
# Assessment of magnitude and factors that affect care givers' disclosure of HIV diagnosis to their HIV infected children in Addis Ababa Ethiopia 2013/2014.

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**A Thesis submitted to School of Graduate Studies of Addis Ababa University, College of Health Science, School of Public Health In Partial Fulfillment of the Requirement for the Degree of Masters in Public Health**

**May, 2014**

**Addis Ababa, Ethiopia**

## ACKNOWLEDGEMENTS

I am greatly indebted to my advisor, Dr. Mulugeta Betre Gebremariam, for his continuous guidance, constructive comments, valuable suggestion, and support in all directions he provided me since the start of this work.

I also acknowledge the help I got from AAU, SPH. and I thank the A.A Regional Health Bureau, all hospitals and health center health workers and experts who helped me during data collection.

All Supervisors, data collectors and respondents should be acknowledged for their willingness. Further I would like to extend my thanks to AAU librarians and computer room staffs for their assistance.

Special thanks goes to my family and friends too numerous to mention, who contributed to the success of my studies in various ways, both big and small. I extend my great gratitude to my lovely son Nebeyou Wondwossen.

At last, but above all, Glory and special praise be to God, Jesus Christ and His mother St. Virgin Mary for the special help.

## LIST OF ACRONYM

| | |
|---|---|
| **AAU** | **Addis Ababa University** |
| **AARHB** | **Addis Ababa Regional Health Bureau** |
| **AIDS** | **Acquired Immuno Deficiency Syndrome** |
| **ART** | **Anti-retroviral Therapy** |
| **DHS** | **Demographic and Health Survey** |
| **ETB** | **Ethiopia Birr** |
| **FGD** | **Focus Group Discussion** |
| **HAART** | **Highly Active Anti-retroviral Therapy** |
| **HIV** | **Human Immunodeficiency Virus** |
| **MOH** | **Ministry of Health** |
| **MTCT** | **Mother to Child Transmission of HIV** |
| **NGOs** | **Non Governmental Organizations** |
| **PMTCT** | **Prevention Mother to Child Transmission** |
| **RTUTF** | **Reedy To Use Therapeutic Food** |
| **SRS** | **Simple Random Sampling** |
| **UNAIDS** | **United Nation for HIV AIDS** |
| **VCT** | **Voluntary Counseling and Testing** |
| **WHO** | **World Health Organization** |

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## ABSTRACT

**Background:** Most studies conducted on HIV disclosure to infected children report on the challenges experienced by caregivers to disclose HIV status to their HIV infected children. Therefore it‟s essential to look for factors that affect care givers' disclosure of HIV diagnosis to their HIV infected children in these settings.

**Objective:** To assess magnitude and factors affecting care givers' disclosure of HIV diagnosis to their HIV infected children in Addis Ababa Ethiopia.

**Methods:** A facility based cross-sectional study was conducted. A study was conducted from February 2014 to April 2014 among 372 primary caregivers of HIV infected children aged 6-15 years in nine health facilities, Addis Ababa, Ethiopia. Data were collected through structured pre tested questionnaire. It consisted of both closed- and open-ended questions. Data were entered into EPI Info version 3.54 and analyzed by using SPSS version 21 for windows. Descriptive statistics such as frequency, mean, median, standard deviation, and range were used to summarize the results. Bivariate and multivariate logistic regression analyses were done. Qualitative study were used to support the quantitative study. Data were summarized by using tables.

**Results:** Based on caregivers reports, 111 (29.8%) of the children knew about their HIV positive status. Marital status of caregivers, age of the child, Caregiver‟s HIV status, those caregivers discuss about disclosure issue with healthcare providers and children who get aid or support from charity organizations. were found to have statistically significant association with disclosure of HIV positive status to HIV infected children at $p<0.05$ in multivariate analysis.

**Conclusion:** Parents or guardians may have a critical need for health education and counseling in order to develop a plan for disclosing to their children. Addressing and scaling up efforts on stigma and discrimination in neighborhoods, communities, and school settings; and developing guideline for disclosure of children with HIV/AIDS in Ethiopian context will increase the rate of disclosure of children‟s HIV positive status.

# 1. INTRODUCTION

## 1.1. BACK GROUND

HIV/AIDS has created an enormous challenge to mankind since its recognition; close to 35 million people are globally infected, out of which about 2.5 million are children under 15 years of age. Of these children, 90% live in sub-Saharan Africa(1). About 134,586 children estimate live in Ethiopia and from these, around 16,000 children are on treatment (2). With the start of providing care and highly active antiretroviral therapy (HAART) to children, there has been a significant reduction in morbidity and mortality of HIV infected children and more of them are surviving through childhood and into adolescence with improved quality of life(3). Along with the increasing survival of HIV-infected children through adolescence and adulthood, disclosure of the diagnosis of HIV infection has become a more common clinical dilemma. One of the most difficult issues that families with HIV-infected children and their medical providers face is when and how to talk about HIV to infected children(4).

## 1.2 STATEMENT OF THE PROBLEM

Even if from the previous transmission of HIV is decrease from infected mother to the child, but new pediatrics cases are diagnosed day-to-day(5).As pediatric antiretroviral therapy (ART) expands, an increasing number of HIV-infected children will attain adolescence and adulthood(6).This population of children is now older, healthier, and living with HIV as a chronic illness. However, the prospect of a longer lifespan for children on ART brings new challenges, and the issue of HIV disclosure becomes more significant because of the multiple benefits of disclosure for the children and their caregivers including psychosocial and clinical outcomes(7).How ever, Caregivers and healthcare workers are presented with group of challenges around disclosure,(8).Young adults have to make decisions about romantic relationships, sexual activity, experimentation with drugs and alcohol, and planning for the future. For the HIV positive adolescent, these choices can be made only with an accurate and appropriate understanding of their infection status and the nature of HIV(9). According to EDHS 2011, young people are more likely to have sex before age 15 or

age 18, this expose them to the risk of pregnancy and exposure to STI including HIV/AIDS(10). Published rates of disclosure among this population are widely varied; a recent review of pediatric disclosure literature from the United States, Canada, and Europe reported that 25–75% of HIV infected children had been informed of their HIV status(11). But still the frequency of disclosure is low especially in developing countries including Ethiopia(12).The American Academy of Pediatrics that strongly encouraged disclosing HIV infection status to school aged children and younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity.(13). Despite emerging evidence of the benefit of disclosure, Clinicians and other members of multidisciplinary teams should collaborate with caregivers of HIV-infected children to disclose HIV diagnosis to the child in a developmentally appropriate manner(14).in addition to adolescent developmental process like sexuality and others issues. As children mature, however, lack of disclosure may risk for accidental disclosure as a result of overhearing caregiver discussions increases, and such accidental disclosure may lead to both maladjustment and distrust of adults impair treatment understanding and participation and increase psychological and behavioral problems(15). Thus this study assessed the magnitude and factors that affect care givers‟ disclosure of HIV diagnosis to their HIV infected children in Addis Ababa Ethiopia.

## 1.3 SIGNIFICANCE OF THE STUDY

Disclosure of diagnosis to children with chronic diseases has been found to be beneficial. Studies have shown that children with serious illnesses are able to comprehend illness and death at very early ages and, when informed of their illness and the consequences, fare better social and psychologically impacts than children who remain uninformed(6). HIV-specific studies have shown that children who know their infection status score higher in quality of life assessments, have improved medication adherence and it becomes an important issue for children who have reached an age at which they begin to explore their sexuality(8). It is also important to society at large as an increasing number of children living with HIV are reaching adolescence and adulthood. Children need to know their status by the time they become sexually active so as to avoid further transmission or even second generation vertical transmission. But in our country disclosure rates have found extremely low, caregivers face challenges to disclosure because of the stigma associated with HIV and modes of its transmission and disclosure of HIV diagnosis to children remains understudied and there is no well defined guidelines regarding disclosure exist. To fill this gap, thus this study is important and finding is hoped that will be reveal new insights in to the problem and to inform disclosure model development.

## 2. LITERATURE REVIEW.

### 2.1 Over view of HIV and AIDS in children

Today, in sub-Saharan Africa, more than 90% of HIV infection in childhood is acquired from the mother(1).In Ethiopia Population structure of the country is young dominating like that of other developing countries. About 44% of population comprises those under the age 15.The exact prevalence of HIV in children is not known; however, there are currently 134,586 children under 15 years living with HIV/AIDS in Ethiopia. Cognizant of this, the government of Ethiopia has launched fee-based antiretroviral treatment in 2003 and free ART in 2005. In late 2011, around 250,000 people were on antiretroviral therapy (ART), from these, around 16,000 children are on treatment in Ethiopia(2).

Currently less than 10% of HIV infected pregnant women in sub Saharan Africa receive any form of prevention of mother-to-child transmission (PMTCT)(3). But, ART has radically changed the nature of course of HIV infection in countries where it has been successfully implemented. HIV-infected children now survive to adolescent and adulthood. Such issues as disclosure of HIV status to children are becoming important. And need to be addressed as part of their care and support. According to a review of different studies disclosure rates of HIV status to HIV positive children live in developed country estimated to range from 10% to 75%(4). But this number is much lower in sub-Saharan African country(6).

### 2.2 Magnitude of disclosure among HIV infected children

As we all know, due to the recent improvements in access to antiretroviral therapy, dramatic decline of mortality and morbidity of HIV-infected children has been observed Despite the benefits of disclosure the rate is low which is indicated in many authors. Research done in Gondar disclosure rate is only about 39.5%(16).This finding is similar to study conducted in South Africa is 34%(17).In similar setting research done in Addis Ababa only about 17.4%(12). But it is very low as compared to studies done in high-income countries; to increase the rate, it is important to know the factors that affect disclosure of HIV diagnosis among HIV infected children.

## 2.3 Factors affecting disclosure of HIV infected children

### 2.3.1 Age of the child

Identifying the reasons caregivers delay or do not disclose is important. One of the reasons on why parents/caregivers give for non-disclosure is that the child is too young to understand about his/her illness, a study done in Gondar the mean age of disclosure was 10.7 years and 57% caregivers mentioned that the child is too young(16).The same is true in South Africa, 9.8 years is the mean age of disclosure and 47% of caregivers mentioned that the child is too young(7).It is true that children may be too young to understand their disease, but this needs to be discussed and validated with caregivers so that age-appropriate disclosure can be conducted, based on the child‟s level of understanding(8).

Across studies, several factors have been associated with a caregiver‟s decision not to disclose the HIV diagnosis to their child. Most commonly cited is a belief that a child is „not old enough or ready‟(9). Or else is not sufficiently mature to understand and/or cope with the diagnosis(11). Several studies found that caregivers were concerned that if they disclose, their child would not keep the diagnosis private, related family secrets might be disclosed outside the home, or that children would be exposed to isolation and negative reactions from community and family(9, 11). Many HIV positive mothers have reported the concern that their child will be angry with them for transmitting the virus(13).Caregivers who decide to disclose the diagnosis to their child tend to cite many reasons for this decision including child‟s older age was predictor of disclosure, Caregivers felt mid-teenage years are appropriate time for disclosure.(14).

### 2.3.2 Guilty feeling of parents

Most caregivers feel guilty for having transmitted the HIV virus to the child. This may result in questions from the child that they are not ready to answer. Studies cite cases of fear in parents that the child might ask how they got the disease, be angry at them for giving him HIV and act out these feelings many parents are reluctant to tell their children that they are infected with HIV. Mothers in particular may feel guilty for having infected their children or worry that their own status may become known(15).

2.3.3 Socio-demographic characteristics of caregivers.

Educational status of the caregivers was also statistically significantly associated with disclosure. Children with caregivers that have education at or above primary level are statistically significantly less likely to be informed of their result than those with illiterate caregivers(12). But a study done in South Africa caregivers who completed the 12th grade were less likely to disclose the HIV diagnosis to the child, in comparison with caregivers with a secondary education(7).In Thailand, as more children whose caregivers reported having financial problems knew their diagnosis than those whose care givers did not report to have any financial problems(19). caregivers‟ religious engagement (religious beliefs); being orthodox christians were associated with disclosure of children HIV positive status relative to their counterparts with other religion(28).

2.3.4 Fear of stigma and discrimination

Most of caregivers want to protect the child from the stigma they experience themselves that is why caregivers fear that the disclosure to the child will lead to inadvertent disclosure by him or her to others, so that the secret of the family will be known, leading to discrimination against the child and the whole family. 73% of caregivers fear the child will disclose to others, and that this is especially sensitive in large families with both HIV positive and negative members(7). The study states that “as HIV infection remains highly stigmatized in many communities, disclosure of pediatric HIV infection may also be accompanied by threats to the child‟s physical and/or psychological health(14).

Stigma and discrimination play an important role in determining the process and effects of disclosure and that expected it play a major role in parental and children‟s decision making on and the impact of disclosure of HIV status. This also implies that children may experience stigma even without it through secondary disclosure(13).Although many of them realize that the child has to be told, they felt helpless since they did not know how to do this in the least painful way possible. Therefore, they tend to postpone this as long as possible(18).

Human Rights Watch research in Kenya shows children who lately find out that they are HIV-infected may be more likely to internalize stigma and feel cheated by those who hide their status. Parents, caregivers, and health workers who avoid telling children about their HIV status can do a lot of harm, unwittingly. They can shatter a child‟s emotional and physical health and carry stigma about HIV to the next generation(15).Several studies have shown that disclosure benefits both children and their caregivers(19).

