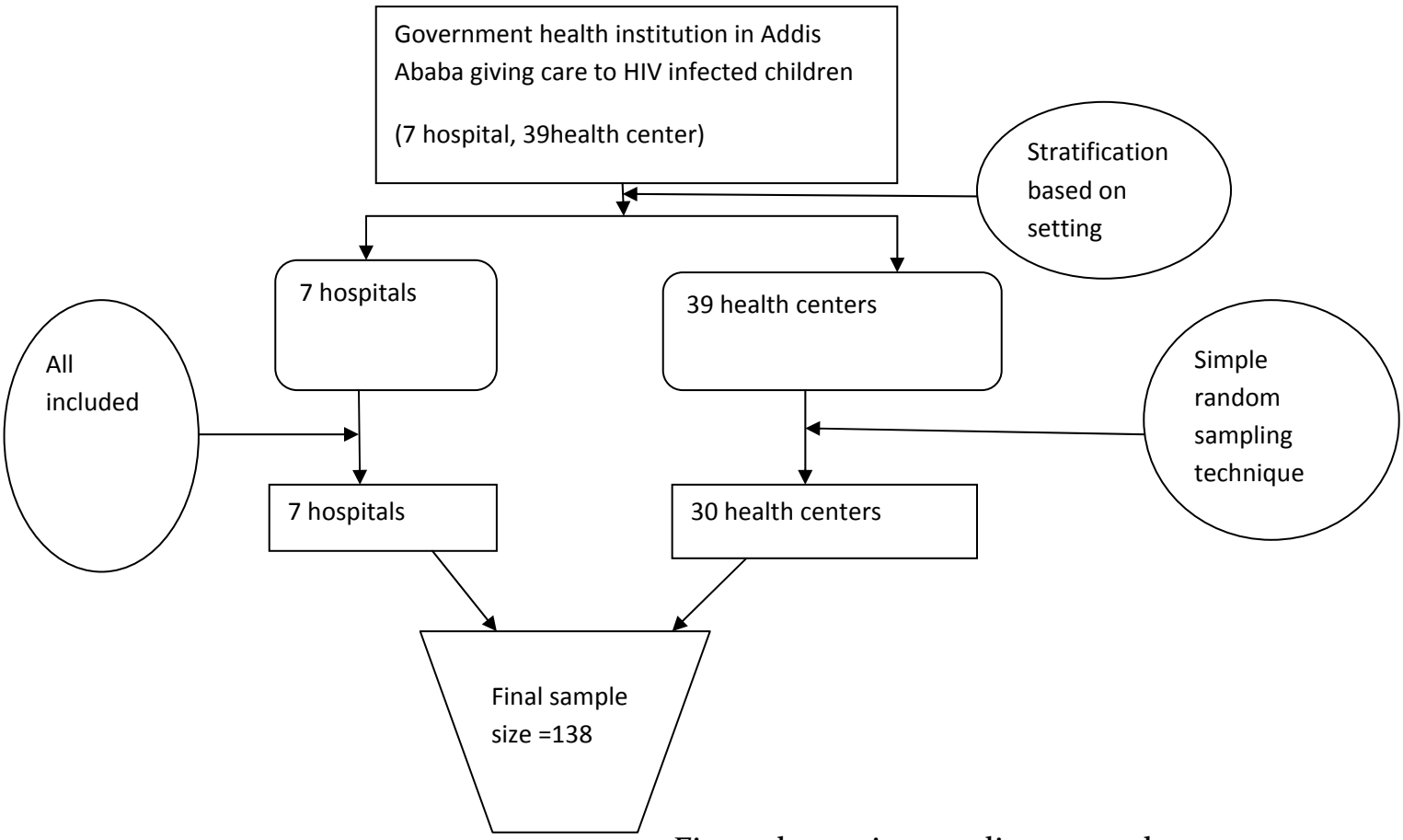

Fig 1 schematic sampling procedure.

