ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH

Assessment of HIV Serostatus Discloser and its Influence on Adherence to ARV Treatment among HIV-infected Adolescents in Addis Ababa, Ethiopia.

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A thesis Submitted to the School of Graduate Studies of Addis Ababa University in partial fulfillment of the requirements for the degree of Masters of Public Health, School of Public Heath

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AAU Addis Ababa University

AAP American Academy of Pediatrics

AIDS Acquired immune deficiency syndrome

ART Anti-retroviral therapy

CD4 Cluster for differentiation 4

CDC Center for disease control and prevention

Epi Info Epidemiological Information

FDRE Federal democratic republic of Ethiopia

FMOH Federal ministry of health

HAART Highly active antiretroviral therapy

HAPCO HIV/AIDS Prevention and Control Office

HIV Human Immunodeficiency Virus

MOH Ministry of health

MPH Master Of Public Health

OR Odds Ratio

PLWHA People living with HIV/AIDS

SD Standard Deviation

SPSS Statistical Package For Social Sciences

WHO World Health Organization

ABSTRACT

Back ground: Along with the increased survival of children infected with HIV, disclosure of HIV status to children remains a complex and a critical clinical issue in the care of HIV-infected children. Disclosed HIV status has been identified as one of the factors associated with better adherence and also essential for the secondary prevention of HIV transmission. However, HIV status disclosure of adolescent represents a challenge for the family and for medical staff.

Objective: To assess the magnitude of HIV serostatus disclosure and its effect on ART treatment adherence among HIV-infected adolescents in ART care and treatment providing health facilities in Addis Ababa.

Methods: A facility based cross-sectional study design was conducted among 403 adolescents receiving ART in the selected six health facilities of Addis Ababa. Caregivers of adolescents of aged 10-18 years, were interviewed using a structured questionnaire. Three days intensive training was given for all supervisors and data collectors. Stepwise logistic regression was conducted to identify the association of disclosure to HIV status and with adherence to ARV medication, Data entry and analyses was carried out using EPI info and SPSS version 16 statistical packages respectively.

RESULT: Three hundred and ninety six parents of adolescents on ART participated in this study making the response rate at 98%. Median age of the adolescents was 14 years. The level of HIV states discloser was 47%. Data showed that age greater than 14 years [AOR = (95% CI) 5.20 = (2.46-12.29)] and lower educational states of the care givers[AOR = (95% CI) 5.20 = (2.46-12.29)] were significant predictors for being disclosed. Similarly being disclosed to their HIV status and being in a fixed dose HAART regimen [AOR=(95% CI)9.94,(4.48-22.08)] and [AOR and (95% CI) 8.40= (2.48-28.47)] respectively were significantly associated with good HAART adherence.

CONCLUTION: More than half (53%) of the adolescents who participated in the study did not know their HIV serostatus however, disclosed HIV status was significantly associated with good HAART adherence. The disclosure process should be thus systematically encouraged and organized among adolescent populations in order to improve their ARV medication adherence and prevent further HIV transmission.

1. INTRODUCTION

1.1 BACKGROUND: Children account for approximately 2 million of all people living with HIV and AIDS worldwide. Almost 90% of all HIV infected children live in sub-Saharan Africa (1). With the advent of antiretroviral therapy (ART), there has been a significant reduction in morbidity and mortality of HIV-infected children and most of them are surviving through childhood into adolescence.

Adolescents are characterized by remarkable physical, mental and social changes and difficulties related to their sexual lives, Adolescents in their first sexual debut are at high risk of HIV acquisition and transmission in areas of generalized epidemic (2).

Emotional and behavioral disorders have been described in Africa throughout adolescence. Virological failure has also been observed among adolescents (3-5) such as in a US series where it was observed in 67% of 154 adolescents, mainly associated with the lack of adherence and suboptimal ART use (6).

On the other hand, adolescence is a developmental period characterized by considerable social, biological and physical change, where youth gradually assume more autonomy and take on adult roles and behaviors (7, 8). The American Academy of Pediatrics (AAP) argued that adolescents fully informed of their status can tackle illness and issues of dying and immediate future, consider the consequences of their sexual behavior, and participate in their own medical treatment (9). Caregivers and medical providers have continued to struggle with decisions about the timing and content of HIV disclosure conversations with an aging population of HIV-infected children (10).

For adolescents, the AAP has established that health care professionals have an ethical obligation to provide counseling to respond to the needs of adolescent patients and to insure that adolescents have an opportunity for examinations and counseling apart from their parents (11). Consequently, physicians should provide full disclosure of HIV status to their adolescent patients. Physicians are also obligated to encourage adolescents to involve their parents in their care. Adolescents need to be informed about their illness to assist in

their own care and to reduce the risk of transmitting the infection to others through unprotected sex or behaviors associated with illicit drug use (11).

Reasons for non-disclosure to children by families in industrialized countries included the child's young age, the desire to protect the child or have the child live a "normal" life and the fear of psychological harm or social stigma following disclosure; concerns that the child will not understand or be unable to keep a secret or that disclosure would change family relationships; and being unsure of what to say or fear of questions about transmission (10). In developing countries, reasons to not disclose and concerns around disclosure included the child's young age; concerns about causing psychological harm, being judged by the child, the child telling others, and social stigma, and caregivers feeling emotionally challenged or unprepared to answer subsequent questions (12-17).

Knowledge of HIV status may affect compliance with antiretroviral therapies and influence children's participation in healthcare decision-making (12). In Ethiopia, it is recommended that adolescents 14 years of age and older should know their HIV status (13). Nevertheless, some parents and health care professionals are reluctant to inform children about their HIV infection status (18).

1.2 STATEMENT OF THE PROBLEM

Along with the increased survival of children infected with HIV, disclosure of HIV status to children remains a complex and a critical clinical issue in the care of HIV-infected children. Disclosed HIV status has been identified as one of the factors associated with better adherence and also essential for the secondary prevention of HIV transmission (19, 20).

However, published rates of disclosure in children from resource rich countries vary widely, from 18% to 77% (21, 22), partly due to the lack of conclusive guidelines on when and how to disclose the diagnosis of HIV to children. Though limited, studies available on rates and effects of HIV disclosure on children are mainly from resource rich countries (23). There is scarcity of data on disclosure from resource limited settings, where the majority of HIV infected children live. Moreover, studies from resource limited settings have mainly been qualitative in design with small samples sizes making it difficult to

generalize the findings (23). Our study intends to *assess the magnitude* of HIV serostatus disclosure and its effect on ART treatment adherence in HIV-infected adolescents in Addis Ababa. The study is hoped to generate useful insight on the vulnerability of HIV serostatus discloser, that in turn will help to achieve and maintain treatment success.

1.3 SIGNIFICANCE OF THE STUDY

Even though, knowledge of once own HIV serostatus has a great impact to achieve treatment success as well as prevention and control of HIV disease transition, many studies in sub-Saharan Africa, show that prevalence of HIV serostatus disclosure in adolescent is very low. The purpose of this study is to fill the research gap on the magnitude of HIV serostatus disclosure and its significance on treatment adherence in HIV-infected adolescents. This study will have a significant input in assessing the magnitude of HIV serostatus disclosure and its significance on treatment adherence at the health institution level in the study area and beyond.

This study will also be important for different stakeholders addressing the issues related to HIV serostatus disclosure and treatment adherences success.

For participants

Increase awareness of participant towards HIV status discloser, associated factors and treatment adherences

For profession

It gives dependable input to arrange different types of trainings which will change the attitude towards HIV states discloser.

For the professionals or for the researchers

Any researchers or professionals working with similar topics of related discovery can use this work as baseline data.

For stake holders

Gives good background to adjust their service based on the actual data to arrange different educational programs and trainings to fulfill the gap.

2. LITRATURE REVIEW

2.1 Conceptualization

Two conceptualizations of disclosure emerge from the pediatric HIV literature. The first approach treats disclosure as a single event, the provision of the diagnosis of HIV or AIDS to an individual (24-26), the second construes disclosure as a process. Disclosure as a process has been documented in two different ways. One way is from the perspective of the caregivers and is the process undertaken to disclose, which incorporates the time up until full disclosure (27, 28). The other is from the perspective of the children and is the process of information received, which can, but does not necessarily include events both before and following disclosure (29, 30).