2.3.5 Adherence to treatment

Regarding treatment and adherence there is a general expectation that after disclosure the child will be able to participate in his or her own care and support. For example, parents of children who refuse to take medicine or go to the clinic may wish to use disclosure as a means of creating better involvement by the child to all treatment, but more specifically for improved adherence to ART(20).Children who do not know they are HIV-positive may be less likely to take their medication regularly, which can lead to drug resistance and death(15). There are also instances when disclosure happens accidentally by parents who come up with the truth in a burst of anger at their child‟s unwillingness to take the drugs. Studies state that disclosure of HIV status has resulted in better adherence as the majority (58%) of children who knew their HIV status adhered well to their HAART regimen (14). In addition to the poor adherence (15)awareness of his/her HIV status and the long term of the never-ending treatment process(21).Other studies have found that children who knew their status are less adherent or non-adherent (11).One other possibility is that after disclosure parents assume that children will take full responsibility for their medication, as in one study which found that prematurely releasing responsibility for ART to children results in poor adherence(14).Caregivers used various methods of deception when telling the children about their illness, such as telling a lie, selectively telling some information and hiding the HIV status behind other conditions unrelated to HIV illness. A similar pattern of inaccurate disclosure occurred among caregivers who reported that their children did not know their HIV/AIDS status and that they had never told them about the actual diagnosis.(19).Disclosure of the diagnosis of HIV infection or AIDS to a child is an

emotionally charged and controversial issue. HIV infection, with advent of antiretroviral therapy, is now more of a chronic illness with need for regular follow ups and strict adherence to medications. But unfortunately its unique nature like relentless progression, associated social stigma, risk of person to person transmission and simultaneous affliction of multiple members of the same family make it different from other chronic diseases like malignancies were reported to result from nondisclosure(20).It also becomes an important public health issue as these children grow and become sexually active and might unknowingly transmit the virus to the uninfected population(21).Concealing HIV status may lead to or exacerbate depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life. Considering all this, thus this study will be like to fill the gap based on the finding results by identifying those factors which affect caregivers" decision towards disclosure of HIV status to their HIV infected children and to assess the prevalence of HIV disclosure among HIV infected children.

**2.4.Outcome of disclosure on HIV infected children.**

The American Academy of Pediatrics in 1999, that admitted "studies on the impact of HIV infection/AIDS disclosure to children are limited", but that it was still important to disclose to children, taking into account "their age, psychosocial maturity, the complexity of family dynamics, and the clinical context"(13).Concealing HIV status may lead to or exacerbate depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life(6).

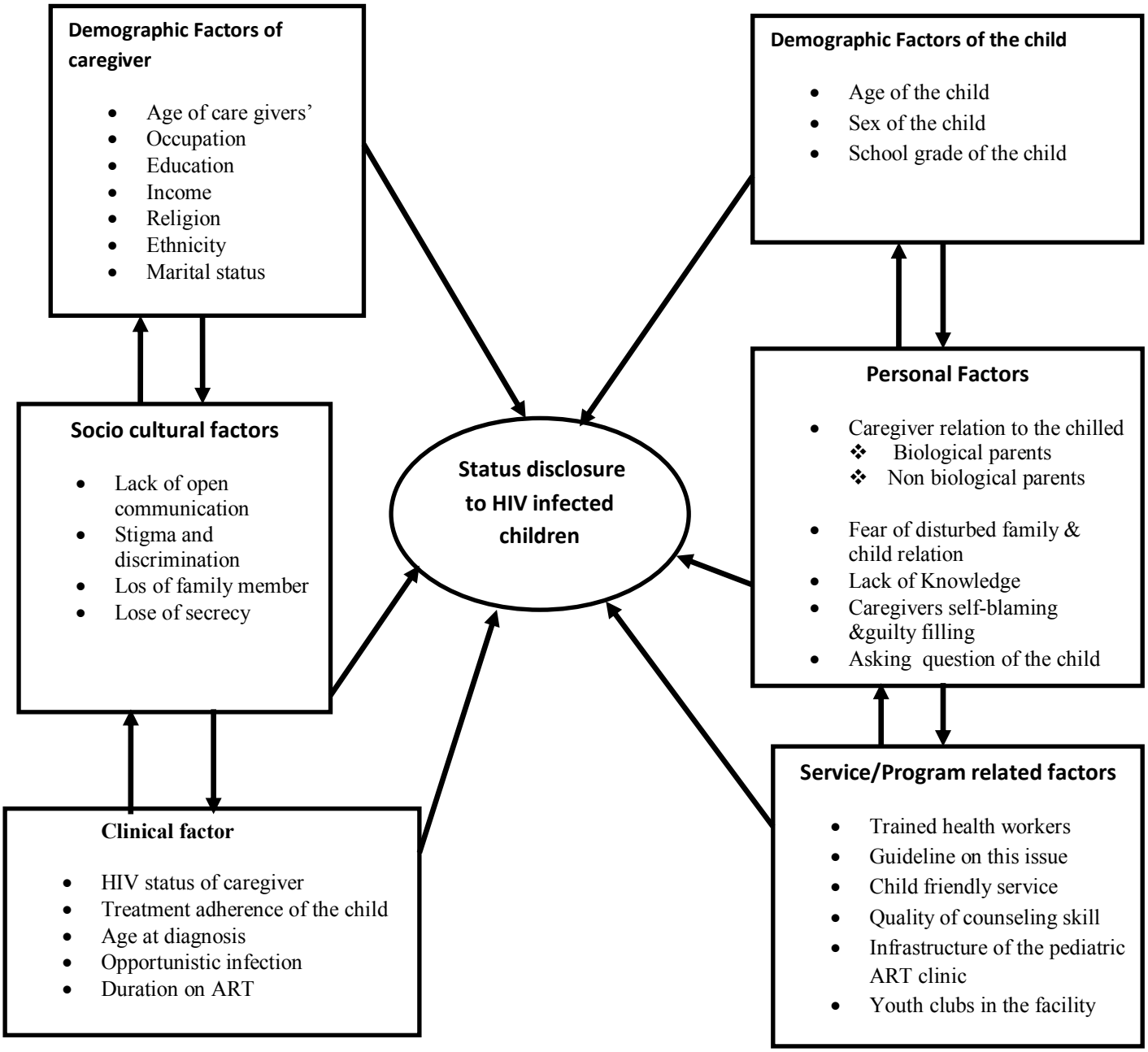
Children who know their diagnosis were shown to have a better adjustment to their chronic illness, a higher self-esteem and less psychological distress. Their care givers likewise reported less psychological distress and lower rates of depression. Moreover, disclosure has been shown to have important implications for the success of HAART treatment. Furthermore, in the context of sex education, disclosure becomes an important issue for children who have reached an age at which they begin to explore their sexuality(20).

In developed countries such as the USA, there are guidelines for disclosure of HIV positive status to children developed by the American Academy of Pediatrics which contains detailed instructions on the process of disclosure(13).

There is also guidelines for Pediatric HIV/AIDS Care and treatment in Ethiopia, issued by the Federal HIV/AIDS Prevention and Control Office(FHAPCO) and Federal Ministry of Health (FMOH) give broad advice on disclosure of their HIV status to children but it needs detailed instructions on the process of disclosure(2).

**Figure 1: Conceptual Frame work, On Factors That Affect Caregivers' Disclosure Of HIV Diagnosis To Their HIV Infected Children In Addis Ababa.**

Conceptual frame work adapted from literatures.



3. OBJECTIVE.

**3.1 General objective:**

- ✓ To assess the magnitude and factors that affect care givers‟ disclosure of HIV/AIDS diagnosis to their HIV infected children in Addis Ababa Ethiopia.

**3.2 Specific objectives:**

- ✓ To assess the magnitude of HIV/AIDS diagnostic disclosure among HIV infected children.
- ✓ To describe factors that affect caregivers' disclosure of HIV/AIDS diagnostic status to their HIV infected children.
- ✓ To identify outcomes of HIV/AIDS diagnostic disclosure on HIV infected children.

## 4 : METHODS AND MATERIALS

### 4.1 Study area:

The study was conducted in Addis Ababa City Administration pediatric ART providing health facilities. Addis Ababa is the capital city of Ethiopia located at the foothills of the Entoto Mountains, and the seat of the African Union and the Economic Commission for Africa.

Under the regional health bureau there are a total of 56 health facilities which includes Government, Private and Non-Government organization serves for 6,999 children ever enrolled for ART, 3,915 had ever started ART and 2,400 children currently taking ART. Out of these there are 37 government health facilities which provide pediatric ART service in the city administration.

### 4.2 STUDY DESIGN AND PERIOD

**Study design**: It employed quantitative design supplemented by qualitative design.

**Quantitative :** Facility based cross-sectional quantitative study was conducted using administered questionnaire.

**Qualitative:** key informant in depth interviews with care givers and health experts, was conducted to supplemented the quantitative study in order to explore and understand some aspects of disclosure issues and factors that affect it in which detail of may not get addressed in the quantitative study.

**Study period:** The study was conducted from February 2014 to April 2014.

### 4.3 population

**4.3.1. Source population:** All primary caregivers of HIV infected children in regular follow up at the health facilities providing pediatric ART service in Addis Ababa.

**4.3.2. Study population:** Primary caregivers of HIV infected children aged 6-15 years in regular follow up at the selected health facilities providing pediatric ART service in Addis Ababa.

**Inclusion and exclusion criteria for the study population**

**Inclusion criteria:**

- primary caregivers of the child age 6-15 years who were on care and support follow-up in pediatric ART clinic.
- Caregivers who had been previously counseled on the importance of drug adherence, clinical follow up and other health related issues of the child.

**Exclusion criteria**

- Adults accompanying children who were not primary caregivers for the child or who did not know the child‟s HIV status were excluded .
- Caregivers who were not at least 18 years of age.
- Caregiver accompanying children who are live in orphanages.

**4.4. Sample size determination**

The sample size is determined by using single population proportion determination formula as shown below. Previous study conducted in Addis Ababa revealed the prevalence of HIV/AIDS disclosure among children living with HIV/AIDS were 17.4% (12).

**n**= $(z\ \alpha/2)^2$* p (1-p)/$d^2$ = $(1.96)^2$ (0.17) (0.83) / $(0.04)^2$ = 339

By adding a non-response rate of 10%, the total calculated sample size of 373 caregivers were required.

**Where:**

n = the desired sample size for the cross-sectional survey

Z= percentiles of standard normal distribution corresponding to 95% confidence level

P= the assumption of prevalence of HIV/AIDS disclosure among children living with HIV/AID would be 17.4%.

d=the margin of error (precision) 4%

**4.5 . Sampling procedure**

The study was conducted in a total of 9 governments pediatric ART and care providing facilities. To determine the study subjects to be included in to the study, the following steps were followed. First, 9 government health facilities out of 37 pediatric ART and care providing facilities were selected by simple random sampling(Lottery method). Second, the sampling frame (list of HIV infected children of those age 6-15 years and currently on care and support follow up) was obtained from the registration book .Third, the number of respondents caregivers‟ of children to be included in to the study (sample) is determined proportionally in accordance with the total number of children in the sampling of the selected health facilities. Finally the respondents were selected by systematic random sampling by taking every four client and only participants who were interested in the study were interviewed for quantitative study.

For qualitative studies ten key informants were purposefully selected from Hospital, Health center and Regional health bureau. purposeful sampling procedure is used to select key informants because different localities might have different disclosure experiences and socio-demographic characteristics .

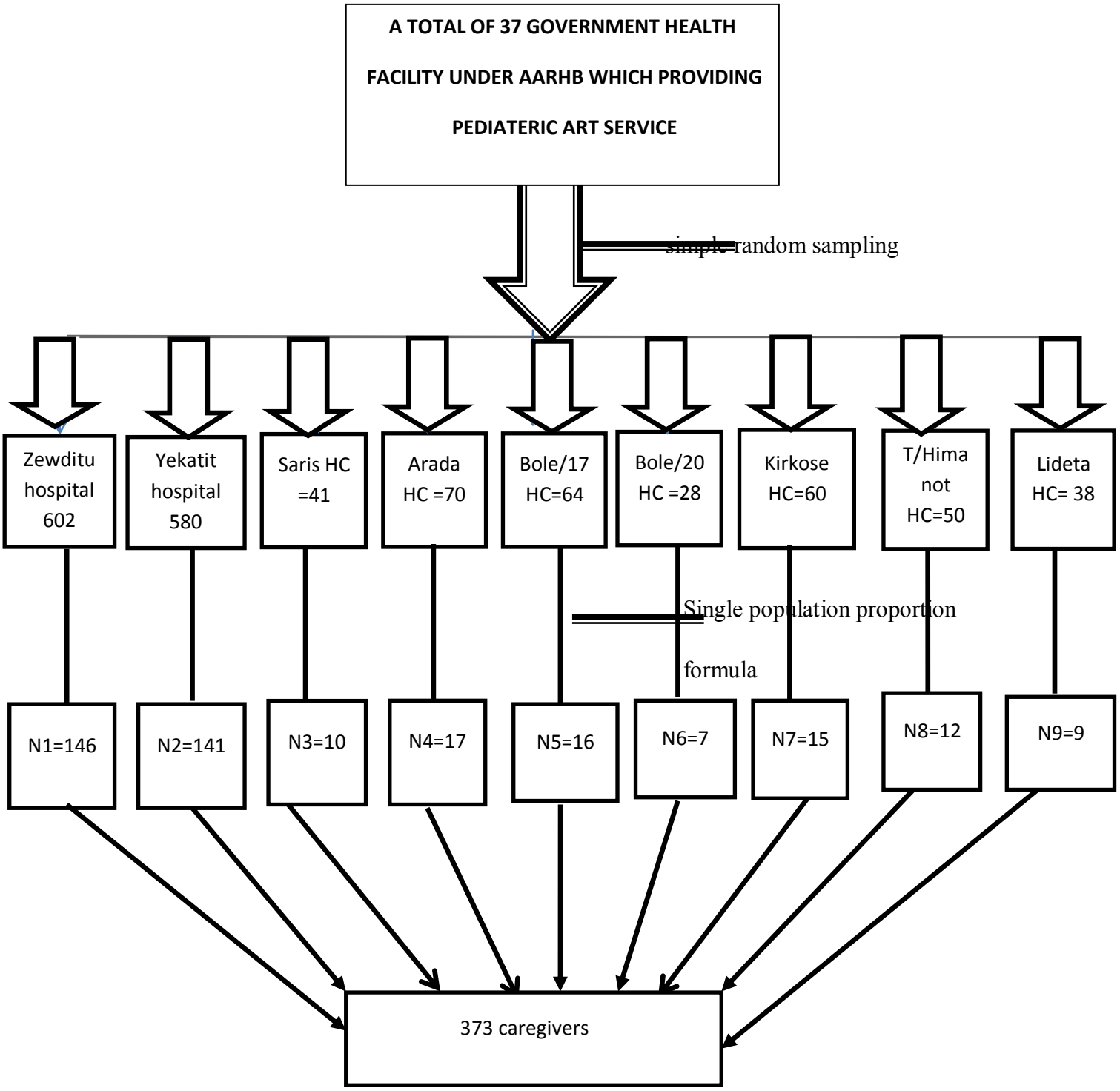



**Figure 2:Schematic Presentation of sampling procedure for quantitative method.**

### 4.6.Measurement/variables

### 4.6.1. Dependent Variables:

- Disclosure of HIV statues to HIV infected children.