4.9 Data collection tools and procedures

Structured and standardized questionnaires (Annex 1) were developed in English and pre tested for validity**.** Data was collected using these Structured and standardized questionnaires by trained data collectors and supervised by the principal investigator**.** The questionnaires were adapted from different studies considering the local situation of the study area .The principal investigator checked completeness of the data collected daily. Any error in data collection was rectified before proceeding with the next day's data collection activity

4.10 Data processing and analysis

Data was initially cleaned, entered in to SPSS version 20 and analyzed. Descriptive statistics, binary regression, and multivariate logistic regression tests were used**.** Descriptive statistics was used to give a clear picture of dependent and independent variables. Bivariate and multivariate analysis was also used to check for association between dependant and independent variables using SPSS version 20 statistical software. A 95% confidence interval, Odds ratio and P value were also used to check for association between dependent and independent variables. P value less than 0.05 was considered as statistically significant. Frequency table and association table were used to present the summarized data.

5. Operational definitions

HIV infected Children: Refers to an individual living with HIV between the age group of 0 to 18 years.

Disclosure: Telling a child that he/she has HIV in the body.

Health care worker/provider: An individual who provides preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities

6. Ethical Consideration A written legal permission regarding the study was obtained from the department of pediatrics and child health, Addis Ababa University and from Addis Ababa health bureau. A written consent was taken and confidentiality of the participants was kept during the study and dissemination of the result.

7. Dissemination of results The interpreted results discussion and recommendations will be submitted to the department of pediatrics, policy makers and later on the article will be submitted to a reputable journal

8. Results

8.1 Socio demographic characteristics

Out of 138 HCPs included in the study the majority 96(69.6%) were females. The age distribution of the participants range from 21 to 58 yrs and majority of them 81 (58.7%) were 21 to 29 yrs. Nurses account more than half of the study participants 75(54.3%). Work experience of the participants ranged from 4 months to 30 years with more than half of them76(55.1%) had experience of 5 to 10 years. More than half of the study participants 80(57.9%) were working in health centers. (Table 1)

Table1. Socio demographic characteristics of healthcare providers in Addis Ababa, Ethiopia, October, 2017. (N=138)

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

8.2. Healthcare providers' attitude about pediatric HIV disclosure

Most of HCPs 134(97.1%) believed that children will benefit if they are disclosed and 65.7% have disclosed a child at least once as compared to non from those who said disclosure is not important [OR = 2.913; 95%CI: 2.306-3.682; p value: 0.016]. The benefits of disclosure stated were: to protect others from being infected (adolescents), for children to understand the disease (HIV), it is their right and for medication adherence.

Among the participants, 37% of them think disclosure is not timely in our set up. The barriers of untimely disclosure given were: lack of training on disclosure, lack of guidelines on disclosure, lack of parents/care givers readiness and parental refusal.

Almost all HCPs (99.3%) believe parents/caregivers require help from HCPs in disclosing their children in the form of offering psychological support, providing practical guidelines and medical information as well as preparing children for disclosure.

8.3. Appropriate setting for pediatric HIV disclosure

Concerning the right age of disclosure about half of participants 67(48.6%) said the child should be told between 11 and 14 years , 29(21%)said between 8 and 10 years, 20 (14.5%) said between 5 and 7 years, 18(13%) said between 15 and 18 years and 4(2.9%) said between 3 and 4 years. The results showed that almost two third 85 (61.6%) stated an older age above 10 years as the right age to tell children about their HIV status

Most of the HCPs 111(80.4%) think disclosure is a shared responsibility for both HCPs and parents/care givers, while 22 (16.0%) thought the caregivers are the appropriate people to disclose to children and only 5(3.6%) said that HCWs should initiate disclosure.

Coming to the best place to disclose children most of HCPs 114 (82.6%) believe health facility is the best place to disclose children and these HCPs have disclosed children better (70.2 %) than those who said home as the best place (33.2%) [OR = 4.706; 95%CI: 1.841– 12.032; p value: 0.001] and they stated that disclosing at health facility will benefit children as they will obtain reliable answers for their questions and concerns.

8.4. The practice of health care workers in disclosing to HIV infected children

Significant numbers of HCPs 50(36.2%) haven't ever disclosed a child. The barriers stated by the participants were presented on table 2.