Although it is possible to conceptualize disclosure as a process of information provision to an HIV-positive child, for this study we felt it would be more understandable to examine disclosure as a condition surrounding the first mention of HIV or knowledge of having HIV infected. Specific research questions included in this paper are: is the adolescent knew his own HIV sero status or not? When is the most appropriate time to inform? Who should be involved in the disclosure? Adolescent's reaction after disclosure? And questions related to treatment adherence.

It is believed to be important that HIV infected children know their status and its implications in increasing detail as their development permits. The importance of disclosure has been supported by studies demonstrating the association of HIV disclosure to children with improved medical, behavioral, and psychological outcomes. Studies have also demonstrated improved CD4 counts (31), increased medication adherence (32, 33, 34), decreased behavioral problems, and closer relationships between the child and caretaker.

HIV disclosure to children has also been associated with improved psychological outcomes, such as decreased parental depression, increased self-esteem, and decreased reports of psychological distress (35, 36, 37). Other studies found no significant differences in outcomes of general health, mental health, and social behavior (38). These inconsistent

findings underscore the need for further improvement of the disclosure practice and determining the effects of disclosure on long-term child and adolescents health outcomes.

Studies conducted in the United States, Canada, and Europe indicated that the proportion of HIV-infected children who had not been told or disclosed their HIV status ranged from 25 to 70 percent in the U.S. and Canada and it was as high as 75–82 percent in Europe (24,39)In a US prenatally HIV-infected cohort, HIV disclosure was observed to occur at younger age over time, which may suggest a decline in the perception of HIV stigma[38]. In this industrialized country, the social and medical network may have been strengthened, leading to this condition. Reasons and factors influencing disclosure in industrialized countries include increasing age and/or cognitive development, concerns that the child would learn his/her status from other sources or become sexually active, the deteriorating health status of the child or the desire to improve health care and medication adherence, questioning by the child or the child's right to know, and the need to maintain trust or not keep secrets from the child (10).

Despite evidence from industrialized countries indicating that informing children can have positive psychosocial and clinical outcomes (40, 41), limited research has been conducted on when, and how HIV-infected children are told about their illness.

In resource-limited settings, despite local interventions, such as peer support groups, or community organizations for social support, stigma and fear of negative reactions or psychosocial outcomes may remain strong barriers to an earlier HIV disclosure to children (2). Few studies published to date included information on disclosure prevalence among HIV-infected children in developing countries, which ranged from 24–30 percent, and was higher in older versus younger age groups(20,42). Limited availability of antiretroviral regimes, high levels of stigma and low levels of HIV status disclosure among adults in developing countries may mean that disclosure to children in these settings is lower than what has been documented elsewhere. Studies from developing countries largely document reasons for not disclosing rather than for disclosing, a reflection perhaps of the low prevalence of HIV disclosure. Studies identified improving treatment adherence,

the child's concerns about their health status, and the child's desire to know about their health as factors that have influenced disclosure similar with that of developed countries (18).

In Ethiopia published studies are not found in HIV status discloser except one study conducted in 2008 (43), suggested that prevalent of HIV discloser among children's is 17.4% which is very low and there are also many adolescents still undisclosed in HIV care units in Addis Ababa.

2.2 HIV sero status discloser and adherences to ARV medication

One important factor for the success of treatment is adhering to the treatment prescribed, ***Adherence*** means taking a medicine as prescribed by the health care provider.

Taking medicines the right way is very important for treatment success. If the child/adolescent is HIV infected and misses or takes reduced doses or stops taking the medicine, HIV can learn to survive despite the medicine. This may cause the infection to change or get stronger, and the current prescribed medicines may no longer work. This could lead to drug resistance or treatment failure (44).

Few studies from developing countries to date have documented outcomes of disclosure (39). Some have found delayed or nondisclosure of HIV status to be associated with poor adherence (45). A Thai study found more positive attitudes towards HIV-infection and a better understanding of the importance of adherence to drug regimens (46). Thus, disclosure is important for helping children understand the need for ART and for creating trusting relationships that facilitate adherence (47) yet research on disclosure and adherence is not conclusive. In a recent qualitative study some caregivers reported that their children became more adherent to antiretroviral medications after learning their diagnosis some studies, including this one, have documented immediate negative reactions from children upon learning their HIV status (48, 49, 50).

A disclosure model for pediatric patients living with HIV in Puerto Rico (51) reported that Six months post disclosure, 70% of the participating youths endorsed feeling 'normal' and

parents and caregivers reported that approximately 58% had improved adherence. And the majority of youths (85%) and caregivers (97%) thought the disclosure was a positive event one study conducted in sub Sahara Africa, adolescents became more conscious of the importance of properly taking medications following disclosure. The findings here are also similar with findings seen in Benin and Thailand (52, 50).

2.3 Measurement Tools for Adherence in Children/adolescent

The ability to fully understand adherence has been hampered by limitations in the measurement of tools. ART adherence can be measured using multiple methods, which can be categorized as subjective or objective. Subjective measures include provider assessment and child and caregiver self-report. Objective measures consist of pharmacy refill data, announced and unannounced pill counts, and electronic monitoring (52). There is no gold standard for adherence measurement, and all measures have advantages and disadvantages, depending on individual preferences, available resources, and the goal of clinical care versus research.

Adherence measurement in children and adolescents is more complicated than measurement in adults due to two principal reasons. First, the goal of the measurement is to learn the behavior of the child; however, that behavior is often influenced to varying degrees by the behavior of one or more caregivers, medical providers, or others. For self-reported measures, the child may be too young to provide information directly and the report must come through the caregiver. Even when the child can provide primary information, studies have shown poor concordance of the data (32), and the accuracy of both measurements is unclear. Second, most existing adherence measures are designed for adults who take pills with infrequent regimen changes. They do not account for the role of the caregiver, the complexity of pediatric regimens, or the measurement of syrups. Objective measures, such as pharmacy refill, that do not depend on these factors are therefore appealing, but do not actually confirm that pills were ingested. Additional research and tools are needed.

3. OBJECTIVES

3.1 GENERAL OBJECTIVE

To *assess the magnitude* of HIV serostatus disclosure and its effect on ART treatment adherence among HIV-infected adolescents in ART care and treatment providing health facilities in Addis Ababa.

3.2 SPECIFIC OBJECTIVES

- *To determine the magnitude of HIV status disclosure by parents/ caregivers of adolescent who acquire HIV through vertical transmission in Addis Ababa.*
- *To assess the effect of HIV status discloser in HIV infected adolescents on adherence to ARV treatment.*

4 METHOD AND MATERIAL

4.1 STUDY AREA AND PERIOD

The study was conducted in Addis Ababa the capital city of Ethiopia and Addis Ababa has a population size of over 3 million (3038096) with annual growth rate of 2.1. In 2004E.C there have been 3434 adolescents who were on ARV treatment in health institution of Addis Ababa.(2012,A.A health biro annual report)

The city has 10 public hospitals 27 old health centers ruled by the Addis Ababa Health Bureau and 10 new health centers are opened recently. Furthermore, the city has 2 hospitals, three health centers and 31 different level clinics establish by non-government organizations (NGOs). The city also has 30 private hospitals and more than 700 different level private clinics.

From the above health facilities a total of 6 health institutions were selected purposively which have been providing HIV/AIDS care and treatment services and since large number of adolescents in their treatment care, from October 2012 to July 2013 were selected. Three Public Hospitals, run by A.A Regional Health Bureau, except ALERT Hospital which is governed by FMOH, two Public Health Centers and one NGO Clinic (WWO) were selected as they have large number of adolescents in their ART units.

4.2 STUDY DESIGN

A facility based cross sectional study was conducted in Addis Ababa health institution.

4.3 SOURCE POPULATION

All care givers of adolescents who were on ARV treatment present during the data collection period in the selected health institutes of Addis Ababa city.

4.4 STUDY POPULATION

Care givers of adolescents HIV infected age 10-18, Who were taking highly active antiretroviral therapy (HAART) and who were on follow up as well present during the data collection period in the selected 6 health institutes were sampled.

4.5 INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria;

Care givers of HIV infected adolescents on HAART

- Age 10-18,Who were taking highly active antiretroviral therapy (HAART)
- Who have been taking HAART for a minimum of 12 weeks.

Exclusion criteria;

- Adolescents who came alone (without their caregivers) at the time of the study
- Caregivers/ adolescents who were ill(unable to communicate ,unconscious) at the time of the study

4.6 SAMPL SIZE CALCULATION AND SAMPLING TECHNIQUE

For the first objective sample size calculation is done by using a single proportion formula by considering the following assumptions.