### 4.6.2. Independent variables are:

- **Socio demographic variables of caregivers-** Age, religion, education, occupation, marital status, ethnicity, monthly income and relation to the child.
- **Socio demographic variables of the child -** Age of the child, school grade of the child, with whom the child live (biological parents or non biological parents) and lost any of nucleus family member with HIV.
- **Socio cultural factors -** Lack of open communication, los of family member, stigma ,discrimination, lose of secrecy.
- **Personal Factors -** Caregivers' relation to the chilled (biological parents non biological parents) , fear of disturbed family & child relation, lack of knowledge, caregivers self-blaming and guilty filling, asking question of the child.
- **Clinical factor -** HIV status of caregiver**,** treatment adherence of the child**,** age at diagnosis, **o**pportunistic infection**,** duration on ART.
- **Service/program related factors -** Trained health workers, guideline on this issue**, c**hild friendly service**, q**uality of counseling skill, Infrastructure of the pediatric ART clinic**, y**outh clubs in the facility.

### 4.7. Data collection technique

#### 4.7.1 Data collection Method and Tools:

- Face to face interview
- In-depth interview of key informant

- **Structured Questionnaire:** The questionnaire were prepared initially in English, and then translated to Amharic for interview and back to English by different person to check for consistency.
- **Semi-structured interview guide :** Open ended interview guide were prepared for In-depth interview participants.

### 4.7.2 Data Collection procedures:

Data collection was conducted by 6 trained data collectors and 2 supervisors. the responsibility of the data collectors was to fill out questionnaires after obtaining written consent from the study participants and informed assent from the chilled. They were trained for 1 day before the actual survey by principal investigator (PI). During data collection the principal investigator was supervising the data collectors and supervisors . All questions were tested before administration.

For the Qualitative part, in depth interview was conducted until saturation of ideas among volunteer participants. In depth interview were conducted in Amharic and audio recorded with the participants permission. It was last for about 60 to 90 minutes; written informed consent was obtained for each individual participant prior to the start of the interview. The interviews were undertaken by the principal investigator.

### 4.8. Data quality assurance

To ensure the quality of data, data collectors and supervisors were trained by principal investigator for 1 day before the actual survey. A pre-test was employed prior to full scale research to test the instrument and strategies by using 37 eligible caregivers from non study health facilities. The questionnaire was assessed for its clarity, consistency, completeness and skip patterns, in addition both principal investigator and supervisor conducted, daily monitoring for completeness, correcting mistakes and checking errors. The collected data was cleaned before the analysis. In depth interview was held until the point of saturation and the discussion points were recorded to audio tape recorder and notes taken simultaneously.

### 4 .9 . Data processing and analysis

**Quantitative data:** Data were first checked and arranged manually by the PI. The collected data was compiled and entered into EPI Info version 3.5.4 . The entered data was transferred to SPSS version 21 computer soft ware for further processing. The collected data cleaned before the analysis, descriptive statistics was calculated. Bivariate analysis between dependent and independent variables were performed using frequency, $X^2$ and binary logistic regressions respectively. Multivariate logistic regression analysis was done to control (adjust) for possible confounding variable. Those variables which showed significant association on bivariate analysis were adjusted to each other to identify independent determinants. During the analysis P-value and/or 95% confident interval of odds ratio were used to determine the significance of the association. P-value <0.05 or CI not containing 1 were taken as significant association. Results were presented in texts, tables and graphs.

**Qualitative data:** The qualitative data from the interviews with caregivers and health professionals were analyzed using content analysis. Then by importing the transcribed text into the Open Code programme to facilitate the coding process . Units of relevant meaning were examined line-by-line and coded by the PI. As part of the analysis four categories were developed that illustrated the manifest meaning of the findings, while the single theme represents the overall joint interpretation of the qualitative information and reflects the latent meaning of the data.

### 4.10 . Ethical consideration

Formal letter was obtained after the approval of the proposal by the Ethical Committees of, Addis Ababa University College of Health Science School of Public Health. Addis Ababa Regional Health Bureau was also review the plan and write a formal letter for the health institutions in order to have appropriate support during data collection period. After obtaining consent of heads of study health facilities via request made by support letter of the regional Health Bureau and introduction of the objectives of the study, appropriate support was obtained to conduct the study in the facilities. The study participants were briefed about the aim of the study, confidentiality of their responses and the importance of providing the right information. Written consent was obtained before participant interview from each individual and informed assent for minors. Also

participants were informed about the purpose of the study and the study was based on their willingness to participate in it. Participants were fully informed that if they are not willing to participate they have the full right not to be involved in the study and ensured that their choice not to participate in the study might not affect their medical treatment. There was no any identifying names on the questionnaire and tape recorded Interviews were carried out privately in a separate room. The information gathered during this study was remain confidential and ensured that it handled exclusively by the investigators and no one will be able to recognize them in the report.

### 4.11 Dissemination of the results

The study findings will be disseminated to the School of Public Health, to Addis Ababa Regional Health Bureau, and a copy of this material will be given to the selected health facility and other stakeholders. Findings will get presented in different seminars and workshops. It may also be published in a scientific journal.

### 4.12 Operational definitions of terms

**Disclosure: -** Disclosure is the act of disclosing, uncovering or revealing; bringing to light; exposure (Webster Dictionary, online). For this study, disclosure is when caregivers said that the child knows his/her HIV/AIDS diagnosis regardless of who told the child. (16).

**Primary caregivers: -** For the purpose of this study, caregiver was defined as an adult aged ≥18 years, who lives with the child and is responsible for the day-to-day care of the minor, including but not limited to biological parents, and identified through eligibility screening.

**Child: -** According to the Convention for Child Rights, to which Ethiopia is party," a child means every human being below the age of eighteen years". But For this study, a child is defined as between the age 6 and 15.

From age 6, with the most common reasons for this age being the emerging ability of child to understand the concept of health and disease, and/or when they start formal schooling and interacting with peers (6,13).

## 5. RESULTS

### 5.1 SOCIO DEMOGRAPHIC PROFILES OF THE CAREGIVERS

A total of 372 primary caregivers of children aged 6-15 years living with HIV have provided information about the children under their care; making response rate of 99.7%. Three-quarters, 282 (75.8%) ,of the primary care givers were biological parents, followed by relatives, 40 (10.8%). Majority of them were females, 281 (75.5%). More than half of the respondents, 212(57.0%), were Amhara. The highest level of education 140(37.6%) of them attended primary education, whereas the 55(14.8%) cannot read and write. The great majority, 262(70.4%), of the respondents were Orthodox Christian; and 107(28.8%) housewives. More than half, 242(65.1%),were married. The median monthly income among participants was 500 Ethiopian birr per month. The finding of the selected socio demographic characteristics of the respondents primary caregivers are depicted in Table1.

Table 1: Distribution of respondent primary caregivers of HIV positive children 6-15 yrs by the socio demographic characteristics in Addis Ababa , Ethiopia, 2014 (n=372).

| Variable (n=372) | Frequency | Percent % |
|---|---|---|
| **Age of care givers** | | |
| 18-24 | **17** | **4.6** |
| 25-34 | **132** | **35.6** |
| 35-44 | **156** | **42.1** |
| $45^{+}$ | **66** | **17.8** |
| **Sex of caregiver** | | |
| Female | **281** | **75.5** |
| Male | **91** | **24.5** |
| **Religion** | | |
| Orthodox | **262** | **70.4** |
| Muslim | **41** | **11.0** |
| Others | **69** | **18.5** |
| **Educational status** | | |
| Cannot read and write | **55** | **14.8** |

Table1(continu...)

| Variable (n=372) | Frequency | Percent % |
|---|---|---|
| Read and write | **21** | **5.6** |
| primary education(1-8) | **140** | **37.6** |
| Secondary education(9-12) | **110** | **29.6** |
| Tertiary(Certificate-Diploma and above) | **46** | **12.4** |
| **Ethnicity** | | |
| Amhara | **212** | **57.0** |
| Oromo | **85** | **22.8** |
| Tigre | **41** | **11.0** |
| Others | **34** | **9.2** |
| **Marital status** | | |
| Married | **242** | **65.1** |
| Single | **31** | **8.3** |
| Widowed | **77** | **20.7** |
| Divorce | **22** | **5.9** |
| **Occupation** | | |
| Unemployed | **14** | **3.8** |
| Daily laborer | **58** | **15.6** |
| Government employ | **64** | **17.2** |
| Private employ | **78** | **21.0** |
| House wife | **107** | **28.8** |
| Merchant | **35** | **9.4** |
| Others | **16** | **4.3** |
| **Monthly income (in ETB)** | | |
| <500 | **179** | **48.1** |
| >=500 | **193** | **51.9** |
| **Relationship to the child** | | |
| Mother | **215** | **57.8** |
| Father | **67** | **18.0** |
| Grand parents | **35** | **9.4** |
| Siblings | **14** | **3.8** |
| Relatives | **40** | **10.8** |

### 5.2 Socio-demographic profile of the child.

Of 372 children ages 6 - 15 years in the sample, more than half 219 (58.9%) were girls, 153 (41.1%) were boys. The mean age of the children was 10.8 years, (SD = 2.3, range 9 years). Almost three quarters, 267 (71.8%), of the children were between 10 - 15 years of age. The majority 320 (86.0%) of the children attended their primary school. Nearly three quarter of them, 284 (76.3%), were living with their biological parents. About one quarter, 96 (25.8),of them had lost their father with HIV, followed by 61(16.4%) who had lost their mother and 36 (9.7%) had already lost both mother and father.

Children whose age was 10-15 years were found with the highest disclosure rate 107 (40.1%). Biological parents were found with the lowest in disclosure rate 63(22.2%).

The finding was supported by qualitative study

According to the In-depth interview respondents, majority of the caregivers who disclose child's HIV status to the child were non biological caregivers. The findings of the selected socio demographic characteristics of the index children are depicted in Table2.

Table2:Distribution of children age 6-15 years by Socio-demographic characteristics in Addis Ababa, Ethiopia, 2014 (n=372).

| Variable (n=372) | Frequency | Percent% |
|---|---|---|
| **Mean±SD** | **10.8±2.3** | |
| **Age of the child** | | |
| 6-9 years | **105** | **28.2%** |
| 10-15 years | **267** | **71.8%** |
| **Sex** | | |
| Girl | **219** | **58.9%** |
| Boy | **153** | **41.1%** |
| **School grade** | | |
| Not started education | **2** | **0.5%** |
| Kindergarten (KG) | **38** | **10.2%** |
| Primary school (1-8) | **320** | **86.0%** |
| Secondary school (9-12) | **12** | **3.2%** |

**Table 2 (continu....)**

| Variable (n=372) | Frequency | Percent% |
|---|---|---|
| **With whom the child does, currently, live with** | | |
| Biological parents | **284** | **76.3%** |
| Grand parents | **44** | **11.8%** |
| Siblings | **8** | **2.2%** |
| Relatives | **36** | **9.7%** |
| **Child lost any of his/her nucleus family member with HIV** | | |
| Yes | **158** | **42.5%** |
| No | **214** | **57.5%** |
| **Mother only** | | |
| Yes | **61** | **16.4%** |
| **Father only** | | |
| Yes | **96** | **25.8%** |
| **Siblings** | | |
| Yes | **2** | **0.5%** |
| **Both mother and father** | | |
| Yes | **36** | **22.9%** |

### 5.3 Clinical characteristics of the primary caregivers and children age 6-15 years.

Majority, 268 (72.0%), of the caregivers were HIV-positive and of whom 186(67.9%) were on HAART. All 215 (100%) of the biological mothers were HIV positive and about 53(79.1%) biological fathers were HIV positive, and 19(43.1%), grandparents were not screened for HIV. Nearly two-third of the children, 243 (65.3%), were diagnose while still under five years of age; the mean age at diagnosis was 4.8 years (SD = 2.3); the majority, 163(43.8%), had to get transferred for HIV screening from the outpatient department; 315(84.7%) of children were on HAART already; and the mean age when children were started on HAART was 6.1 years (SD = 2.4). Also, 330 (88.7%) of them took cotrimoxazole with ART or Pre-ART. Of all the children currently on HAART, only 293(78.8%), were of good, treatment adherence status. Majority, 172 (46.2%) of the children had a WHO clinical stage II disease at the time of the study; 337 (90.6%) children, had history of opportunistic infections (OIs) and 72 (19.4%) were hospitalized previously. Some 88(23.7%) of the study children get variety of aid or support from different charity organizations; including counseling, money, material and food 7(1.9%), 66(17.7%), 29(7.8%) and 20(5.4%) respectively. Details of the pertinent findings are depicted in table 3

Table 3:Distribution of clinical characteristics of caregivers and children age 6-15 years at pediatric ART clinics in Addis Ababa , Ethiopia, 2014 (n=372).

| **Variable (n=372)** | Frequency | Percent % |
|---|---|---|
| **HIV status of caregiver** | | |
| Positive | **268** | **72.0** |
| Negative | **85** | **22.8** |
| Not tested | **19** | **5.1** |
| **Did the caregiver start ART** | | |
| Yes | **186** | **67.9** |
| No | **82** | **29.9** |
| **Age at diagnosis of HIV positive status of the child** | | |
| **Mean±SD** | **4.8±2.3** | |
| 1-5 years | **243** | **65.3** |
| 6-9 years | **111** | **29.8** |
| 10-15years | **18** | **4.8** |
| **WHO clinical stage of the child** | | |
| Stage I | **31** | **8.3** |
| Stage II | **172** | **46.2** |
| Stage III | **165** | **44.4** |
| Stage IV | **4** | **1.1** |
| **Did the child start ART** | | |
| Yes | **315** | **84.7** |
| No | **57** | **15.3** |
| **Age when ART was initiated** | | |
| **Mean±SD** | **6.1±2.4** | |
| 1-5 years | **132** | **35.5** |
| 6-9 years | **157** | **42.2** |
| 10-15 years | **27** | **7.3** |
| **Other medication other than ART** | | |
| Bacterium | **330** | **11.3** |
| Anti-TB | **8** | **2.2** |

Table 3 (continu....)

| Variable (n=372) | Frequency | Percent % |
|---|---|---|
| Multi-vitamin | **53** | **14.2** |
| RTUTF | **48** | **12.9** |
| **Treatment adherence of the child** | | |
| Good | **293** | **78.8** |
| Fair | **69** | **18.5** |
| Poor | **10** | **2.7** |
| **Did you discuses about disclosure issue with your child's healthcare provider** | | |
| Yes | **159** | **42.7** |
| No | **213** | **57.3** |
| **Did health care provider adequately cover the issues like disclosure** | | |
| Yes | **99** | **57.6** |
| No | **60** | **42.4** |
| **Did the child get support aid from other organizations** | | |
| Yes | **88** | **23.7** |
| No | **284** | **76.3** |
| **Kind of support did he/she get** | | |
| counseling | **7** | **8.0** |
| money | **66** | **75.0** |
| material | **29** | **33.0** |
| food | **20** | **22.7** |

### 5.4 Prevalence of children's HIV positive status

Based on caregivers reports, 111 (29.8%) of the children under their care knew about their HIV positive status. Of this, 85(22.8%), of the children were in the age of 10-15 years. The mean age at disclosure was 10.9 years (±1.8years). the corresponding findings are depicted in table 4.