Table 2 Barriers of HCPs for not disclosing children in Addis Ababa health facilities, Ethiopia, October, 2017. (N=50)

Barriers of disclosure	Frequency*	Percentage*
lack of guidelines on disclosure counseling	26	52.0
lack of training on disclosure counseling	31	62.0
lack of caregivers readiness and ability to disclose children	40	80.0
lack of knowledge when and how to disclose	33	66.0
fear the child will react negatively to his parents	8	16.0
Others (Preferred if parent disclose, parental refusal)	3	6.0

* one participant mentioned more than one choice as a barrier

The attitude and practice of HCPs affected the probability of disclosing the HIV status to children and adolescents. Counseling parents/caregivers to facilitate disclosure [OR = 3.762; 95%CI: 1.503– 9.414; p value: 0.01],believing disclosure benefits children [OR=2.913; 95%CI: 2.306-3.682); p value: 0.016] and thinking health facility is better place for disclosure than home [OR=4.706; 95%CI: 1.841-12.032; p value: 0.001], increased the odds of disclosure to children (table 3) and the entry points for disclosure stated were: when patients have poor drug adherence, when patients have poor clinical attendance, when patients begin persistently asking questions why they are taking drugs.

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

4.5 Factors associated with pediatric HIV disclosure

Bivariate regression was done to assess the HCPs characteristics which increased their probability of disclosing the HIV status of Children and adolescents and the result showed that counseling parent/caregivers to facilitate disclosure [COR = 3.762; 95%CI: 1.503– 9.414; p value: 0.01], believing disclosure benefits children [COR=2.913; 95%CI: 2.306-3.682); p value: 0.016] , thinking health facility is better place for disclosure than home [COR=4.706; 95%CI: 1.841-12.032; p value: 0.001], having isolated room for disclosure[COR=2.571;95%CI:1.226-5.419; p value: 0.013], working at health centers than hospitals[COR=4.239;95%CI:2.029-8.859; p value: 0.001], age of HCPs being between 21 to 29 years[COR=0.441;95%CI:0.27-0.896; p value: 0.02], taking training on pediatric HIV disclosure [COR=18.3;95%CI:17.606-43.883; P value:0.002] and availability of guidelines for disclosure [COR =33.3; 95%CI:9.262-49.5;p value:0.008] increased the odds of HIV status disclosure to children and adolescents. Among all these factors, only training on pediatric HIV disclosure [AOR=6.264; 95%CI: 1.978-19.841, p value: 0.001] and availability

of guidelines for disclosure [AOR =8.350; 95%CI: 1.737-40.126,p value: 0.001] increased the odds of HIV positive status disclosure to children by HCPs in the multivariable analysis (Table 3).

Table 3.Association of selected HCPs variables with disclosure of HIV status to children among HCPs, Addis Ababa/Ethiopia, 2017; OR = odds ratio, N=number

Variables	Category	Disclosed a child		Crude OR (95% CI)	Adjusted OR^(95%CI)
		Yes	No		
Age of HCWs	21-29 years	58	23	0.441(0.27-0.896)**	0.478(0.176-1.370)
	30-58 years	30	27	1	1
Sex	Female	59	37	1	1
	Male	29	13	0.715(0.33-1.548)	2.175(0.658-7.193)
Work place	Hospital	26	32	1	1
	Health center	62	18	4.239(2.029-8.859)*	0.318(0.051-1.994)
Disclosure benefits children	Yes	88	46	2.913(2.306-3.682)**	
	No	0	4	1	1
Disclosure is timely in our set up	Yes	66	21	4.143(1.976-8.687)*	0.565(0.109-2.942)
	No	22	29	1	1
Counseled parents for disclosure	Yes	79	35	3.762(1.503-9.414)**	1.013(0.239-4.289)
	No	9	15	1	1
Better place to disclose a child	Health facility	80	34	4.706(1.841-12.032)*	3.612(0.814-16.022)
	Home	8	16	1	1
Disclosure guideline available	Yes	85	23	33.3(9.262-59.5)	8.350(1.737-40.126)*
	No	3	27	1	1
Trained on disclosure	Yes	75	12	18.3(17.606-43.883)	6.264(1.97-19.841)*
	No	13	38	1	1
Have isolated room for disclosure	Yes	44	14	2.571(1.226-5.419)**	1.176(0.367-3.765)
	No	44	36	1	1