From the previous study conducted in Addis Ababa, Prevalence of HIV discloser was 17.4% (18), 95%CI , 80% power ,5% marginal error

$$N=\frac{z_{\alpha/2}^2 p(1-p)}{W^2}$$

Where $z_{\alpha/2}=1.96$

P=17.4% (prevalence of HIV discloser)

W=5%

$$=\frac{(1.96)^2\ 0.174(1-0.174)}{(0.05)^2} \qquad =374.4$$

For the second objective sample size calculation is done by using a single proportion formula by considering the following assumptions.

Since we couldn't found published study conducted in Addis Ababa, consider Prevalence of adolescent's adherence to ARV medication 50%, 95% CI, 80% power, 5% marginal error

$$N=\frac{z_{\alpha/2}^2 p(1-p)}{W^2}$$

Where $z_{\alpha/2}=1.96$

P=50% (prevalence of adolescents adherence to ARV medication)

W=5%

$$=\frac{(1.96)^2\ 0.50(1-0.50)}{(0.05)^2}$$

=403

	prevalence	Confidents interval	Power	marginal error	Non response rate	Sample size
1st objective	17.4%	95%	80%	5%	5%	374.4
2ndobjectie	50%	95%	80%	5%	5%	403

From the above two calculated sample size we took 403 which is the maximum one in order to overcome the short coming of the technique and maximize the strength of the study.

4.7 Sampling procedure

Out of the 38 public & NGO pediatric/adolescent ART sites in ADDIS ABABA, 6 sites were purposively selected in which large number of adolescents on HAART are confined to these

areas. based on 2011 Addis Ababa regional health biro annual report the number of adolescent in Yekatit 12 , Zewditu , Alert Hospitals were 344 ,553, 709 respectively. Kotebe & Bole 17 Health Centers were 79, 83 respectively and 186 in WWO. These are health facilities with highest number of adolescents using ART. Simple random sampling technique was used to recruit study subjects from the selected ART units proportional to the unit's client size.

By referring clients registration book using their unique ART number for a month prior to data collection, average number of clients visit to the study ART units per month was determined to select clients interviewed throughout the data collection period.

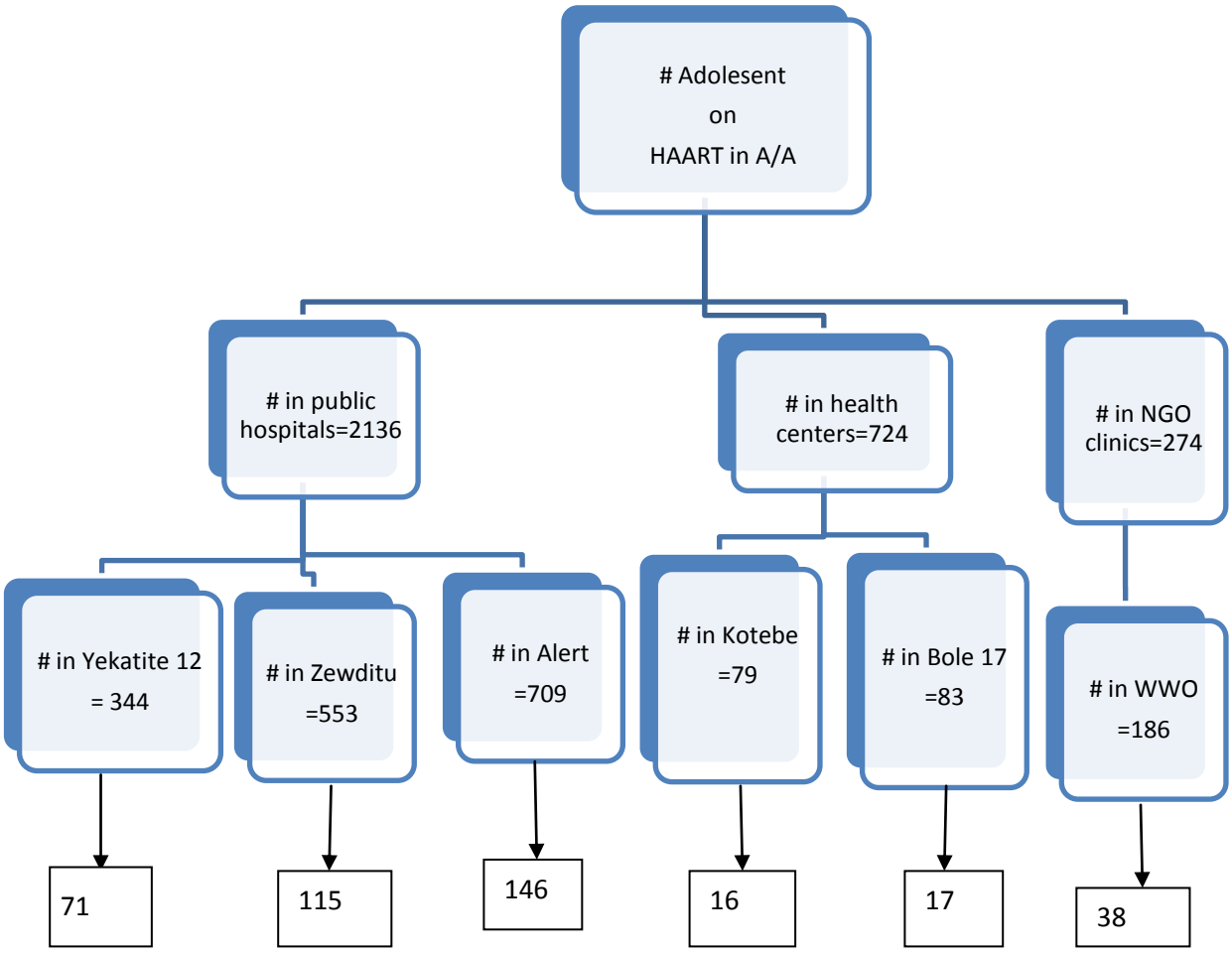


Figure 1 Schematic representation of sampling procedure of the study.

4.8 DATA COLLECTION INSTRUMENT and PROCEDURE

Data was collected from February 8-may 10, 2013 by using a standard structured, pretested questionnaire. The questionnaire was adapted from pediatrics AIDS clinical trials group standard questionnaire and from different literatures and was systematically addressed the objectives of the study. The questions were first developed in English and

translated to Amharic then back to English by different interpreters to see the consistency. Training was conducted for 10 data collectors and 2 supervisors for consecutive days on the data collection procedure, technique and similar understanding of the questionnaire. pre-testing of the questionnaire was undertaken in 5 percent of the sample size in the selected sites and eligible adolescents for the study before the actual data collection data by the actual data collectors. The difficulty and ambiguity of the questionnaire was restructured. The final version of the questionnaire was used for the data collection.

4.9 Data collectors

The data was collected by 10 trained nurses. All data collectors participated in pre testing of the questionnaire any un-clarity in the questionnaire tried to reach in consensus. Continues supervision was arranged to control the data collection procedure by two trained health officers.

4.10 VARIABLES

Dependent variable:

- Disclosure of HIV/AIDS serostatus to the participant children
- Adherence to ARV treatment

Independent variable

- Socio-demographic and economic states (age, sex, educational status, family income)
- Family type (biologic, non biological, adoptive/foster)
- Patient clinical states (functional states, WHO clinical stage, CD4 level)
- Caregivers (educational status, marital status, occupation)

4.11 OPERATIONAL DEFINITION

Disclosure: Where the caregiver say's that the child knows his/her HIV diagnosis;

Non disclosure: Where the caregiver say's that the child does not know his/her infection or where the caregiver was unsure if the child knew his/her status.

Caregiver: A person, who lives with the child, participates in the child's daily care and is the most knowledgeable about the child's health. Either biological parents or guardians acting as surrogate parents to the child.

Adherence to treatment; the number of doses currently taken divided by the number of doses prescribed for a given period of time (7 days) by self report adherence measuring tool.

Adherent: if the patient has taken >95% of the prescribed doses correctly.

Non adherent: if the patient has taken less than95% of the prescribed doses.

Working able to perform usual work in or out of the house, harvest, go to school, for children, normal activities or playing)

Ambulatory able to perform activities of daily living

Bedridden not able to perform activities of daily living

4.12 Data quality management

Data quality assurance was in place during questionnaire designing, data collection, data entry. Questionnaire was objective based, logically sequenced, free of scientific terms and non-leading. The data collectors and supervisors were provided with intensive training. The collected data were checked by the principal investigator on daily basis for any incompleteness and/or inconsistency. The questionnaire was also tested for clarity, flow, cultural, moral fitness and time requirement before the actual data collection starts.