Table 4: Distribution of HIV positive status disclosure among children age 6-15 at pediatric ART clinics in Addis Ababa , Ethiopia, 2014 (n=372).

| Variable (n=372) | Frequency | Percent% |
|---|---|---|
| **Child knows his/her HIV status** | | |
| **Yes** | 111 | 29.8 |
| **No** | 261 | 70.2 |
| **At which age did you disclose** | | |
| **Mean±SD** | 10.9±1.8 | |
| **6-9 years** | 26 | 7.0 |
| **10-15 years** | 85 | 22.8 |
| **Who disclosed HIV status to the child** | | |
| **mother** | 46 | 41.4 |
| **father** | 25 | 22.5 |
| **Grand parents** | 22 | 19.8 |
| **relatives** | 16 | 14.3 |
| **Health care workers** | 16 | 14.3 |
| **Hear from friends/neighbors** | 5 | 4.5 |

The prominent reasons for disclosure as mentioned by the primary caregivers of the children were "child thought to be matured" 91(81.3%); majority of the primary caregivers reported that reason for disclosure: the repeated questionings from the children of "what happened to me"103(92.0%), for a good adherence to medication 102 (91.1%), to share responsibility and get relief 87(77.7%),respectively(see figure 3).

Findings are similar with results from In-depth interview.

> *One of caregiver mentioned that the reason why she disclose her child, she was always asking "why she took medication all the time and why other children were not taking medication".*((Aunt of 15 year old girl).

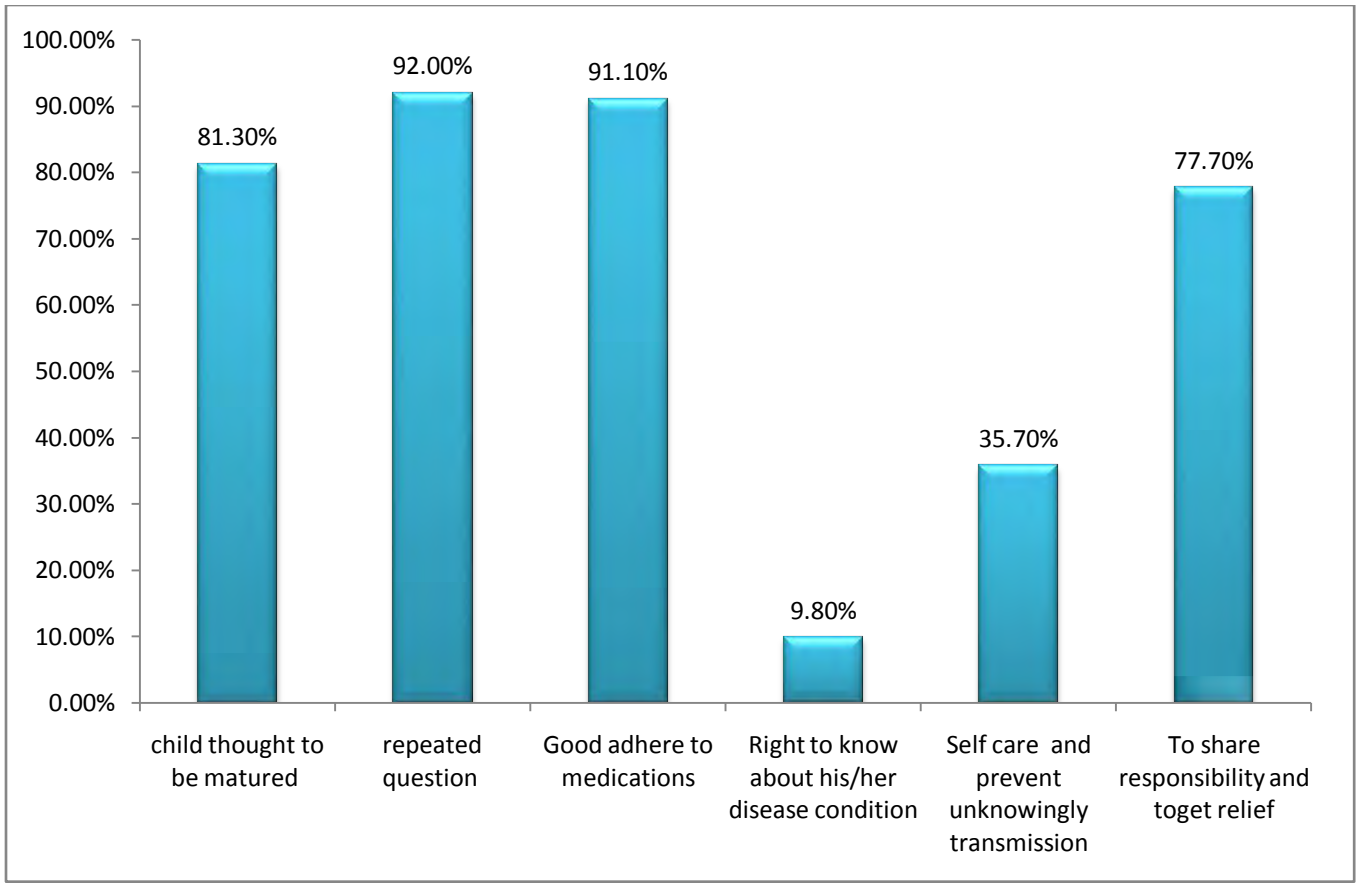



Figure 3 : Respondent primary caregivers mentioned reasons for disclosing HIV-positive status to HIV Infected children in Addis Ababa, Ethiopia 2014.

From the 372 primary caregivers, great majority mentioned reasons for not disclosing the child about his/her HIV positive status were: child is too young 225(86.5%), inability to keep secret 192(73.8%), three quarter,196(75.4%), said that, because I am the one that transmitted the virus so, I felt guiltiness. Lastly, about 101(38.7%) of caregivers delayed disclosure because they believed that they did not know how to tell or how to approach disclosure of HIV diagnosis to their children (due to the lack of the required knowledge and skill) were among some of major reasons(see figure 4).

**Findings are similar with results from In-depth interview:**

> *"All most all the caregiver tend to be protective and resist disclosure, parents fear to disclose HIV status to their children for fear to be blamed by their children, they strongly emphasized that they did not want to tell the child about their HIV status for fear that the child would tell others that they had HIV, that bring negative social*

*reactions, such as increased stigma or discrimination would result, and most caregiver has lack of knowledge to respond to the many questions raised by children". (* key informant from health workers and regional health bureau expert)

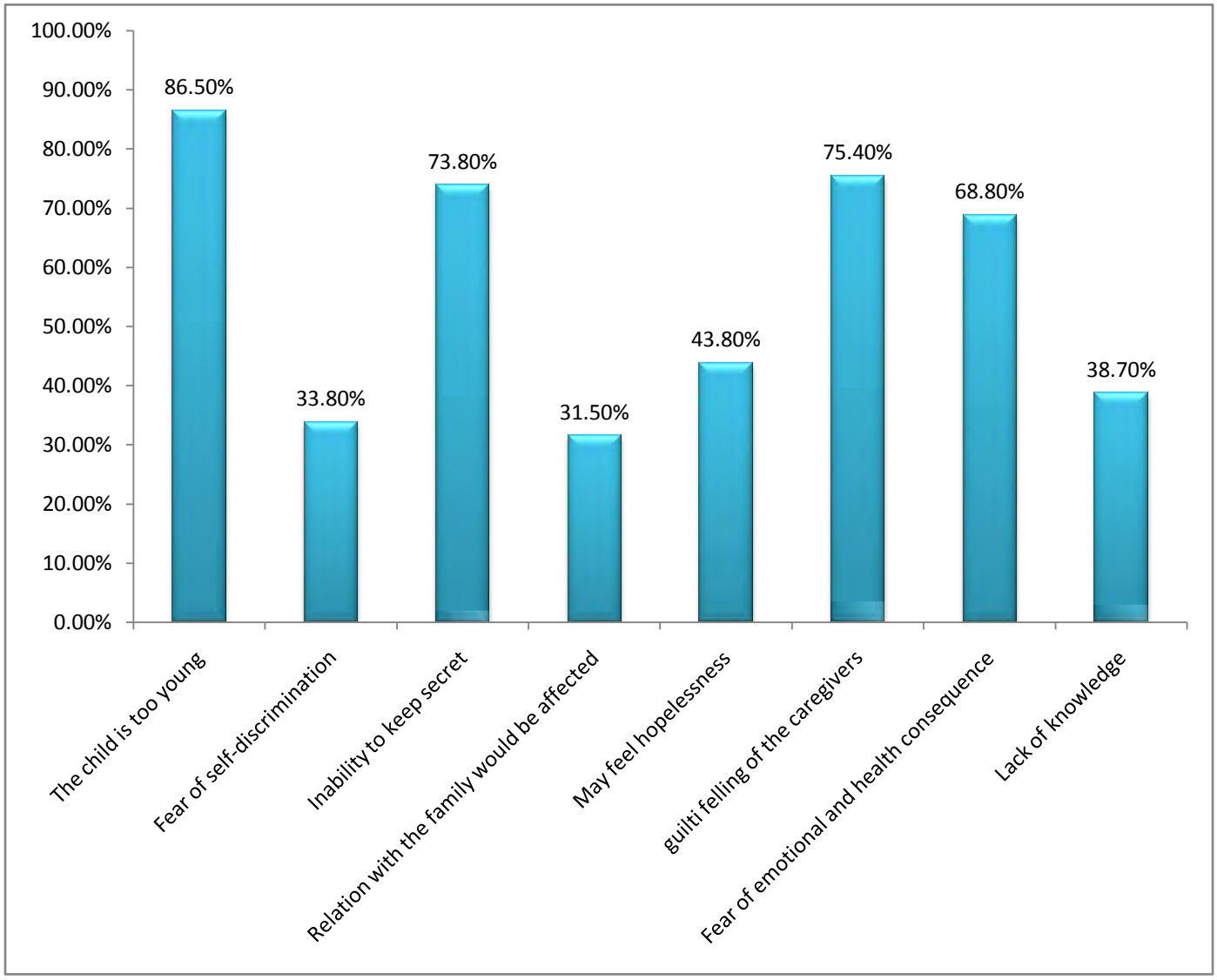



**Figure 4 : Caregivers' percived reasons for not disclosing their children's HIV positive status in Addis Ababa, Ethiopia 2014**

Those children (n=261) who didn't knew about their HIV positive status, when they ask their caregivers the reason on why they had repeated follow up at health facility and daily medication, about 43(16.5%), of their caregivers told them the medication is for TB,and124(47.5%) of the caregivers told them other related diagnosis.Majority

250(95.4%) of the caregivers had plan to disclose them for the future. When caregivers were asked about the age at which the child should know about his/her serostatus, 255 (68.9%) respondents said that the child should be told about his/her HIV status when he/she is at the age of 10-15 years of age, while 101 (27.3%) pointed out that disclosure should be made when he/she was older than 15 years of age and only 2(0.5%) of caregivers didn't know the preferred age for disclosure (see figure 5).