* p<= 0.001

** P<0.05

^ Adjusted only for significant variables in the bivariate analysis

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	Home	8	16	1	1
Disclosure guideline available	**Yes**	**85**	**23**	33.3(9.262-59.5)	**8.350(1.737-40.126)***
	No	**3**	**27**	1	**1**
Trained on disclosure	**Yes**	**75**	**12**	18.3(17.606-43.883)	**6.264(1.97-19.841)***
	No	**13**	**38**	1	**1**
Have isolated room for disclosure	Yes	44	14	2.571(1.226-5.419)**	1.176(0.367-3.765)
	No	44	36	1	1

* p<= 0.001
** P<0.05
^ Adjusted only for significant variables in the bivariate analysis

8. Discussion

With the introduction of ART, the survival HIV infected children increased to adolescents and adulthood making HIV positive status disclosure a tough task for parents and HCPs. This cross sectional study examined the Practices, perspectives and barriers of HIV disclosure to children and adolescents by Health care workers; in Addis Ababa health facilities, Ethiopia. Almost all of the participants (97.1%) felt that disclosure benefits HIV-infected children and they should be told about their HIV status. A Study in south Africa on HCPs showed similar result(89.3%)[2].

From other care giver based studies it was reported that disclosed children have better understanding of their disease condition, have good drug adherence and improved overall health outcomes[6, 15]. In our study for medication adherence, for understanding of the disease(HIV) and for protecting others from being infected(for adolescents) were

the benefits of disclosure stated by Healthcare workers similar to studies at South Africa, Kenya and a systemic review done in sub-Saharan Africa[2, 32, 33].

Although the majority (97.1%) of the HCPs believed that disclosure should be made, we found that more than a third (36.2%) of them has not ever disclosed a child. This finding is in agreement with the findings of a descriptive study in Uganda [34]. The findings clearly show that only HCPs attitude is not adequate to facilitate disclosure of HIV positive status to children and adolescents but it is also dependant on care givers readiness and supports from health institutions or government bodies given to HCPs.

Health officers (75.0%) followed by nurses (62.7%) has better disclosure rate than general practitioners (33.3%) and residents one out of three(33.3%) and this might be because health officers and nurses receive training better than physicians or they may have longer time with their patients as they are less patient burdened. HCPs working at health centers (77.5%) are disclosing better than those working in hospitals (44.8%). This result can be explained by the above result as most of health officers and nurses are working in health centers where lesser workload and patient burden as compared to hospitals. From this paper we also found that HCWs with work experience of five to ten years disclosed children better than those who have an experience of less than five years and greater than 10 years which might be explained with inadequate experience and reluctance by the latter groups respectively.

Although 2.9% of HCPs stated disclosure should start at the age of three years which is similar to one Tanzanian study[35] over half of the healthcare workers (61.8%) suggested age above 10 years as the right age of disclosure to children about their status which is comparable to South African study(69.6%)[2],a systemic review done in sub-Saharan Africa on Perspectives and Practice of HIV disclosure to Children and Adolescents by Health-Care Providers and Caregivers revealed disclosure is appropriate for children up to early adolescence[33] and a study by Gachanja and Burkholder revealed full disclosure should occur for those 10 years and above[36]. This is also consistent with the report from WHO Guideline on HIV Disclosure Counseling for Children up to 12 years of age (2011)[7]. Because children above this age are mature enough and may become sexually active and risk of reinfection with a different strain of the virus or transmitting the virus to a sexual partner, children above 10 years should be disclosed.