4.13 Data Processing and Analysis

Data entry and analyses were carried out using EPI-INFO version 7 statistical package and SPSS version 16 statistical package, respectively. First, descriptive statistics was carried out to explore the socio-demographic characteristics of the respondents and the adolescents, clinical characteristics of the adolescents and their HIV states discloser rate. To find association between the exposure variables and adherence, bivariate analysis was done. to control the effect of confounding variables, multivariate logistic regression was done. Variables, which were showing statistical significant association ($P<0.005$) in the bivariate were included in the final model.

4. Ethical considerations

Ethical clearance was obtained from the research ethics committee of the School of Public Health at the College of Health Science, Addis Ababa University. The regional health office and ethical review committee of participating hospitals also cleared the study at their institution level. The primary care givers was enrolled as a study participants since children and or adolescents less than 18 years were in capable of making an informed decision regarding participation in the research study. Written consent was given for primary care givers followed the provision of information about the study. Consent ensured that participants understood the followings: possible risks and benefits, voluntary participation, assurance of confidentiality, the purpose of the research, how he/she was chosen to participate, data collection procedures and whom to contact when questions and concerns arise with contact details of the investigator for further explanation at any time.

5. Dissemination of results

The study result will be submitted to Addis Ababa University, College of Health Science as partial fulfillment of the requirement for master's degree in public health it will also be disseminated to Addis Ababa health bureau and to FMOH. Attempt will be made to publish the study findings in a peer-reviewed journal and present in scientific conferences.

7. Results

7.1 Socio-demographic and economic characteristics

A total of 396 caregivers of HIV infected adolescents were included in the study with response rate of 98%. Majority, 255 (23.4%) HIV infected adolescents were between 10–14 years of age, 215 (64.3%) were boys and as to the educational states of the adolescent, 270(68.2%) were between grade 1-8, 92(23.2%) Were between grade 9-12 and 27 (6.8%) of them were able to read and write.

A total of 297 (75%) female and 99 (25%) male primary care givers of adolescents responded to the interview. the age of care givers ranges from 19 years to 78 years, of where 144 (36.4%)were between 30-39years. The mean (SD) and the median age of the primary care givers were 34.4 + 10.3 and 40, respectively.

Most of the study participants were belonging to Amhara 148 (37.4%), Oromo 139 (35.1%), and Guragea 45 (11.4%) by ethnicity .The majority of care givers 295(74.5%) were orthodox Christianity followers, and a third of them 120 (30.3%) were married. concerning the educational states of the caregiver, 106(26.8%) have attended secondary school education (9-12) And 99 (25%) were house wives.

Assessment of the average monthly income that the households in which the study participants were living showed that 69.4% of the study participants had monthly income below 1363 birr with the maximum of 7600 birr and minimum of no earning, while the median monthly income was 800 birr.

One hundred and ninety six (53%) of the care givers had family size of 4-6 whilst 124(33.5%) had 1-4. (See table 1 below)

Table 1:-Socio-demographic characteristics of caregivers and adolescents on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa Ethiopia (n=396)

Variables	Frequency (n)	Percentage (%)
Adolescent age		
Age 10-14	249	62.9
Age > 14	147	37.1
Respondents' age		
18-29yrs	47	11.9
30-39yrs	144	36.4
40-49yrs	129	32.6
>=50	79	19.2
Religion of the caregiver		
Orthodox	259	74.5
Muslim	58	14.6
Catholic	25	6.3
Protestant	16	4
Others*	2	.5
Respondents marital status		
Married	120	30.3
Not married	111	28.0
Separated	59	14.9
widowed	67	16.9
Divorced	39	9.8
Caregivers educational status		
Unable to read and write	72	18.2
Able to read & write	60	15.2
Primary(1-8)	96	24.2
Secondary(9-12)	106	26.8
Diploma & above	62	15.7
Respondents occupation		
Merchant	30	7.6
House wife	99	25.0
Student	35	8.8
Government employee	97	24.5
Daily laborer	27	6.8
Private employee	99	25.0
Other**	9	2.3

Others*=Jehovah Other**=NGO employee

7.2 Living arrangement of the adolescents

Out of 396 adolescents, 225(56.8%) of them live with their biological parents and 171(43.2%) of them live with their non- biological parents. Out of the 171 adolescents who live with their non biological parents, 123(71.5%) with their relatives, 23(13.4%) with their adoptive parents and the rest 26(15.16%) were living in foster care institutions. 77(19.4%) of the adolescents had one or more HIV positive siblings living with them.

138(38.8%) of the adolescents both of their parents were alive, 130(32.8%) both parents were dead and 128(32.3%) only one of their parents were dead. (see figure 1 below)

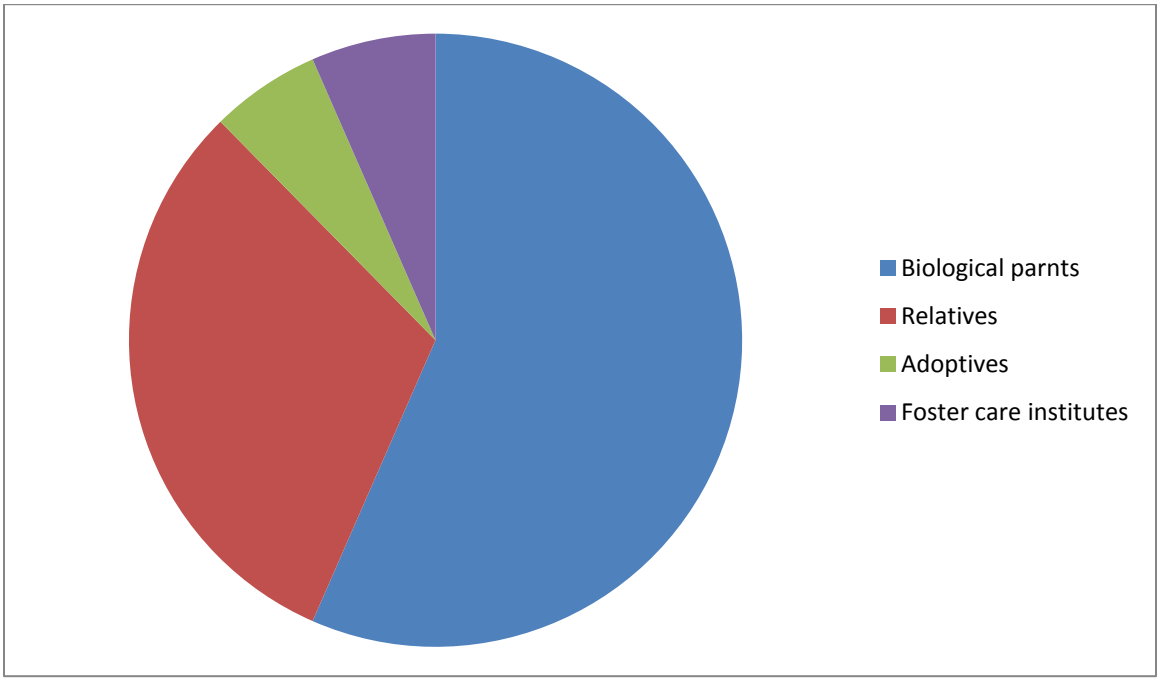
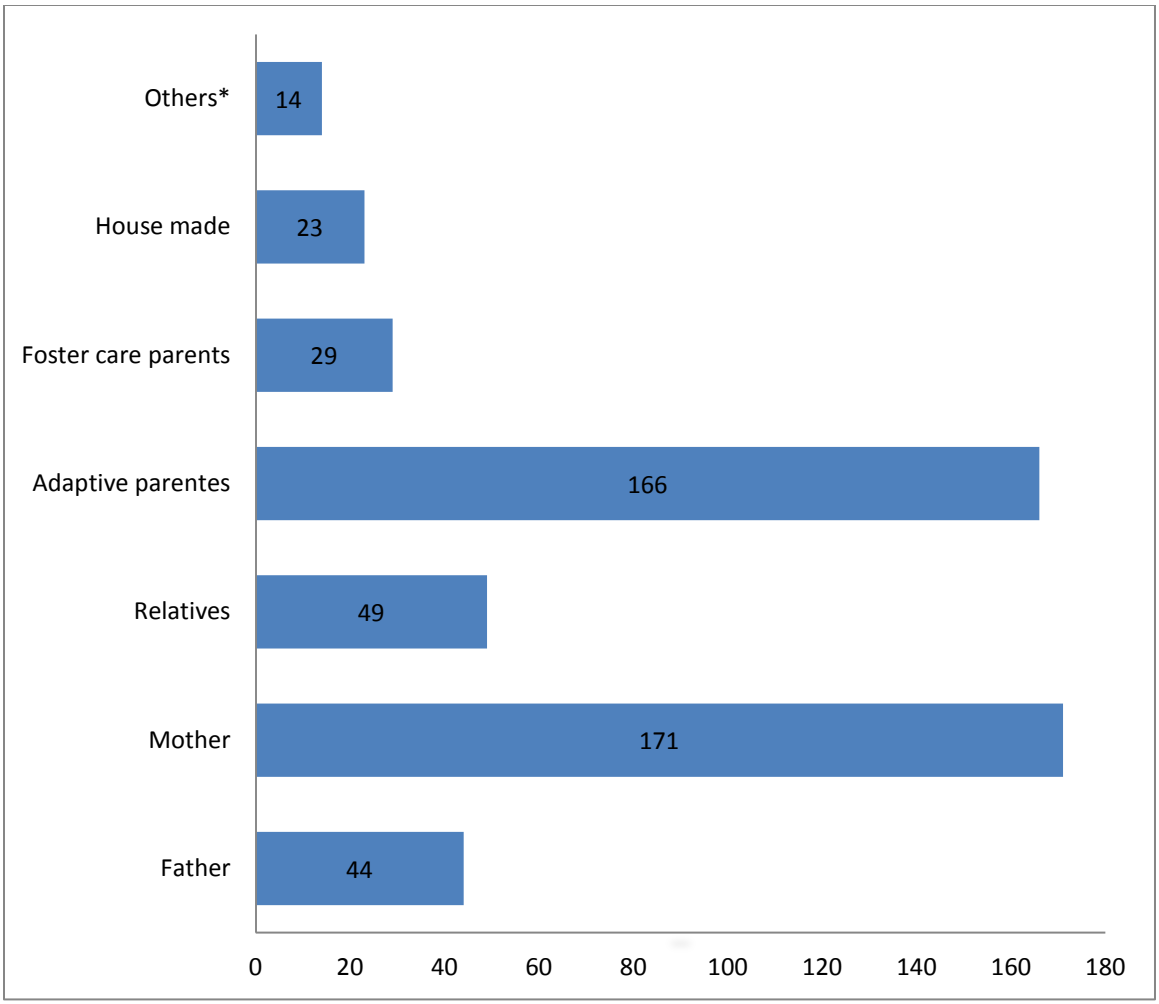