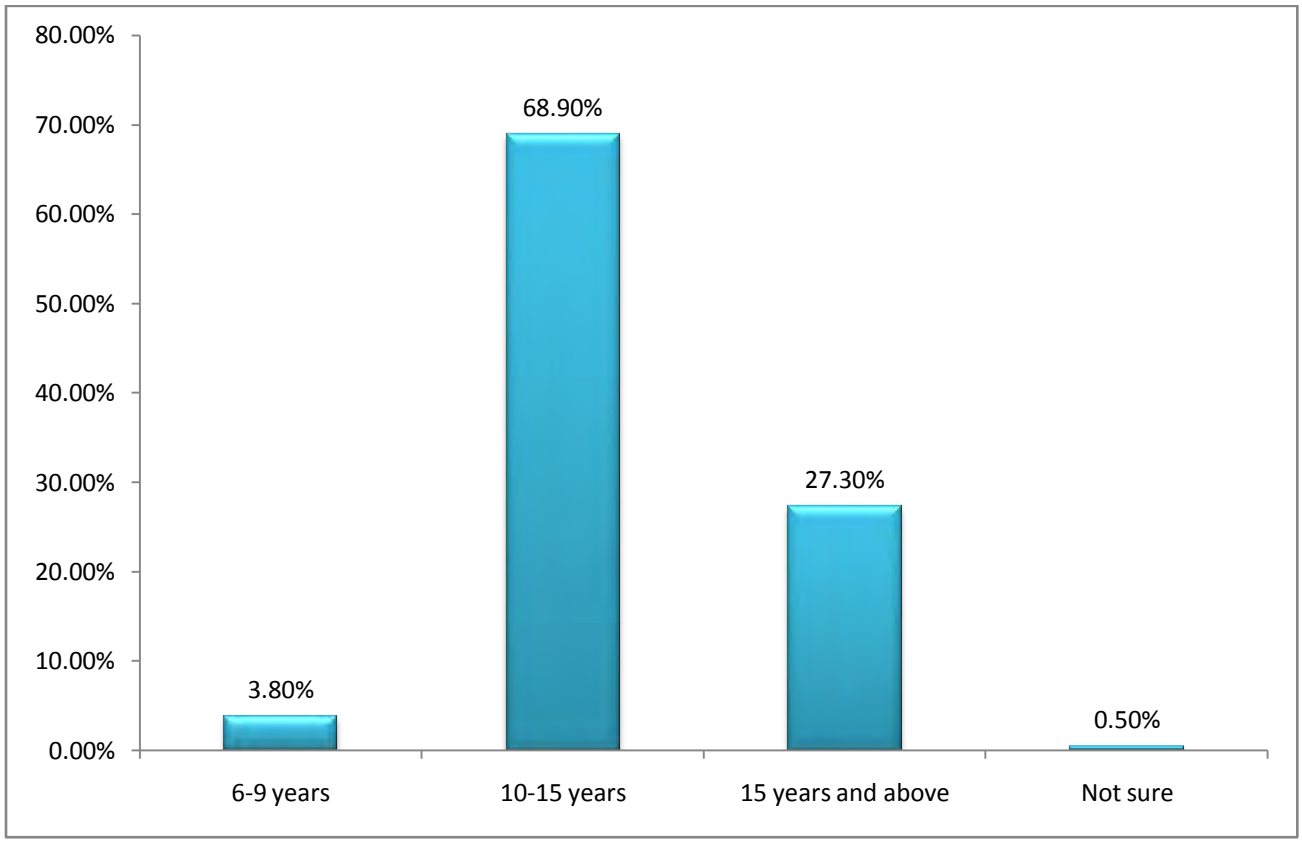



**Figure5:Caregivers' response on the preferred age for their children's HIV positive status disclosure in pediatric ART clinics, Addis Ababa, Ethiopia, 2014**

Caregivers were also asked about the person who should be responsible for the disclosure of HIV status to children, and about 289 (77.7%) of them replied parents (mother/father),and 157(42.2%) health care providers (doctors, nurses and counselors).At the same time, great majority 344(92.5%) of caregivers replied that their child is not being stigmatized due to his/her HIV positive status.

## 5.5 Outcomes Following of HIV Positive Status Disclosure on HIV positive Children.

Among 372 respondents, those111(29.8%) caregivers who disclosed HIV status of their children were asked about the possible different reactions and outcome following disclosure of HIV positive status on their children. Majority,73(65.8%), of the children did cry when they happen to know their HIV status, 43(38.7%) of the children accept when they told that they are HIV positive followed by 15(13.5%) had to feel that hopelessness and only one of the children felt anger when he know his HIV status. Great majority, 96(86.5%) of the children were in good HAART adherence, very few 6(5.4%) were poor adherence. Also, caregivers replied that when they were asked about the child's health condition following HIV status disclosure, more than half, 59(53.2%), claimed about lesser disease progression and increase CD4 count 52(46.8%). For the great majority 110(99.1%),of the children, after their caregivers told them that they are HIV positive, they have not told others about their HIV status . At the same time, caregivers replied that 83(74.8%), got relief after disclosure. Pertinent findings are depicted in table 5.

**Table 5 : Distribution outcome of HIV positive status disclosure on HIV positive children age 6-15 years at pediatric ART clinics in Addis Ababa , Ethiopia, 2014 (n=372).**

| Variable (n=372) | Frequency | Percent |
|---|---|---|
| **Child's immediate reaction encountered after HIV serostatus disclosure** | | |
| Crying | **73** | **65.8** |
| Accepted | **43** | **38.7** |
| Depression | **38** | **34.2** |
| Anger | **1** | **0.9** |
| Hopelessness | **15** | **13.5** |
| **Child's adherence of medication following HIV status disclosure** | | |
| Good adherence | **96** | **86.5** |
| Fair adherence | **9** | **8.1** |
| poor adherence | **6** | **5.4** |
| **Child's health condition following HIV status disclosure** | | |
| Increase CD4 count | **52** | **46.8** |
| Less disease progression | **59** | **53.2** |
| Table 5(continu...) | | |

| Variable (n=372) | Frequency | Percent |
|---|---|---|
| Decrease CD4 count | **16** | **14.4** |
| More disease progression | **3** | **2.7** |
| No change | **34** | **30.6** |
| **What was the child's social relation following disclosure** | | |
| Withdrawal from peers | **3** | **2.7** |
| Increase relation with caregiver's | **79** | **71.2** |
| Blaming caregiver's | **23** | **20.7** |
| Keep secrets | **103** | **92.8** |
| Felt disclosure was important | **21** | **18.9** |
| Took care of him/her self-better | **50** | **45.0** |
| Child being able to protect him/her self and others | **77** | **69.4** |
| **Caregivers concrete feeling following child HIV status disclosure** | | |
| Relief after disclosure | **83** | **74.8** |
| Fell not important disclosure | **6** | **5.4** |
| Disclosure is important and encouraging | **19** | **17.1** |
| No different felling | **3** | **2.7** |

### 5.6 Bivariate Analysis

Crude analysis of the socio-demographic variables on binary logistic regression model showed that, education status of caregiver, marital status and caregivers relation to the child show statistical association with disclosure status to children. Educational status of caregivers was significantly associated $p<0.05$ with disclosure status to children, caregivers who can't read and write were about 3 times more likely to disclose the HIV status to the children when compared to caregivers who can read and write COR=3.33(1.84,6.02). Marital status was another factor that revealed association with disclosure, those unmarried caregivers were 3 times, COR=3.41 (1.57,7.42), and widowed 5 times, COR=4.97(2.87,8.63), more likely to disclose than others. Also grandparents 9 times, COR= 8.93(4.00,19.91), and relatives 3 times, COR= 2.92 (1.45,5.90) were more likely to disclose HIV positive status to HIV infected children as compared to fathers and mothers of the child.

Among the child's socio-demographic variables, age of the child was one of the factors which was significantly associated with disclosure of HIV-positive status in which children 10-15 years of age were 17 times, COR=16.88 (6.03,47.23), more likely to be disclosed as compared to children 6-9 years of age. Children who live with their non biological parents were 5 times, COR = 5.06 (2.61,9.83), more likely to know their HIV positive status as compared to biological one, biological parents were found less likely to disclose their children. And those children who lost any of their nucleus family members with HIV were six COR=6.45 (3.92,10.59) times more likely to be disclosed their HIV-positive status, and specifically when they found lost both mother and father 3 times, COR=3.21 (1.42,7.23), know their HIV status as compared to their counterparts.

Among the caregivers and child clinical variable, HIV status of the caregivers was significantly associated with disclosure of HIV-positive status, those caregivers their HIV status were negative 3 times, COR=3.44(2.05,5.78),and caregivers who is not tested for HIV or not know their status were 8 times, 8.02 (2.91,22.03), disclose their children‟s HIV status as compared to HIV positive caregivers. Likewise age at diagnosis and age of ART initiated were associated with disclosure of the child HIV positive status; children whose diagnosis of age 10-15 years were two times, COR = 1.92 (1.19,3.11), more likely to disclose than age 1-5 years was at 6-9 years. Those children who had start ART at older age 6-9 years and 10-15 years old were more likely to disclose their HIV positive status COR= 4.44 (1.89,10.45) and COR= 6.50 (2.17,19.41) respectively, as compared to those children who had start ART by the age of 1-5 years old. Children who took medication other than ART like Bacterium were 2 times more likely disclosed than those who didn't COR=2.66 (1.39,5.11) . There was also a difference with regard to discussion about disclosure issue with health care provider, caregivers who discuses about disclosure issue were 8 times, COR=7.71 (4.63,12.84), more likely disclose their children than who didn't. Those children who get financial, material, food and counseling support from charity organization were nine COR=9.07 (5.30,15.52) times know their status as compared to their counterpart (Table 6).

**Table 6: Bivariate analysis of factors that affect disclosure of HIV/AIDS diagnosis among HIV infected children ,in Addis Ababa pediatric ART providing Health Facilities, 2014.**

| Variables | Disclosure status (N=372) | | | | COR (95%CI) | p-value |
|---|---|---|---|---|---|---|
| | Yes (n=111) | | No (n=261) | | | |
| **Educational status** | | | | | | |
| Cannot read and write | 29 | (52.9) | 26 | (47.3) | **3.33(1.84,6.02)** | **<0.001** |
| Read and write | 5 | (23.8) | 16 | (76.2) | 1.00 | |
| Primary education(1-8) | 40 | (28.6) | 100 | (71.4) | | |
| Secondary education(9-12) | 21 | (19.1) | 89 | (80.9) | | |
| Tertiary (Certificate, Diploma and above) | 16 | (34.8) | 30 | (65.2) | | |
| **Marital status** | | | | | | |
| Married | 47 | (19.4) | 195 | (80.6) | 1.00 | |
| Single | 14 | (45.2) | 17 | (54.8) | **3.4(1.57,7.42)** | **0.002** |
| Widowed | 42 | (54.5) | 35 | (45.5) | **4.97(2.87,8.63)** | **<0.001** |
| Divorce | 8 | (36.4) | 14 | (63.6) | 2.37(0.94,5.98) | 0.067 |
| **Relationship to the child** | | | | | | |
| Mother | 47 | (21.9) | 168 | (78.2) | 1.00 | |
| Father | 15 | (22.4) | 52 | (77.6) | 1.03(0.53,1.99) | |
| Grand parents | 25 | (71.4) | 10 | (28.6) | **8.93(4.00,19.91)** | **<0.001** |
| Siblings | 5 | (35.7) | 9 | (64.3) | 1.98(0.63,6.21) | |
| Relatives | 18 | (45.0) | 22 | (55.0) | **2.92(1.45,5.90)** | **0.003** |
| **Age of the child** | | | | | | |
| 6-9 years | 4 | (3.8) | 101 | (96.2) | 1.00 | |
| 10-15 years | 107 | (40.1) | 160 | (59.9) | **16.88(6.03,47.23)** | **<0.001** |
| **With whom the child does, currently, live with** | | | | | | |
| Biological parents | 63 | (22.2) | 221 | (77.8) | 1.00 | |
| Grandparents | 26 | (59.1) | 18 | (40.9) | **5.84(1.36,25.13)** | **0.018** |
| Siblings | 5 | (62.5) | 3 | (37.5) | **8.13(1.54,6.39)** | **0.002** |
| Relatives | 17 | (47.2) | 19 | (52.8) | **5.06(2.61,9.83)** | **<0.001** |

**Table 6 (continu...)**

| Variables | | | | | COR(95%CI) | p-value |
|---|---|---|---|---|---|---|
| **Child lost any of his/her nucleus family member with HIV** | | | | | | |
| Yes | 81 | (51.3) | 77 | (48.7) | **6.45(3.92,10.59)** | **<0.001** |
| No | 30 | (14.0) | 184 | (86.0) | 1.00 | |
| **HIV status of caregiver** | | | | | | |
| Positive | 57 | (21.3) | 211) | (78.7) | 1.00 | |
| Negative | 41 | (48.2) | 44 | (51.8) | **8.02(2.91,22.03)** | **<0.001** |
| Not tested | 13 | (68.4) | 6 | (31.6) | **3.44(2.05,5.78)** | **<0.001** |
| **Age at diagnosis of HIV** | | | | | | |
| 1-5 years | 60 | (24.7) | 183 | (75.3) | 1.00 | |
| 6-9 years | 43 | (38.7) | 68 | (61.3) | 2.44(0.92,6.40) | |
| 10-15years | 8 | (44.4) | 10 | (55.6) | **1.92(1.19,3.11)** | **0.007** |
| **age when ART was initiated** | | | | | | |
| 1-5 years | 30 | (22.7) | 102 | (77.3) | 1.00 | |
| 6-9 years | 61 | (38.9) | 96 | (61.1) | **4.44(1.89,10.45)** | **0.001** |
| 10-15 years | 13 | (48.1) | 14 | (51.9) | **6.50(2.17,19.41)** | **0.001** |
| **medication other than ART Bacterium** | | | | | | |
| No | 90 | (27.3) | 240 | (72.7) | 1.00 | |
| Yes | 21 | (50.0) | 21 | (50.0) | **2.66(1.39,5.11)** | **0.003** |
| **Did you discuses about disclosure issue with your child's healthcare provider** | | | | | | |
| Yes | 84 | (52.8) | 75 | (47.2) | **7.71(4.63,12.84)** | **<0.001** |
| No | 27 | (12.7) | 186 | (87.3) | 1.00 | |
| **Did the child get support from charity organizations** | | | | | | |
| Yes | 59 | (67.0) | 29 | (33.0) | **9.07(5.30,15.52)** | **<0.001** |
| No | 52 | (18.3) | 232 | (81.7) | 1.00 | |

### 5.7 Multivariate analysis

As clearly shown on the multivariate logistic regression, after adjusting for other factors, results indicated statistically significant predictor factors; five characteristics were independently and significantly associated with disclosure of HIV positive status to HIV infected children.