In our study most of HCPs (80.4%) viewed disclosure as a shared responsibility for parents/care givers and HCPs which is not parallel with other studies which stated caregivers should take the lead in disclosure[2, 31-33] but the WHO guideline on disclosure counseling to children under 12 years of age (2011) indicated that there is no evidence for either HCPs or caregivers as the appropriate person to disclose, but emphasized that disclosure should be in the best interest of the child[7]. Healthcare workers who were of the opinion that telling children about their HIV status is a shared responsibility, believed parents/caregivers need their assistance to disclose children and the majority of HCWs, see their role in this regard as that of offering psychological support, provision of medical information, providing practical guidelines

and Preparing children for disclosure .These roles are similar to what have been reported by Madiba and Mokgatle[2].

Health facility was stated as the best place for disclosure by most of the HCPs (82.6%) as it will give adolescents the opportunity to obtain reliable answers to their questions and to support care givers during the process of disclosure. These HCPs disclosed children better than those who stated as home the best place of disclosure and might be because they know that care givers need their support during the process of disclosure and believed that disclosure is a shared responsibility as it is revealed above.

More than a third of the health care workers (36.2%) have not ever disclosed a child. Most of the barriers of disclosure identified in the current study were lack of training on pediatric HIV disclosure, lack of guidelines on disclosure counseling to children, lack of knowledge when and how to disclose, lack of parental/ care givers readiness to disclose children and fear of the child will react negatively to his parents were also reported in other studies[2, 3, 32, 37, 38]. Availability of disclosure guidelines and training on disclosure were independently associated with an increased odds of disclosure but HCPs in the current study(37%) and in many sub-Saharan countries are hardly ever trained in pediatric HIV and in disclosure counseling to children, so they lacked skills to assist caregivers to disclose to children[33, 39]. We also found that availability of isolated rooms for disclosure, HCPs with positive attitude towards the benefit of disclosure and those counseling parents to facilitate disclosure were independently associated with increased odds of disclosure. Having disclosure guideline and taking training on pediatric HIV disclosure are expected to facilitate HIV positive status disclosure to children and adolescents which is revealed in our study as HCPs who has guideline disclosed children eight times more than those who do not have (78.8% and 10% respectively) while HCPs who took training disclosed children more than three times as compared to those who did not take training (86.2% and 25.5% respectively) which is similar to studies in other settings [2, 35, 39]. While lake of knowledge when and how to disclose children are major constraints, fear that the child may react negatively to his parents, fear of hurting the child, and parental refusal due to the stigma related to HIV also play a crucial role in delaying disclosure which were also stated by findings from different papers too[2, 33, 35, 39].

When children have poor drug adherence , poor clinic attendance and begin persistently asking questions were the entry points for disclosure reported by HCPs who were engaged in the disclosure process similar with a study by Sariah et al. [35] and Gachanja and Burkholder [36].

Major challenges which faced healthcare providers during and after the disclosure process were negative emotional reactions from children, parental refusal and disappearance from follow up similar with a study in Tanzania[35]

9. Limitation

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

10. Conclusion

Unavailability of guidelines at the health facilities and lack of training on pediatric HIV disclosure for HCPs have been found healthcare providers constraints in the process of disclosure.
We also found the major challenges in the delivery of pediatric HIV disclosure were related to the knowledge gap in pediatric HIV disclosure and the lack of counseling skills, as well as lack of care givers readiness.
The paper revealed the recent published World Health Organization disclosure guideline for children have not yet been adopted and utilized by HCWs in some of the health facilities.

11. Recommendation

Improved availability of guidelines on pediatric HIV disclosure would alleviate the discrepancies that exist among healthcare providers on this issue.
Preparing workshops and practical trainings on pediatric HIV disclosure will give HCWs knowledge and skill to facilitate disclosure as well it will increase their confidence in convincing caregivers to participate in the disclosure process.
Preparing pediatric HIV disclosure model to be used by healthcare professionals for our country.

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13. Annexes

13.1 Annex 1. information sheet

Title of study: Practices, perspectives and barriers of HIV disclosure to children and adolescents by Health care workers; in Addis Ababa health facilities, Ethiopia.