Figure1:-Living arrangement of the HIV infected adolescents on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia(N=396)



Others* neighbors 7, brothers 4, sisters 3

Figure2:-Distribution of Primary care givers of HIV infected adolescents who are receiving HAART in selected health facilities, Addis Ababa, Ethiopia (n=396)

7.3 Clinical back ground of the adolescents on HAART

Most of the children183 (46.2%) were in stage 3 based on WHO classification when started treatment and 184 (46.5%) of the adolescents were currently in stage1(see figure 3).the mean and median CD4 counts, respectively were 200.48cells/mm3 and 185cells/mm3 before ART started were as the mean and median of the current CD4 counts were 762.62cells/mm3 and 565.50cells/mm3, respectively.

A little above average, 212(53.5%) of the adolescents had CD4 count of less than 200cells/mm3 at the start of the treatment. 178 (44.9%) of the adolescents had CD4 count of greater than 600cells/mm3 currently. (figure 4 and 5)

At the start of treatment the functional status of adolescents indicated that 211 (53.3%) were working, 82(20.5%) ambulatory and 104(26.3%) were bed ridden, whereas, their current functional states, after treatment indicated that 364(91.9%) working, 24(6.1%) ambulatory and only 8(2%) were bed ridden.(see figure 3 below)

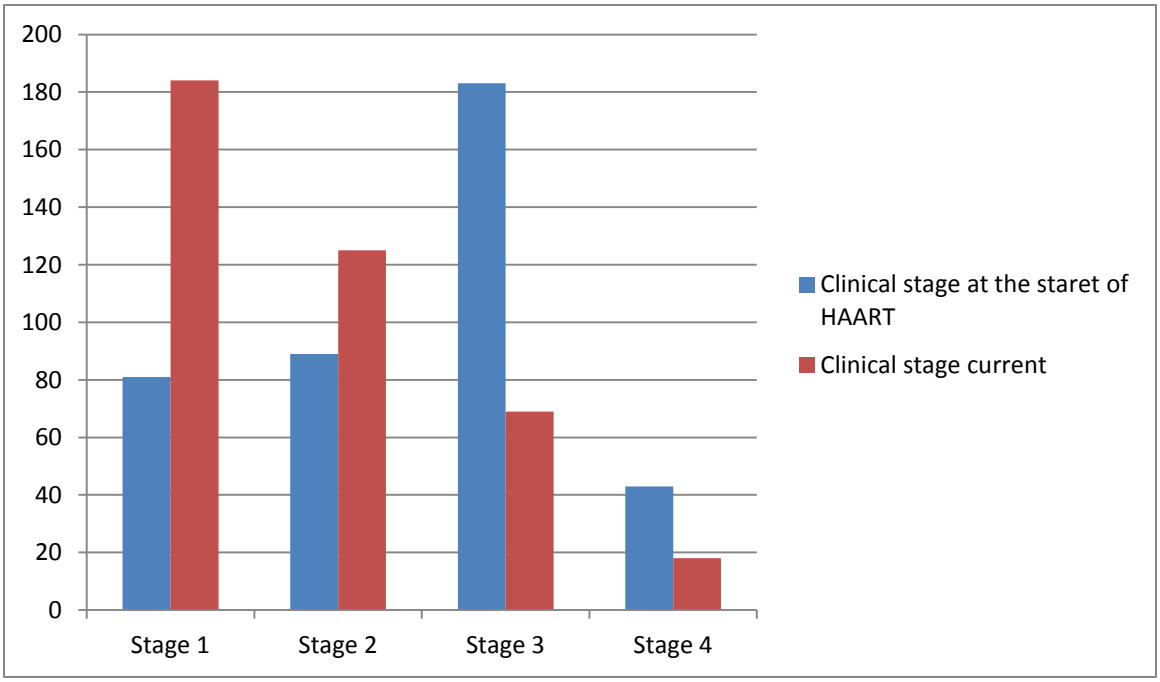


Figure 3:- Clinical stage of HIV infected adolescents on HAART in selected health facilities, Addis Ababa, Ethiopia (n=396)

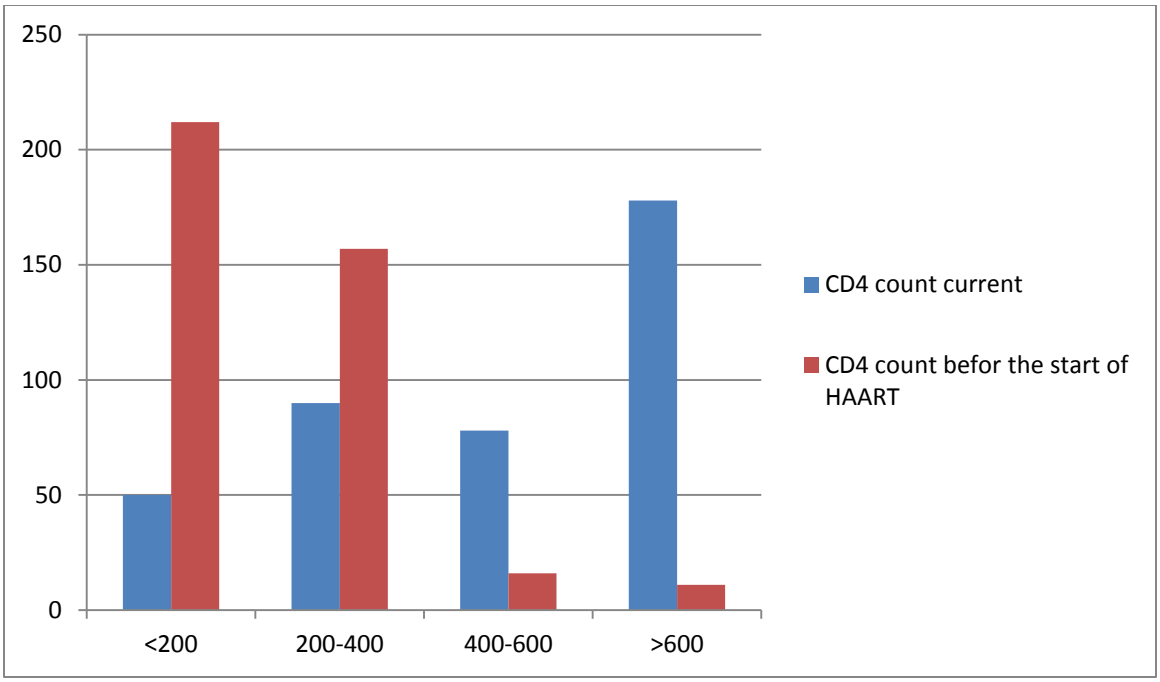


Figure 4:-CD4 count of the HIV infected adolescents on HAART in the selected health facilities, Addis Ababa, Ethiopia (n=396)