Marital status of caregivers AOR=4.12(1.19,14.21), age of the child AOR=27.51 (6.69,113.07), similarly those caregivers who didn‟t live with the virus AOR=6.01 (1.10,32.84) and those caregivers who didn‟t know their HIV status AOR=10.46 (1.04,104.64), caregivers who discussed about disclosure issue with health care provider AOR=8.48 (3.87,18.61) and children who get aid or support from charity organizations AOR=11.50(4.43,29.80). However, factors related to the caregiver such as educational status, factor related to the child such as child‟s HIV diagnosis age, with whom child currently live with, age when ART was initiated and those children who took additional medicines other than ART were found not significantly associated with disclosure of HIV positive status to HIV infected children in this study. Likewise those children who had lost their nucleus family member with HIV were not retained as a significant factor in the multivariate analysis(Table 7).

Table 6 : Determinants of HIV positive status disclosure among HIV infected children age 6-15 years ,in Addis Ababa, Ethiopia, 2014.

| Variables | Disclosure status (N=372) | | | | COR (95%CI) | AOR (95%CI) | p-valu |
|---|---|---|---|---|---|---|---|
| | **Yes (n=111)** | | **No (n=261)** | | | | |
| **Educational status of caregivers** | | | | | | | |
| Cannot read and write | 29 | (52.9) | 26 | (47.3) | **3.3(1.849,6.02)** | 1.00(0.32,3.09) | 0.99 |
| Read and write | 5 | (23.8) | 16 | (76.2) | 1.00 | 1.00 | |
| **Marital status** | | | | | | | |
| Married | 47 | (19.4) | 195 | (80.6) | 1.00 | 1.00 | |
| Single | 14 | (45.2) | 17 | (54.8) | **3.41(1.57,7.42)** | 1.10(0.25,4.88) | 0.89 |
| Widowed | 42 | (54.5) | 35 | (45.5) | **4.97(2.87,8.63)** | **4.12(1.19,14.21)** | **0.02** |
| Divorce | 8 | (36.4) | 14 | (63.6) | 2.37(0.94,5.98) | 1.83(0.45,7.43) | 0.39 |
| **Age of the child** | | | | | | | |
| 6-9 years | 4 | (3.8) | 101 | (96.2) | 1.00 | 1.00 | |
| 10-15 years | 107 | (40.1) | 160 | (59.9) | **16.88(6.03,47.23)** | **27.51(6.69,113.07)** | **<0.001** |
| **With whom the child, live with** | | | | | | | |
| Biological parents | 63 | (22.2 | 221 | (77.8) | 1.00 | 1.00 | |
| Grandparents | 26 | (59.1 | 18 | (30.9) | **5.84(1.36,25.13)** | 1.33(0.34,5.17) | 0.67 |
| Siblings | 5 | (962.5 | 3 | (37.5) | **8.13(1.54,6.39)** | 0.62(0.06,6.12) | 0.68 |
| Relatives | 17 | (47.2 | 19 | (52.8) | **5.06 (2.61,9.83)** | 1.76(0.43,7.20) | 0.42 |
| **Child lost any nuclusefamily memberwith HIV** | | | | | | | |
| Yes | 81 | (51.3) | 77 | (48.7) | **6.45(3.92,10.59)** | 0.98(0.26,3.68) | 0.97 |
| No | 30 | (14.0) | 184 | (86.0) | 1.00 | 1.00 | |
| **HIV status of caregiver** | | | | | | | |
| Positive | 57 | (21.3) | 211 | (78.7) | 1.00 | 1.00 | |
| Negative | 41 | (48.2) | 44 | (51.8) | **8.02(2.91,22.03)** | **6.01(1.10,32.84)** | **0.03** |
| Not tested | 13 | (68.4) | 6 | (31.6) | **3.44(2.05,5.78)** | **10.46(1.04,104.64)** | **0.04** |

**Table 7(continu...)**

| Variable(n=372) | | | | | COR(95%CI) | AOR(95%CI) | P-valu |
|---|---|---|---|---|---|---|---|
| **Age at diagnosis of HIV** | | | | | | | |
| 1-5 years | 60 | (24.7) | 183 | (75.3) | 1.00 | 1.00 | |
| 6-9 years | 43 | (38.7) | 68 | (61.3) | 2.44(0.92,6.40) | 1.19(0.48,2.90) | 0.70 |
| 10-15years | 8 | (44.4) | 10 | (55.6) | **1.92(1.19,3.11)** | 1.23(0.14,10.81) | 0.85 |
| **age when ART was initiated** | | | | | | | |
| 1-5 years | 30 | (22.7) | 102 | (77.3) | 1.00 | 1.00 | |
| 6-9 years | 61 | (38.9) | 96 | (61.1) | **4.44(1.89,10.45)** | 1.16(0.41,3.27) | 0.77 |
| 10-15 years | 13 | (48.1) | 14 | (51.9) | **6.50(2.17,19.41)** | 0.88(0.13,5.93) | 0.90 |
| **Medication other than ART Bacterium** | | | | | | | |
| No | 90 | (27.3) | 240 | (72.7) | 1.00 | 1.00 | |
| Yes | 21 | (50.0) | 21 | (50.0) | **2.66(1.39,5.11)** | 1.54(0.60,3.93) | 0.36 |
| **Did you discuses disclosure issue with healthcare provider** | | | | | | | |
| Yes | 84 | (52.8) | 75 | (47.2) | **7.71(4.63,12.84)** | **8.48(3.87,18.61)** | **<0.001** |
| No | 27 | (12.7) | 186 | (87.3) | 1.00 | 1.00 | |
| **Did the child get supportfromcharity organizations** | | | | | | | |
| Yes | 59 | (67.0) | 29 | (33.0) | **9.07(5.30,15.52)** | **11.50(4.43,29.80)** | **<0.001** |
| No | 52 | (18.3) | 232 | (81.7) | 1.00 | 1.00 | |

## 6. DISCUSSION:

Due to the recent improvements in access to antiretroviral therapy, dramatic decline of mortality and morbidity of HIV-infected patients has been observed, In Ethiopia(22). The prospect of a longer lifespan of HIV infected children brings new challenges related to disclosure including the impact of HIV infection on physical and mental health as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality (11).

In this study, 29.8% of HIV-positive children were disclosed their HIV-positive status. This finding is low as compared to studies done in high-income countries in which the disclosure rate 25-75 percent in the USA and Canada, and 75 to 82 percent in Europe (8,24). The lower prevalence of disclosure in this study might be due to fear of stigma and discrimination by the family members, neighbors and friends.

Since the majority of HIV-infected children acquired the virus from their mothers, disclosure of a child‟s HIV-positive diagnosis often leads to disclosure of other family secrets that leads to stigma and discrimination and believed that their children would be isolated by their friends at school and in the community and fear of negative consequences for the child.

Caregivers also lack knowledge and skills on how to approach/inform their HIV infected children about their HIV diagnosis in this study. On the other hand, in developed countries such as the USA, there are guidelines for disclosure of HIV positive status to children developed by the American Academy of Pediatrics(13) which contains detailed instructions on the process of disclosure but such guidelines do not exist in Ethiopia, although there was an effort of include issues related to disclosure in the „„Guidelines for Pediatric HIV/AIDS Care in Ethiopia‟‟ developed by the Federal HIV/AIDS Prevention and Control Office and Federal Ministry of Health in 2008. This finding is similar to studies conducted in Uganda 29% (25) and Thailand (30.1%)(19). However, the disclosure rate of children‟s HIV positive status In this study was better when compared to the study conducted in Ghana (21%) (14), Kenya (19%)(21) and Nigeria(13.5%)(26). It is also higher as compared to a study conducted in Addis Ababa, Ethiopia (16.3%)(5) and(17.4%) (12). The possible justification can be difference in time period and there

might be also increased awareness on the benefit of disclosure by caregivers. 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. The reason for this might be caregivers‟ belief on their children's age as being too young for disclosure and that which can hinder them from disclosing their children‟s HIV positive status.

When caregivers were asked about the person who should be responsible for disclosure of HIV status to children in this study, about 77.7% of them replied biological mother and 42.2% believed that health care providers. This result is consistent with the study conducted in Odi South Africa(27). Biological mothers were the main caregivers in the sample and made up more than half of the caregivers, but in to respect concrete practice only(41.4%) of the children were disclosed by their biological mothers, more than half (52.9%) of the children were actually disclosed to by people other than their biological parents like grandparents and health care providers.

In this study, caregivers‟ marital status was identified as a factor for disclosure in this study; widowed caregivers were 4 times likely to disclose their children HIV positive status than caregivers currently married. Fundamental to the reasons for disclosure of children HIV positive status was in preparation for the biological parent‟s pending death. Parents disclosed the HIV diagnosis of the child to ensure that the child would be taken care of in the event of the death of the parent (7). Caregivers also disclosed because children were asking questions about the death of one of their biological parent (20).

Age of child was also found to be a significant predictor of disclosure of HIV positive status; children 10-15 years of age were 27.5 times more likely to be disclosed/informed of their HIV positive status as compared to their counterparts. This result is consistent with the finding from developing countries including Ethiopia (5,12,14,16) where children of the same age were significantly more likely to be disclosed than children 6-9 years of age. In this study, the mean age at disclosure was 10.8 years which was high as compared to studies done in New York (7years)and Nigeria (8.7 years) but somewhat comparable with a study conducted in Ghana (11.72 years) (14,24,26). Reason cited by

the caregivers were consistent with that of studies in resource-limited countries; this could be due to the caregivers‟ belief that at early age, namely, child is too young,fear of emotional and health consequences, fear of stigma and discrimination, and fear that the child would not keep the diagnosis to themselves. Caregivers believed that their children were too young to know their status (4,5,24,26). The perception that adolescence is the optimal period for disclosure may relate to the idea that at this life stage, persistent in questioning the reasons as to why they were taking medication and children are now able to cope with this type of information and address any concerns that they may have as they become sexually active (e.g. HIV transmission and unwanted pregnancy) (8,11).

This is supported by qualitative in-depth interview participants and KI.
Most of the caregivers disclose to their children at the age of 10 years and above. with the same reasons mentioned above. This study explore that early age disclosure make children hopeless. The possible explanation will probably that children at early age, their awareness level is very low and lack understanding about the nature of the disease.

*He said so many times, "I will die one day because HIV kills.*

*So I am not important to my family. I am useless person!"*

*(*Grandmother of a boy whose HIV status was disclosed at the age of 10).

This study result showed that caregivers‟ HIV status was significantly associated with HIV positive status disclosure; caregivers who have been HIV negative and not tested (not knowing their status) were six times and ten times respectively more likely to disclose the child‟s HIV positive status than HIV infected caregivers respectively. This could be explained disclosure of a child‟s HIV status is also disclosure of the parent‟s HIV status and hence difficult questions may arise regarding parent's lifestyle. Because HIV is a sexually transmitted disease most caregivers could be are afraid and ashamed to tell their children including that the child might hate them because they are the one who transmitted the disease to the child. Issues of stigma and blame, and the parent–child relationship (19,21,23). Furthermore, parents may fear that the child will inappropriately disclose the parent‟s and child‟s HIV status to others. This study and

others argue that most of the time HIV negative or not tested caregivers were non-biological caregivers. So, HIV negative caregivers disclose because there is less blame and guilt than HIV Infected caregivers disclosure. As a result, HIV status negative and not tested caregivers often disclose shortly after the child come into their care or after the HIV diagnosis(8,11,14).

This is supported by qualitative in-depth interview participants and KI

> *"You see I am an HIV positive. If I disclose to my son, he might not keep the secret. If he tells this to somebody, both of us will be discriminated by our neighbors because we live in a rental house, if the owners find out about our HIV status, they might ask us to leave their house. So, my son might get hurt, might be discriminated, it might have a psychological effect on him, might get sick and hate me. That is why I have not disclosed to my son about his HIV status".(*mother of 10 years of old boy).

This study result showed that discussion experience about disclosure issue with health care providers was significantly associated with disclosure of children's HIV positive status.

Those caregivers who discussed about disclosure issue with their child's health care provider were 8 times to disclose their child's HIV positive status relative to their counterparts. This is consistent with the study indicated in Cape Town, South Africa(30). This result could be explained that one of the most difficult issues that families with HIV-infected children face is when and how to talk about HIV to their children.

In this study, about 38.7% of caregivers delayed disclosure because they lack knowledge this result is the same as indicated in(7,14,25). Disclosing HIV status to the infected child may take several months or even years. So, discussion among providers and caregivers helps to create a disclosure plan. Age-specific considerations for disclosure, ways in which providers can prepare families for the disclosure discussion. Once the diagnosis has been explained to a child, it needs to be reinforced or regularly discussed with the child because many children will not have understood the full

implications of the disease or diagnosis at the time of disclosure. For example, pre-adolescent children can cognitively understand the concepts about the virus but may less likely think of the future implications, such as transmission risks and safe sexual practices(13).To facilitate discussion between caregivers and providers a need for formal recommendations or guidelines in their discussions of HIV disclosure to infected children.

This is supported by qualitative in-depth interview participants and KI.

> *"He was 13 years old at that time. Most of the time when I come with the child for his clinical follow up the Dr usually discusses the issue of disclosing the HIV status to the boy. I had disagreed to the idea at that time. Because I taught It was not the age for him to know yet. He might get sick, he might get shocked, he might get distressed, he might hate himself and so I didn't want him to find out but the doctors insisted he had to know and finally I told him that he lives with HIV virus"*
> (Brother of a 15year old boy).

> *"Due to lack of knowledge on how to disclose to the child, so many caregivers delay disclosure even when their child is above 14 and 15. We health providers agree that discussion ,counseling session and providing information to caregivers facilitate disclosure. But to perform this activity we don't have enough space, we lack trained manpower on this issue(because of high turnover of staff and workload), lack of clearly stated guideline, inconsistence of training on child disclosure, lack of child friendly service and youth clubs. All this problems make discussion and counseling with caregivers about disclosure issue challenging."*
> (Health workers).