I am _____from department of pediatrics, AAU, college of medicine and health sciences. I am going to carry out a study on Practices, perspectives and barriers of HIV disclosure to children and adolescents by Health care workers; in Addis Ababa health facilities, Ethiopia**.** Therefore I am requesting you to participate in this study. During the study, you will be asked questions about your socio demographic characteristics; knowledge about pediatric HIV disclosure .Your records will be kept confidential i.e. it will be locked and only the people working on the study will have access to them. Your name is not mentioned here. Do you want to participate?

Yes (continue)

No (thank for your time)

13.2 Annex 2. Consent Form

The purpose and nature of this study has been explained to me and I understand that my participation in the study is voluntary and no consequences will result if I refuse to participate.

_____ _____ _____

Code of the participant Signature/ finger print Date

_____ _____ _____

Name of investigator Signature

13.3 Annex 3. Questionnaire

Instruction: Tick the appropriate answer.

1. How old are you (age in years) ----------?
2. Sex
   A. Male B. Female
3. Professional qualifications?
   A. pediatrician B. resident C. general practitioner D. health officer E. nurse F. other (specify)
4. Work experience (in years).....?
5. Where are you working currently?
   A. teaching hospital B. referral hospital C. health center
6. Do you think disclosure benefits children and they should be told about their HIV status**?**
   A. Yes B. no
7. If the answer to question No.6 is yes, why? (More than one answer is possible.)

A. For medication adherence.

B. For children to understand the disease (HIV)

C. To protect others from being infected with HIV (for adolescents)

D. Children have a right to know their disease

E. Other (specify) ----------

8. Which age do you think is the appropriate age to disclose (in years)……

9. Do you think disclosure is timely in our setting?
A. yes B. No
10. If the answer to question no.9 is No, Why? (Barriers) (More than one answer is possible)
A. Lack of guidelines on disclosure counseling for children
B. Lack of training on disclosure counseling for children
C. Lack of caregivers readiness and ability to disclose the disease
D. Other……
11. Who do you think is the appropriate person to disclose the HIV status of a child?
A. Parent/caregiver B. Both Parent/caregiver and health care provider C. Health care provider
12. Do you think Parents/caregivers require help from health care providers in disclosing their children?
A. Yes B. No
13. If the answer to question No.12 is yes how? (Multiple responses are possible)
A. Provision of medical information B. Offering psychological and emotional support
C. providing practical guidelines D. Other (specify……)
14. Have you ever counseled care givers to facilitate disclosure?
A. Yes B. No
15. If the answer to question no. 14 is no, what is the barrier?
A. Fear of hurting the child
B. Child is too young and can't understand HIV
C. Afraid of the stigma related to HIV
D. Afraid that the child will react negatively to disclosure

16. Where do you think is the best place to disclose a child (Disclosure Setting)?
A. At health facility B. At Home
17. If the answer to question NO. 15 is A, Why? (More than one answer is possible)
A. For caregiver support during the disclosure process
B. Gives adolescents the opportunity to obtain reliable answers to questions
C. Other (specify)……
18. Have you ever disclosed a child?
A. Yes B. No
19. If the answer to question No.18 is yes, what are your entry points? (More than one answer is possible)
A. When patient begin persistently asking questions
B. When patient has poor drug adherence
C. When patient has poor clinical attendance
D. Other (specify)……

20. If the answer to question No.18 is yes what are your challenges during the process of pediatric HIV disclosure?

A. Negative emotional reaction
B. Parental refusal to disclosure to the child
C. Disappearance from follow up
D. Other (specify.....)

21. If the answer to question no.18 is no, what is your challenge for not disclosing?

A. Because you never faced a pediatric HIV patient
B. Because you don't have the knowledge when and how to disclose
C. Because you fear the child will react negatively to his parents
D. Other (specify.....)

22. Do you have Disclosure guidelines at your institution?

A. Yes B. No

23. Have you received training on disclosure?

A. Yes B. No

24. If the answer to question no. 23 is yes when was the last time was was you took the training (in years)?

25. Do you have any monitoring body on the number of patients disclosed per month or per year?

A. Yes B. No

26. Do you have isolated rooms for disclosure?

A. Yes B. No