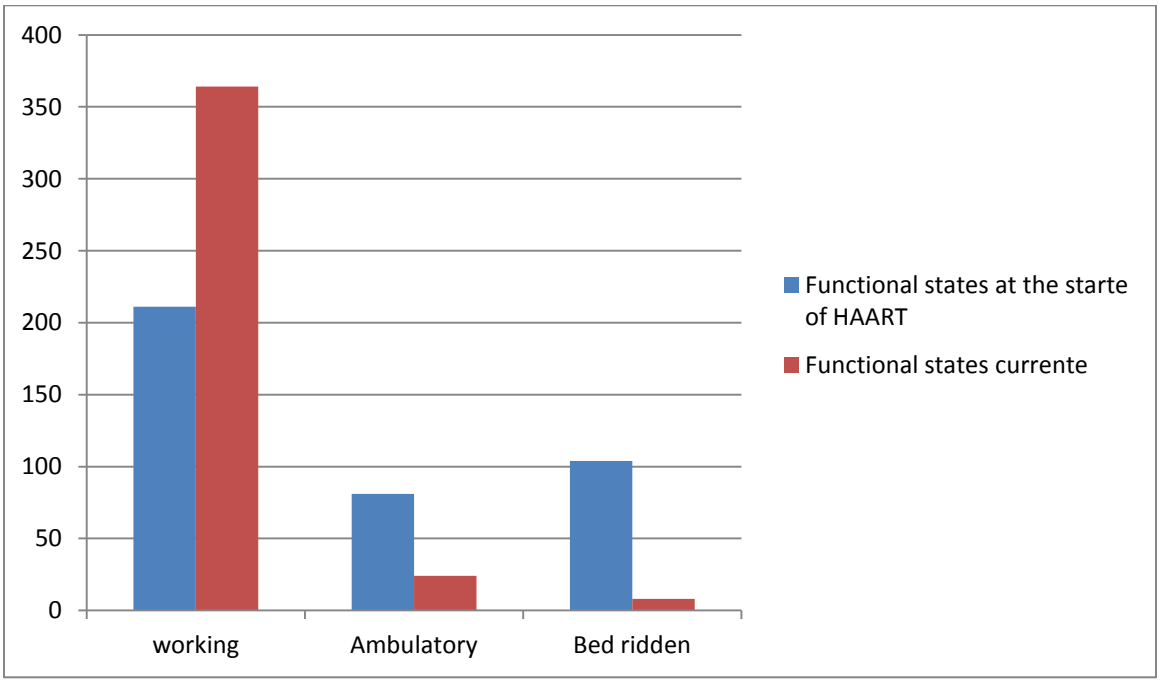


Figure 5:-Functional states of the HIV infected adolescents on HAART in selected health facilities, Addis Ababa, Ethiopia (n=396)

7.4 ART treatment and Health Care Provision

Two Hundred fifty nine (65.4%) had started treatment two years before the survey and 140 (35.4%) of them were on AZT/3TC/NVP base regimen(Figure 6). Majority,328(82.8%) of the adolescents were reported to have been sick before they started HAART but after treatment, only 18(4.5%) of them were sick.

Of the adolescents who were taking medication other than ARVs, Cotirmoxazole as well as anti-tuberculosis medication were the most frequently used with 41 (10.4%) and 24(6.1%) of the adolescents were taking them, respectively. Almost all 393(99.2%) of the care givers felt they had good relationship with health care providers.

Majority of the respondents 374(94.4%) had an open communication with health care providers where 223 (56.3%) of them reported that they had follow up every three month, 130(23.3%) had it every month while, 29 (7.3%) of them reported that they goes to facilities to fill up their regimens only. Most caregivers 288(72.7%) reported to have received food support from the facility where they receive HAART for the adolescents.

Two hundred ninety six (74.7%) respondents indicated that they have got integrated services in the health facilities. Less than half, 138(34.8%) of the participants had to spend 6 to 10 birr transportation cost to reach to the treatment units. (see figure below)

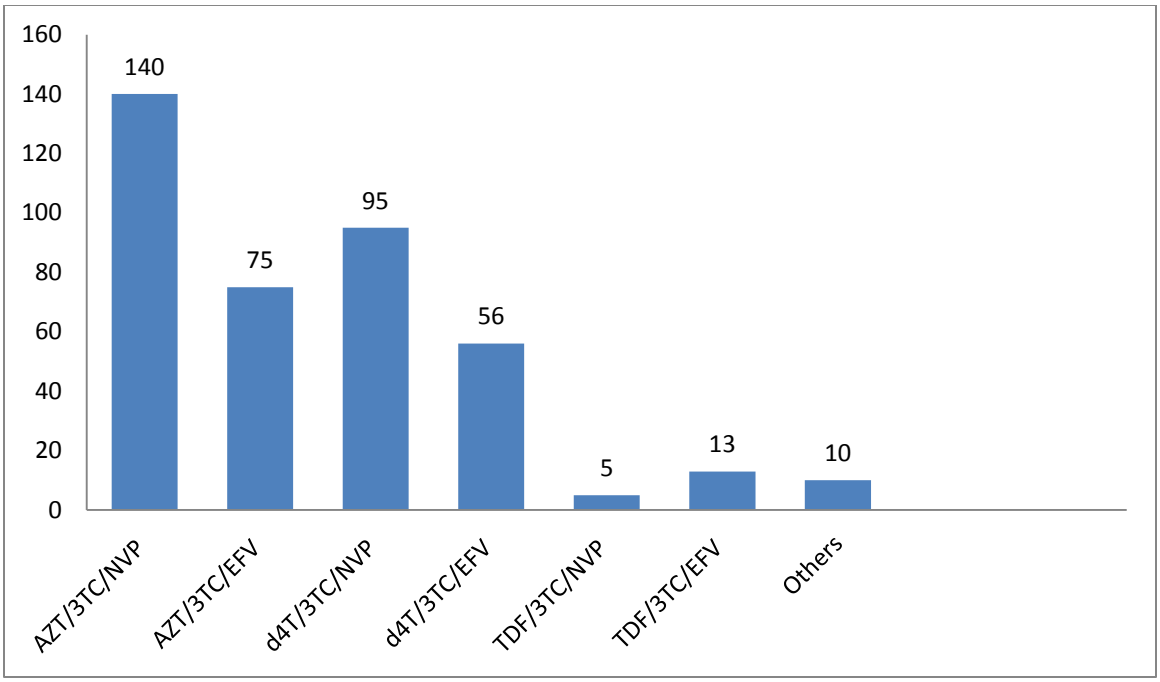


Figure6:-Type of the ARV regimens received by HIV infected adolescents on HAART in selected health facilities, Addis Ababa, Ethiopia(n=396)