Children who got aid or support from charity were found to be significant predictor of disclosure of HIV positive status. Children who get financial, material and food support from charity were 11 times more likely to be disclosed/informed of their HIV positive status as compared to their counterparts. This finding is in conformity with the result in

South Africa and Thailand (17,19) . More children whose caregivers reported having financial problems knew their diagnosis than those whose caregivers did not report to have any financial problems. This result could be explained like that because majority of caregivers in this study were housewives 28.8% and 48.1% of the caregivers' monthly income was <500 Birr per month. Their only source of income might depend on child support. Finally, this could have lead to inform to their children that they lived with the virus. As we all know, most of the charity organization projects found in developing countries including Ethiopia are related with HIV/AIDS program and their main task is support to PLWA.

Therefore, it may be the case that families with a higher socio-economic status are less inclined to disclose the fact of HIV diagnosis to their children, as this is may be potentially threatening(given that the secret may leak) to the family‟s status quo.

Primary caregivers 111(29.8%) who disclosed the HIV status to the children were asked their reasons for informing their child about the HIV diagnosis. The most common response was that the child was thought to be matured 91(81.3%), Other reasons for disclosure were majority, of the children was consistently asking questions about the reasons why they were taking medication day to day 103 (92.0%), 102 (91.1%) of caregivers replied that the child to be adhere to medication, and 40(35.7%) of caregivers was mentioned that, to let the child to take care of his/herself and prevent unknowingly disease transmission. This finding is the same as indicated in various studies in South Africa, Ghana, Kenya and Uganda (7,14,21,25). Qualitative study finding had also identified similar types of result for caregivers' reason for disclosing their children‟s HIV positive status.

*"She always asks me why she was taking medication all the time and why other children were not taking medication".*

(Aunt of 15 year old girl).

Caregivers who had not informed their children about their HIV diagnosis 261(70.2%)also responded reasons for not disclosing. Majority 225(86.5%) of the caregivers believed that their child was too young to understand the HIV

diagnosis, 192(73.8%) delayed disclosure with fear that the child would tell others about their diagnosis, 88(33.8%) believed that if they tell the child about his/her HIV diagnosis; they would be discriminated from other family members and friends;179 (68.8%) delayed disclosure for fear of negative emotional and health consequences on the child. Caregivers believed that disclosure would stress, hurt and worry the child;114(43.8%) might feel hopelessness,196(75.4%) the child will believe that they are the one who transmitted the virus and so felt guilty; lastly 101(38.7%) caregivers delayed disclosure because they did not know how to tell or how to approach the disclosure of the HIV diagnosis to their children. Caregivers who had not informed their children about their HIV diagnosis (n = 261) response to the child's continuous questions of why repeated hospital visit and daily ART taking, about 124 (47.5%) of them told other related diagnosis, while 43(16.5%) like TB,40(15.3%) cardiac and 54(20.7%) allergic follow up. This finding is the same as indicated in various studies including Ethiopia, Thailand, Nigeria and Kenya(16,19,21).

Qualitative study finding had also identified similar type of result for caregivers reason for not disclosing their children‟s HIV positive status.

> *"I fear to be blamed by my child. of course it's not the right time to tell him because he might tell his friends at school and might be stigmatized. due to this his general health would be affected. He always asks me why he was taking medication and why he has to go to the hospital all the time and why other children were not taking medication. I would tell him he is taking medications because of a cardiac condition and if he doesn't take it properly ,he would probably die. even I tell him not to tell to other children that he was taking a medicine for his heart".*
>
> (Mother of 10 year old boy).

Prior to disclosure most caregivers were fearful of the child‟s reaction to the disclosure. After learning about their HIV diagnosis, responding to the question of how their children reacted to learning about their HIV diagnosis.

Some caregivers reported that, the child‟s first reaction to disclosure was crying, depression, anger and hopelessness (8,20). 43(38.7%) caregivers reported that their children reacted well to the disclosure and were able to accept the diagnosis (20). In this study some of the children were instructed to keep the diagnosis secret, due to the stigma associated with HIV and AIDS.

However, even when children were not instructed to keep the diagnosis secret103(92.8%) they still kept the diagnosis secret. These findings are similar to other studies (21,23). Interesting finding were that, in this study, only one (0.9%)child has told to another person that he is HIV positive. This result could be explained that because of their awareness of the secretive nature of the disease. After knowing their status 77(69.4%) of children are able to protect his/herself and others (30). This might be due to being responsible to protect others due to their awareness and behavioral change.

Qualitative study finding had also identified some of similar type of outcomes.

> *"She told me that she wants to have a boyfriend and she even had started a relationship with a boy currently and asked me what she will do for future relationships in relation to prevention. I told her It is better to discuss that with her health workers".* (Aunt of 15 year old girl).

Child's adherence of medication following HIV status disclosure, majority 96(86.5%) pertaining the children were good adherence for medication. These findings are similar to other studies (9,13,20).

The finding is supported by Qualitative study.

*Majority of the caregivers mentioned that after disclosure their children had good adherence to medication. The possible explanation was that the child doesn't want to be sick due to poor adherence.*

Concrete feeling of caregivers following child HIV status disclosure was 83(74.8%) of the caregivers get relief. The finding is in line with other studies (30). Possible explanation will be, once the child knows his/her status caregivers pre-disclosure will

resolve feelings including stress and the child start to take the medication independently, without supervision and reminding. All this give relief to the caregiver.

## 7. STRENGTH and LIMITATION of the STUDY

**Strength of the study**:

- The quantitative study was supplemented by qualitative study

**Limitation of the study:**

This study had several limitations.

First, the study did not look at the family dynamics including the decision-making process in the family as there might be more other caregivers and/or family members who were involved in disclosing the diagnosis to children.

Second, as HIV infected children who were residing in orphanages were excluded from the study, little is known about the practice of disclosure within those institutions and caregivers might not remember the child‟s age at diagnosis or duration on ART may have resulted in recall bias.

Third, all information provided about children was from parental/caregiver reports which could be biased and may not reflect the child‟s perceptions and might not recall the children‟s reaction to disclosure and might have under or over estimated the reactions.

The sensitive nature of HIV/AIDS could result in social desirability bias.

8. Conclusion and recommendation

### 8.1 Conclusion

This study revealed that the rate of disclosure of HIV positive status to HIV infected children was better (29.8%) as compared to previous study in Addis Ababa but low as compared to other settings. Caregivers‟ marital status, children older than 10 years of age, caregivers HIV status, those caregivers who discuses about disclosure issue with health care provider and children who get aid or support from charity organizations were significantly associated with disclosure of HIV positive status to HIV infected children and were the independent determinant factors for disclosure of HIV positive status to HIV infected children in the multivariate analysis.

Caregivers delayed disclosure because they thought their child was too young to understand the HIV diagnosis and their child would not keep the diagnosis private (subjecting the child and the family to social rejection or that children would be exposed to isolation) and fear of negative reactions from school friends and community, guilty feeling of the caregivers.

Disclosure was also delayed because caregivers believed that they lacked disclosure skills and relied on the support of the health care providers to disclose the HIV positive status to their children. It is important to target young children living with their biological parents and from higher socioeconomic classes.

In this study the outcome of disclosure was positive for most children although further assessment of these important issues is needed. Health workers should also be trained to develop skills that build beneficial relationships with child caregivers in order to improve care services. Provision of child friendly services, guidelines, children‟s support groups will help children to know about HIV/AIDS and allow them to discuss more about the barriers of disclosure. It may provide a window of hope and possibilities in the improvement of child HIV disclosure.

### 8.2 Recommendation

Based on the findings of the study, the following areas were identified and specific recommendations were made.

**To The Ministry of health, Ethiopian Pediatrics Association and Regional health Bureau.**

- There is a need for the development of new appropriate disclosure guidelines and modules for health care providers and parents/caregivers as there was a low rate of disclosure; moreover, parent/caregivers expressed the need for assistance from the health care providers for future disclosures. Such guidelines should particularly focus on how to disclose the diagnosis of HIV to the infected children.
- Ensure training and up-dates of the health care providers on these issues.

- Parents/caregivers need to be counseled by trained health professionals about disclosure to children of their infection status. This counseling may need to be repeated throughout the course of the child‟s illness so that caregivers could decide on the proper time to disclose.
- Establishing peer clubs in each pediatric ART service providing facilities will help children to know about HIV/AIDS and allow them to discuss more about the barriers of disclosure.
- Modify the infrastructure of the pediatric ART clinic for enough space to provide a discussion section with caregivers.
- It is important that addressing and scaling up efforts on stigma and discrimination by giving health education to the community.

**To health care providers**

- Must ensure continuous professional development on pediatric HIV positive stating disclosure counselors.

**To community**

- Institutionalized tailor made systematic education for children across the life cycle.
- Integrated household and school counseling and support program.

**Researchers**

- Further research should be conducted on: Involving children living with HIV in order to address issues related to physical, social, and emotional consequences the disease has and compare children who know their HIV status with those who do not know in relation to these parameters.

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**Annex I**

Addis Ababa University College of Health Science School of public health, individual information sheet to study the assessment of magnitude and factors that affect care givers‟ decision towards disclosure of HIV diagnosis to HIV infected children in Addis Ababa Ethiopia.

**INFORMATION SHEET**

Good morning/afternoon, my name is_____ and I am health professional working in_____ I am also apart of team carrying out this study. The purpose of this study is to assess factors that affect care givers‟ decision towards disclosure of HIV diagnosis to HIV infected children in Addis Ababa Ethiopia. We believe that the study findings will help in order to improve health care service and full fill the HIV/AIDS disclosure issue of children. If you participate in the study, it will not take us more than 15 minutes. Your name will not be written on this form, thus the information you provide will not be known to others. Interviews will be carried out privately in a separate room, and there is no risk involved in participating in the study. Your participation is purely voluntary, and you can withdraw any time if you are not comfortable about the questionnaire without compromising the services you ought to get from any place you want to get it. However, we hope that you will participate in this study since your views are important.

Do you have any questions?

If you have any question you can contact the principal investigator at any time convenient for you using the following address:

**Name of principal investigator-** Roman Negewo Desta

**Address-** Addis Ababa, Ethiopia

Cellphone:0911654894 E-mail:roman12rw@yahoo.com

if you need more information pleases contacts:

Addis Ababa University (SPH IRB).**ADDR** Tel +251115157701. **POBOX** 9086.

**Annex II**

Addis Ababa University, College of Health Sciences, School of Public health, individual consent form to study the assessment of magnitude and factors that affect care givers‟ decision towards disclosure of HIV diagnosis to HIV infected children in Addis Ababa Ethiopia.

**Written Consent Form**

You have been already briefly informed about the study and clearly understand the objective. Now please tell me if you agree to participate in the study?

1. Agreed, Thanks! Conduct the interview

2. Did not agree, Thanks! Proceed to the next eligible participant

I the selected participant heard the information in the study information sheet & understood the purpose and benefit of the study. I understood that all the information regarding me like name and all answers given by me must not be transferred to a third party. I also understand that I can decide whether or not to take part in the study or even withdraw from the study at any time.

Your signature below indicates that you agree to participate in this study.

Participant's signature----------2013

Interviewer name: _____ signature_____2013

Supervisor Name: _____Signiture_____2013

**Name of principal investigator-** Roman NegewoDesta

**Address-** Addis Ababa, Ethiopia

Cell phone: 0911654894 E-mail:roman12rw@yahoo.com

if you need more information pleases contacts: Addis Ababa University

(SPH IRB).**ADDRES** Tel +251115157701 **POBOX** 9086

Addis Ababa University, College of Health Sciences, School of Public Health. Structured questionnaire on Demographic Characteristics of caregiver and children, clinical characteristics, magnitude and factors that affect care givers‟ decision towards disclosure of HIV diagnosis to HIV infected children in Addis Ababa Ethiopia 20013/14.

**Annex III**

**PART I - Information on socio-demographic characteristics of caregivers'**

| S.No. | Question | Coding categories | code | skip |
|---|---|---|---|---|
| 101 | How old are you? (caregiver's age in completed years) | ---------- | | |
| 102 | Sex of the respondent? | Female | 1 | |
| | | Male | 2 | |
| 103 | What is your religion? | Orthodox | 1 | |
| | | Muslim | 2 | |
| | | Catholic | 3 | |
| | | Protestant | 4 | |
| | | Others specify | 99 | |
| 104 | A) Do you read and write simple sentence in any language you speak? | Yes | 1 | |
| | | No | 2 | |
| | B) What is the maximum level of education you attained? | Non formal--------- | 00 | |
| | | Grade---------- | | |
| 105 | What ethnic group do you belong to? | Amhara | 1 | |
| | | Oromo | 2 | |
| | | Tigray | 3 | |
| | | Wolita | 4 | |
| | | Others (specify) | 99 | |
| 106 | Marital status? | Married | 1 | |

| | | | | |
|---|---|---|---|---|
| | | Single | 2 | |
| | | Widowed | 3 | |
| | | Divorce | 4 | |
| 107 | What is your current occupation /employment? | Unemployed | 1 | |
| | | Daily laborer | 2 | |
| | | Government employ | 3 | |
| | | Private employ | 4 | |
| | | House wife | 5 | |
| | | Merchant | 6 | |
| | | Others | 99 | |
| 108 | What is your estimated total monthly income per (ETB)? | ---------- | | |
| 109 | Total fmaily size? | ---------- | | |
| 110 | What is your Relationship to the child? | Mother | 1 | |
| | | Father | 2 | |
| | | Grand parent | 3 | |
| | | Siblings | 4 | |
| | | Relatives | 5 | |
| | | Others | 99 | |

**PART II- Information on socio-demographic characteristics of the child.**

| Ser No. | Question | Coding Categories | Code | Skip |
|---|---|---|---|---|
| 201 | Age of the child? (age in complete year in year) | ---------- | | |
| 202 | What is the sex of your child? | Girl | 1 | |
| | | Boy | 2 | |
| 203 | School grade of the child? | Not started education | 1 | |
| | | Kindergarten | 2 | |

| | | | | |
|---|---|---|---|---|
| | | Primary school (1-8) | 3 | |
| | | Secondary school (9-12) | 4 | |
| 204 | With whom the child does, currently, live with? | Biological parents | 1 | |
| | | Grandparent s | 2 | |
| | | Siblings | 3 | |
| | | Relatives | 4 | |
| | | Others | 99 | |
| 205 | Has the chilled lost any of his/her nucleus family members with HIV? | Yes | 1 | |
| | | No | 2 | If answer is no skip toQNo 301 |
| 206 | If answer is yes lost whom? (multiple answer is possible) | Mother only | 1 | |
| | | Father only | 2 | |
| | | Siblings | 3 | |
| | | Both mother and father | 4 | |