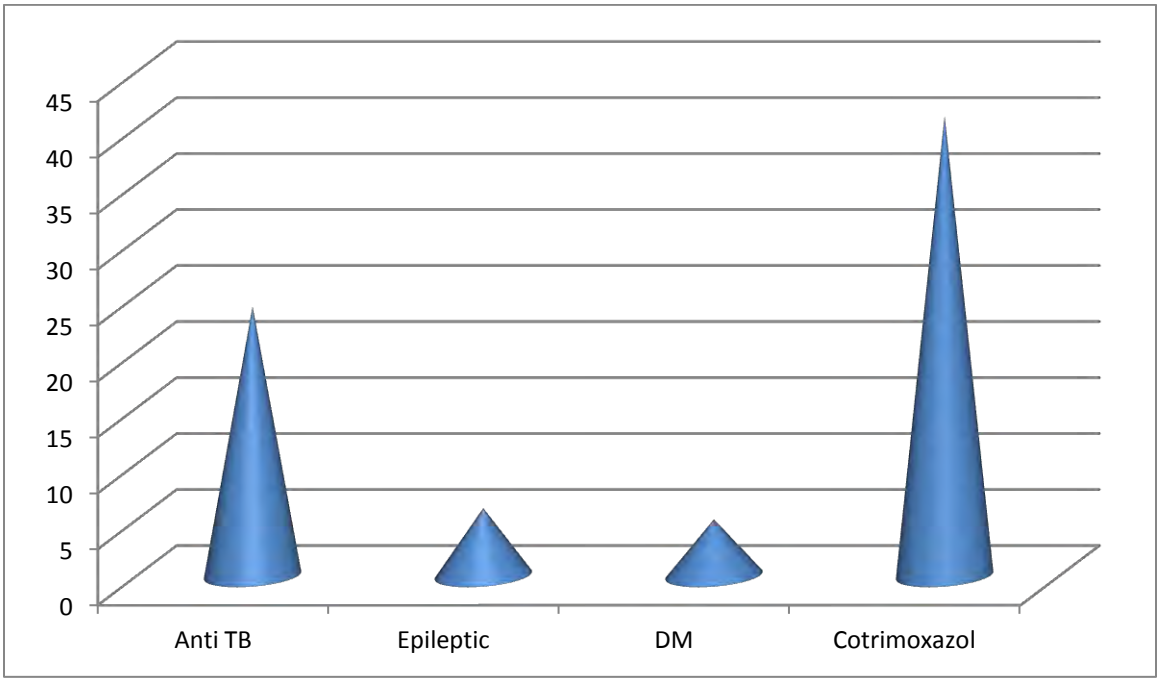


Figure7:-Type of the medications that adolescents took with their ARVs in the sampled health facilities, Addis Ababa, Ethiopia (n=396)

7.5 HIV states discloser, Perception of care givers about age of disclosure

Two hundred and ten (53%) of the adolescents who participated in the study did not know their HIV serostatus. Majority 175(83.3%) of the adolescents who were not informed about their HIV states were between the age of 10-14 years and only 35(16.7%) of them were greater than 14 years of age. Among those who were not informed, 79 (39.3%) caregivers reported that their children were told that they had Tuberculosis (TB) and that their children assumed they were being taken to the health facility for TB appointments.

When caregivers were asked about the age at which the child should be informed/ know about his/her serostatus, 119 (58.9%) respondents said that the child should be told about his/her HIV status when he/she is older than 18 years of age, while 67(33.2%) pointed out that disclosure should be made at the age of 14 and above.

186 (47%) of the disclosed adolescents, 135 (69.9%) of them were told their sero states after they start ARV treatment. When caregivers were asked how were the adolescent told their HIV status, 123(64.1%) of them responded that it was planned and 61 (31.8%) of them responded unplanned. Majority of the respondents 243(61.4%) had responded that the adolescents HIV sero states was disclosed to other person, 224 (56.6%) to their family members, 36 (9.1%) to their friends and 24 (6.1%) of them disclosed to staffs of the foster care institution. Most 235 (59.3%) of the adolescents didn't know their parents HIV sero states. (see table 2 below)

Table 2:-Reaction of adolescents after discloser and person involved in the HIV status discloser process in the sampled Health Facilities, Addis Ababa Ethiopia (n=396)

Variables	Frequency (n)	Percentage (%)
Who involved in HIV states discloser process		
Mother	83	43.5%
Father	21	10.9%
Health care provider	79	41.4%
Others*	8	4.2%
Reaction of the adolescent after discloser		
Depressed	22	9.9%
Irritable	18	8.1%
Cried a lot	37	16.7%
Nothing happened	103	46.6%
Shocked	41	18.5%

Others* Other family members

7.6 Predictors of disclosure of HIV status

The discloser status of adolescents on ART was significantly associated with age of the adolescents, educational states of the care givers and living in foster care institutes.

Comparing adolescents in the 15–18 years age group to adolescents in the 10-14 age group, were less likely to be informed about their HIV status [AOR =(95% CI) 0.182, = (0.078–0.421)].

Children with caregivers who have no education were more likely to be informed about their HIV status than their counterparts [AOR = (95% CI) 5.20,= (2.46-12.29)].

The analysis in a logistic regression also indicated that the living arrangement of adolescents was statistically significant associated with disclosure. Adolescents living in the foster care institutes were less likely to be informed of their result than those who were living with their relatives and with their adoptive parents. [AOR =(95%CI)8.70=(2.11–35.81)] and [AOR = (95% CI) 10.05=(81.95–51.87)] comparing adolescents living in the foster care institutions vs. with their relatives and with their adoptive parents, respectively, but the association disappeared when adjusted for other variables. (see table 3 below)

Table 3:-Determinants of HIV status discloser of adolescents on ART, binary logistic regression, Addis Ababa Ethiopia (n=396)

Variables	Disclosed	Not Disclosed	OR(95%CI)	Adjusted OR(95%CI)
Age of the adolescent				
Age 10-14	74	175	0.13(0.06-0.27)*	**0.18(0.078-.42)***
Age > 14	112	35	1.00	1.00
Educational states of the care givers				
Unable to read and write	11	61	5.54(2.46-12.49)*	**39.34(5.79-67.04)***
Primary(1-8)	59	37	0.62(0.32-1.19)	0.69(0.22-2.18)
Secondary(9-12)	59	47	0.79(0.42-1.49)	1.69(0.54-5.29)
Diploma & above	31	31	1.00	1.00
Non biological living arrangement				
With relatives	52	71	1.00	1.00
Adaptive	12	11	1.67(0.27-1.64)	1.155(0.361-3.70)
Foster care institution	22	4	0.13(0.04-0.41)*	1.15(0.028-1.047)
Dose the parents alive				
both alive	47	91	2.12(1.29-3.48)*	3.71(.398-34.67)
both dead	72	58	0.88(0.54-1.44)	0.85(0.293-2.51)
one alive	67	61	1.00	1.00

* Significant correlation

7.7 Relationship of HIV status discloser and adherence

Out of the total interviewed care givers 309(77.3%) of them reported that their adolescents had good adherence to ART (completed 95% of their drugs prescribed in the past 7 days). Among those who have ever missed a dose or more in the past one month, 89(82%) of them because of refusal to take the medication forgetting to give the pills 41(36%) and compliant about too many pills to take 34(33%).

Analysis done to look for contributing factors for adherence of ART among HIV positive adolescents on ART showed females were less adherent than males [COR= (95% CI) 0.445=(0.203-0.977)] but the association disappeared when adjusted for other variables. Apparently, age group15-18 years was related with adhering better to the ART pills prescribed than age group10-14 years (AOR=(95% CI) 4.880=(1.755-13.57)].

The analysis also showed that the HIV states discloser of adolescents was also statistically significantly associated with their adherence to ARV medications. Adolescents who have already known their HIV states were more likely to adhere to their medications than those who do not know their states [AOR and (95% CI) 5.619= (2.123-14.874)] . Similarly adolescents with NVP based fixed dose ARV medication were more adherent than those with other than loss or not fixed doses .(AZT/3TC/NVP) and (d4T/3TC/NVP) were [AOR 37.56, 95% CI 6.73-209.37] and [AOR 31.53, 95% CI 5.52-179.93] respectively.(see table)

Table 4:- Relationship of HIV status discloser and HAART adherence of adolescents on ART, binary logistic regression, Addis Ababa Ethiopia (N=396)

Variables	Adherent	Non adherent	OR(95%CI)	Adjusted OR(95%CI)
Age of the adolescent				
Age 10-14	186	81	1.00	1.00
Age > 14	138	9	4.88(1.75-13.57)*	**3.44(1.52-7.82)***
Sex of the adolescent				
Male	172	44	1.00	1.00
female	135	46	0.44(0.203-0.977)*	0.863(0.464_1.53)
HIV states discloser				
Disclosed	176	10	5.61(2.12-14.87)*	**9.94(4.48-22.08)***
Not disclosed	130	80	1.00	1.00
Type of ARV medication				
AZT/3TC/NVP	124	16	3.67(1.422-9.480)*	**9.21(2.80-30.31)***
AZT/3TC/EFV	46	29	0.751(0.30-1.88)	1.29(0.39-4.18)
d4T/3TC/NVP	84	13	3.06 (1.14-8.19)*	**8.40(2.48-28.47)***
d4T/3TC/EFV	33	23	0.68(0.26-1.76)	1.96(0.59-6.47)
Others*	19	9	1.00	1.00

Others* = second line and TDF based ARV medications * Significant correlation

8. Discussion

This study had assessed the rate of HIV states discloser, factors related to HIV states discloser and associations between of HIV states discloser with adherence to ARV medications among HIV infected adolescents who are on HAART.