**PART III- Information on clinical characteristics of caregivers and children in Addis Ababa.**

| Ser. No. | Question | Coding Categories | Code | Skip |
|---|---|---|---|---|
| 301 | HIV status of caregiver? | Positive | 1 | |
| | | Negative | 2 | If answer is 2or3 skip to Q No 304 |
| | | Not tested | 3 | |
| 302 | If the answer is 1 for Ques No 301 to whom | To my partner | 1 | |

| | | | | |
|---|---|---|---|---|
| | did you actually disclose your positive status?<br><br>(Multiple answers possible) | To my child | 2 | |
| | | To my relatives | 3 | |
| | | To my friends | 4 | |
| | | No one know | 5 | |
| | | Religiousfathers | 6 | |
| 303 | Did the caregiver start ART | Yes | 1 | |
| | | No | 2 | |
| | | Others(specify) | 99 | |
| 304 | From where the child got referred for HIV screening? | Hospital in patient | 1 | |
| | | Hospital out patient | 2 | |
| | | PMTCT | 3 | |
| | | Community clinic | 4 | |
| | | Private clinic | 5 | |
| | | NGO clinic | 6 | |
| | | Governmenthospital | 7 | |
| | | Governmenthealthcenter | 8 | |
| | | Others | 99 | |
| 305 | Age at diagnosis of HIV positive status of the child? | ---------- | | |
| 306 | WHO clinical stage of the child? | Stage I | 1 | |
| | | Stage II | 2 | |
| | | Stage III | 3 | |
| | | Stage IV | 4 | |
| 307 | Most resent CD4 count of the child | ----------In number | | |
| 308 | Did the child start ART? | Yes | 1 | |

| | | | | |
|---|---|---|---|---|
| | | No | 2 | If answer is No skip to Q No 311 |
| | | Others(specify) | 99 | |
| 309 | If Ques No 308 answer is yes,age when ART was initiated | ---------- | | |
| 310 | Duration on ART? | ---------- | | |
| 311 | What other medication took the child other than ART? | Bactrim | 1 | |
| | | Anti-TB | 2 | |
| | | Multi-vitamin | 3 | |
| | | RTUTF | 4 | |
| 312 | How is treatment adherence of the child? | Good | 1 | |
| | | Fair | 2 | |
| | | poor | 3 | |
| 313 | Has the child ever been affected with opportunistic disease previously? | yes | 1 | |
| | | No | 2 | |
| 314 | Did the child get hospitalized previously? | yes | 1 | |
| | | No | 2 | |
| 315 | Did you discuses about disclosure issue with your child's health care provider? | yes | 1 | |

| | | | | |
|---|---|---|---|---|
| | | No | 2 | If answer is No skip to Q No317 |
| 316 | If the answer for Ques 315was yes, did the health care provider adequately cover the issues like disclosure? | yes | 1 | |
| | | No | 2 | |
| 317 | Did the child get support from other organizations? | yes | 1 | |
| | | No | 2 | If answer is No skip to Q No401 |
| 318 | If the answer for Ques317was yes, from where did he/she get support? | Government organization | 1 | |
| | | NGO | 2 | |
| | | Other (specify) | 99 | |
| 319 | What kind of support did he/she get? (Multiple answers possible) | counseling | 1 | |
| | | money | 2 | |
| | | material | 3 | |
| | | food | 4 | |
| | | Others ( specify) | 99 | |

**PART IV- Information on HIV positive status disclosure among HIV positive children In Addis Ababa.**

| Ser. No. | Question | Coding Categories | Code | Skip |
|---|---|---|---|---|
| 401 | Child knows his/her HIV status? | yes | 1 | |
| | | No | 2 | If answer is No skip to Q No405 |
| 402 | If answer for Q 401 yes, at what age did you disclose? (write age in year) | At----------years of age | | |
| 403 | Who disclosed about his/her HIV status to the child?<br><br>(Multiple answers possible) | mother | 1 | |
| | | father | 2 | |
| | | Grand parents | 3 | |
| | | relatives | 4 | |
| | | Health care workers | 5 | |
| | | Hear from friends/neighbors | 6 | |
| | | Others(specify) | 99 | |
| 404 | Why did you decide to disclose for your child about his/her HIV status?<br><br>(Multiple answers possible) | because child thought to be matured | 1 | |
| | | Because repeated question of the child what happen to him/her | 2 | |
| | | To take or adhere to medications | 3 | |
| | | Right to know about his/her disease condition | 4 | |
| | | to take care of his/her selves and prevent unknowingly | 5 | |

| | | | | |
|---|---|---|---|---|
| | | disease transmission | | |
| | | To share responsibility and to get relief | 6 | |
| 405 | If you didn't disclose, why you didn't decide to disclose the child about his/her HIV status?<br><br>(Multiple answers possible) | Because the child is too young | 1 | |
| | | Fear of self-discrimination | 2 | |
| | | The child inability to keep secret | 3 | |
| | | Future relation with the family would be affected | 4 | |
| | | He/she may feel hopelessness | 5 | |
| | | Because I am the one that transmit the virus so, I fell guiltiness | 6 | |
| | | Fear of emotional and health consequence | 7 | |
| | | Lack of knowledge | 8 | |
| | | Others(specify) | 99 | |
| 406 | If you didn't disclose, what you told the child the reason for visiting health facility? | For TB follow up | 1 | |
| | | For cardiac follow up | 2 | |
| | | For allergic follow up | 3 | |
| | | Others(specify) | 99 | |
| 407 | Do you have a plan to disclose in the future about his/her HIV status to your child? | yes | 1 | |
| | | No | 2 | |
| 408 | The age at which the child should know about his/her HIV status? | ---------- | | |

| | | | | |
|---|---|---|---|---|
| | | | | |
| 409 | Who should have the responsibility of disclosing HIV status to the child? (Multiple answer possible) | mother | 1 | |
| | | Father | 2 | |
| | | Grand parents | 3 | |
| | | Health workers | 4 | |
| | | Others (specify) | 99 | |
| 410 | Do you think the child gets stigmatized due to his/her HIV positive status? | yes | 1 | |
| | | No | 2 | |

**PART V Information on outcome of HIV positive status disclosure on HIV positive children In Addis Ababa.**

**This portion of the questionnaire is filling only for caregivers who had disclosed the child's HIV positive status to the child**

| S No. | Question | Coding Categories | Code | Skip |
|---|---|---|---|---|
| 501 | What was the child's immediate reaction encountered after HIV serostatus disclosure? (Multiple answers possible) | Crying | 1 | |
| | | Accepted | 2 | |
| | | Depression | 3 | |
| | | Anger | 4 | |
| | | Hopelessness | 5 | |
| | | Others(specify) | 99 | |
| 502 | How is the child's adherence of medications following HIV serostatus disclosure? | Good adherence | 1 | |
| | | Fair adherence | 2 | |
| | | poor adherence | 3 | |
| | | Others(specify) | 99 | |
| 503 | What is the child's health condition following HIV status disclosure? (Multiple answers possible) | Increase CD4 count | 1 | |
| | | Less disease progression | 2 | |
| | | Decrease CD4 count | 3 | |
| | | More disease progression | 4 | |

| | | | | |
|---|---|---|---|---|
| | | No change | 5 | |
| 504 | What was the child's social relation following HIV serostatus disclosure? (Multiple answers possible) | Withdrawal from peers | 1 | |
| | | Increase relation with caregiver's | 2 | |
| | | Blaming caregiver's | 3 | |
| | | Keep secrets | 4 | |
| | | Tooled to other people | 5 | |
| | | Felt disclosure was important | 6 | |
| | | Took care of him/her self-better | 7 | |
| | | Chilled being able to protect him/her self and others | 8 | |
| 505 | What was respondent( caregiver's) concrete feeling following the child HIV status disclosure? (Multiple answers possible) | Relief after disclosure | 1 | |
| | | Fell not important disclosure | 2 | |
| | | Disclosure is important and encouraging | 3 | |
| | | No different felling | 4 | |
| | | Others(specify) | 99 | |

**THANK YOU!**

**Annex IV: In depth interview guide**

Addis Ababa University College of Health Science School of public health, individual information sheet to study the assessment of magnitude and factors that affect care givers‟ decision towards disclosure of HIV diagnosis to HIV infected children in Addis Ababa Ethiopia.

Good morning/afternoon, my name is_____ and I am a second year MPH student at Addis Ababa University. I will conduct a study on factors that affect care givers‟ decision towards Disclosure of HIV diagnosis among HIV infected children in Addis Ababa Ethiopia. The purpose of this study is to measure the magnitude and identify factors that affect caregiver‟s decision to disclose their children HIV/AIDS status. We believe that the study findings will help in order to improve health care service and full fill the HIV/AIDS disclosure issue of children in Addis Ababa. Your name will not be written on this form Interviews will be carried out privately in a separate room. I will use a tap record to insure the accuracy of data collection but information that you will give us will be kept confidential and will be used only for research purpose. You have full right to take part or to interrupt the interview at any time if you are not comfortable about the questionnaire. But the information that you will give us during discussion is quite useful to achieve the objective of the study and to bring change in the chilled HIV/AIDS disclosure issue.

You have been already briefly informed about the study and clearly understand the objective.

Now please tell me if you agree to participate in the interview.

1. Agreed Thanks! Conduct the interview

2. Did not agree Thanks! Proceed to the next eligible participant

Your signature below indicates that you agree to participate in this study.

The participant sign----------2013

Interviewer name: _____ signature_____2013

**Part I-socio demographic information**

1.How old are you ?

2.Sex?

3.do you read and write simple sentences in any language

You speak?

5.what is the maximum level, education you attained?

6.what is your marital status?

7.What is your current occupation?

8.What is your total monthly income?

9.What is your relation to the child? Probe for actual relationship,

10.Age of the child?

11.Sex of your child?

12.School grade of the child?

13.With whom the chilled currently live with?

14.Is the chilled lost any of his/her family members with HIV?

If yes, lost whom?

**Part II Information on HIV/AIDS status disclosure and clinical characteristics.**

1.what is your HIV status?

2.Does the child know that he/she has HIV/AIDS?

3.If yes, probe; would you explain the reason?

is there anything else?

4.At which age did you disclose?

Why did you disclose to your child at this age?

Probe-Would you explain further

5.Do you intend to tell the child about his/her status sometime?

If yes, at which age did you want to disclose your child about his/her HIV status?

probe; would you explain the reason?

**PART III Information on outcome of HIV positive status disclosure on HIV positive children.**

1.You told me that you already disclose your child about his/her HIV status what was your child treatment adherence following disclosure ?

If good adherence, probe; would you explain the reason ?

If poor adherence, probe; would you explain the reason?

2.What was your child's health condition following HIV status disclosure?

probe; would you explain more?

Can you give an example?

3. What was the child's social relation following HIV serostatus disclosure?

probe; would you explain more?

Can you give an example?

4. What was your feeling following the child HIV status disclosure?

probe; would you explain more?

**In depth interview guide for health care providers and experts working in AARHB**

1.Can you mention those factors which could be affect care givers to disclose their children HIV status?

probe; would you elaborate more?

2.At which age should the child disclosed about his/her HIV status?

probe; would you explain the reason?

Can you give an example?

3.what was the challenge for health care providers in relation to status disclosure of the children?

probe; would you explain it more?

4.Does the child face challenge in relation to his/her HIV positive status during adolescent period?

Probe; would you explain it by comparing for disclosed children and for those not disclose children?

Can you give an example?

5.disclosure is the burden of caregivers, to share or minimize this burden as a health professional or as an expert what will be done?

probe; would you explain?

6.At a program level what will be done related to disclosure of HIV positive status to HIV infected children?

probe; Would you explain?

NOTE:-**For all questions probe as needed for more information.**

**THANK YOU!**

**Table 8: Socio-demographic profile of the healthcare professionals interviewed in Addis Ababa, 2014**

| Respondents | Respondent health facility | Respondent health profession | Sex | Age |
|---|---|---|---|---|
| 1 | Hospital | Pediatrician | F | 37 |
| 2 | Hospital | Nurse | F | 40 |
| 3 | Health center | Nurse | F | 32 |
| 4 | Regional Bureau | Expert | F | 36 |

**Table 7: Socio-demographic profile of the caregivers interviewed in Addis Ababa, 2014,**

| Caregiver | Facility | Caregiver relation to the child | HIV status | Sex | Age |
|---|---|---|---|---|---|
| 1 | Health center | Grand parent | Not tested | F | 70 |
| 2 | Hospital | Aunt | Negative | F | 38 |
| 3 | Hospital | Brother | Negative | M | 34 |
| 4 | Hospital | Mother | Positive | F | 35 |
| 5 | Hospital | Mother | Positive | F | 30 |
| 6 | Hospital | Mother(Expert patient) | Positive | F | 25 |

## Table 9:The theme, categories and codes as identified from the qualitative data

| Theme: Disclosure affect by caregivers and child reason stigma, child age and service related | | | | |
|---|---|---|---|---|
| Categories: | 1–caregivers and child for reason | 2-Disclosure increase hope, maintain healthy life and facilitate adherence | 3-Disclosure minimize risk | 4-Recognition of limited access to service |
| Codes: | -Discrimination<br>-Secret<br>-Too young<br>-Guilty filling<br>-Affect health<br>-Affect relation<br>-Ask source of infection | -Want to be healthy<br>-Want to be live long<br>-Want to be active in daily life<br>-Want to be success full<br>-Sociable | -Take responsibility<br>-Prevent others<br>-Self care<br>-Adherence<br>-Awareness<br>-Take responsibility | -Lack guidelines<br>-Lack of training<br>-poor infrastructure<br>-Shortage manpower<br>-Absence/ shortage discussion with caregivers<br>-Work load |