We found that more than half of HIV-infected adolescents on ART were not aware of their own HIV status. Older adolescents and adolescents who were living with caretakers who had low educational status were more likely to have been informed about their HIV status. Adolescents whose HIV status is disclosed were more likely to had good HAART adherence. Adolescents with NVP based fixed dose ARV medication were more adherent than those with other than NVP based ARV regimens. Adolescents who were aged 15-18 years were more likely to adhere to the ART pills prescribed than those aged 10-14 years.

Generally, the prevalence of disclosure vary widely across studies and settings, the range from 18% to 77% was reported in children and adolescents from resource rich countries (10).The frequency of disclosed HIV status in our study was higher than previously reported figures in studies conducted in Ethiopia (17.4%,), Thailand (30.1%,), Zambia (31.8%) and Uganda (29%).This could be because of their younger age where the children were younger (mean age of 8–9 years) (41,18) or Ghana, with a median age of ten (22) also which may suggest a decline in the perception of HIV stigma by care givers could also lead to this increased prevalence of discloser. However, our finding was lower than findings from developed countries which involved adolescents older than 13 years. (24) Indeed, disclosure was often associated 10 or even older supporting our observations (41,18, 38).

In our study, most caregivers prefer to delay disclosure up to older ages (above 14), this being consistent with previous findings (35). In addition, it has been documented that parents view children over the age of 12 as emotionally mature for disclosure of HIV status (35,5). In many studies, older children were found to be a determinant factor for the children's' knowledge about their HIV status.

Bor R. Disclosure Vancouver conference review (55) reported 100% disclosure in children 16 years of age and older and likewise; Cohen J School-related issues among HIV infected children in Massachusetts (56) reported that 95% of children older than 10 years of age were aware of their HIV status. Similar findings were also documented elsewhere (18, 19). This could be due to the caregivers' belief that at early age, the child is lacking the emotional and cognitive maturity needed to understand the disease and implications (19,24, 29, 39). The perception that adolescence is the optimal period for disclosure may relate to the idea that at this life stage, children are 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.

Despite a delayed HIV disclosure reports in studies from resources limited countries like ours (Ethiopia) it was observed to occur at younger age over time in industrialized country, (38,10) Reasons and factors influencing earlier age disclosure in this countries include increasing age and/or cognitive development; concerns that the child would learn his/her status from other sources or become sexually active; the deteriorating health status of the child or the desire to improve health care and medication adherence; questioning by the child or the child's right to know, and the need to maintain trust or not keep secrets from the child, and that diagnostic disclosure to children with HIV should not be delayed because of fear of a negative impact on their quality of life. (10, 23)

Relationship between HIV disclosure and educational level has been documented elsewhere (31,32).Wiener L, The HIV-infected child: Am J Orthopsychiatry (39) found that more children who knew their HIV status came from families with a higher socio-economic status and as education is a proxy indicator of higher social economic status. In our study, illiterate caregivers were more likely to disclose the adolescent's HIV status than caregivers with a higher educational level. Illiterate caregivers stayed at home most of their times, because of not having jobs this will lead them to have closer interaction and communication with their children's this could be the reason for this higher rate of discloser.

Complete HIV sero states disclosure helps to motivate HIV-infected children and/or adolescents to adhere to their daily HAART regimen. It enables children to understand HIV infection and to make sense of disease-related experiences and the importance of adherence (39,48). When complete parental disclosure occurred, both the child and the caregiver viewed drug administration as a shared responsibility and the child was motivated to adhere. Other medical benefits of disclosure include the child's ability to participate more fully in treatment and illness prevention and to take responsibility for their own treatment in the event of future parental death (31). On the other hand, non-disclosure strained both the child and the caregiver, since the caregiver needed to apply a combination of force and persuasion to get the child to adhere. This led to forced adherence and in some cases to children's purposeful non-adherence.

In our study nearly 67% of the caregivers who had disclosed cited that when the primary care givers are not around the adolescent himself/herself are the once who take care of their own medications. It is possible that after disclosure, children took charge of their illness and medication leading to improved adherence. In studies in Zambia and the Democratic Republic of the Congo, a common reason caregivers gave for disclosure is the hope that by knowing their status, the children will have better adherence to treatment (36, 31).

Similarly adolescents with NVP based fixed dose ARV medication (AZT/3TC/NVP and d4T/3TC/NVP) were more adherent than those with other than loss or not fixed doses. It has been also mentioned in a US cohort of homeless and marginally housed adolescents study that adherence was higher in EFV/FTC/TDF based fixed doses regimen compared to non-one-pill-once-daily therapy. (53) in contrast with our finding Among a cohort of newly diagnosed ART-naïve patients, once-daily dosing of ART resulted in higher adherence than twice-daily dosing but Pill burden among once-daily regimens did not predict adherence, suggesting that factors other than pill burden should drive regimen selection.(54).

9. Strength and limitation of the study

The limitation of the study

- Its focus on what has been told to the child, rather than what the child has discerned about his/her health, Youth may learn of their HIV status on their own, by piecing together clues, or overhearing conversations, or even directly from providers, without caregiver knowledge.
- Caregivers of the child may respond inappropriately to the counselors as if they were the one in nearby to them and might mask some important information pertaining HIV states discloser.
- Caregivers might be prone to social desirability bias and recall bias.
- The cross sectional nature using a snapshot of adherence at one point in time of the assessment may hinder to exactly identify the predictor of adherence unlike longitudinal study.
- There is no gold standard assessment of adherence was measured using self-report from the caregivers, which tends to overestimate the prevalence of adherence.
- Adherence classification cut off points may not be perfect in different set up to compare and contrast the finding.
- Additional qualitative study would have explored more on the reasons for disclosure

The strength of the study

- Addressing an important timely public health issue
- Inclusion of several sites(health facilities) in Addis Ababa

10. Conclusion

In conclusion, most of HIV-infected adolescents on ART in Addis Ababa were not aware of their HIV status. However, our study showed a strong beneficial effect of HIV disclosure on adherence to HAART. Disclosure is occurring at older adolescence ages, which may suggest fears about potential HIV-related stigma and discrimination.

From this research finding, the prevalence of HIV states discloser of adolescents in Addis Ababa were 356 (47%), This was associated with age greater than 14 years [AOR = (95% CI) 5.20 = (2.46-12.29)] and lower educational states of the care givers[AOR = (95% CI) 5.20 = (2.46-12.29)]. Adolescents in the 14–18 years age group were more likely to be informed about their HIV status also adolescents with caregivers who have no education (illiterate) were more likely to be informed about their HIV status than their counterparts. The main reason for non-discloser reported by care givers was fear of stigma and discrimination on their children's.

Other socio demographic variables, care givers and adolescent related factors and also there clinical related variables hadn't significant association with adherent in the present study.

The discloser states of the care givers were strongly associated with the adolescents HAART adherence. Adolescents who have already known their HIV states were more likely to adhere to their medications than those who do not know their states. [AOR and (95% CI) 5.619= (2.123-14.874)]

11. Recommendation

Our study showed a strong beneficial effect of HIV sero states disclosure on HAART treatment adherence it leads to the need to shift the emphasis from whether or not to disclose to the HIV-infected adolescent to providing culturally sensitive support to caregivers and age-appropriate information on the HIV status of the adolescent.

Implication for care givers

- Caregivers and health providers should have a co-responsibility to decide on the proper time to disclose.

Implication to health providers

- To increase disclosure rate, it is important to target children from educated caregivers and younger children age less than 14 years.
- Intensified information education and communication to de-stigmatize the disease might have far reaching impact
- The HIV disclosure status of adolescents need to be systematically recorded and reported in the patients' charts.

Implication to program managers

- Pediatric HIV programs should have a systematic and a staged-approach protocol in place to provide support and skill set to facilitate disclosure of HIV status to HIV-infected children.
- Current and future guidelines that consider HIV states disclosure need to be adopted and distributed to all Pediatric HIV facilities which will guide health providers to perform their tasks accordingly.

Implication for further research

- Further longitudinal studies should look at the effect on other outcomes such as quality of life, anxiety, depression, school performance, family and social relations and sexual risk behaviors. This would provide deeper understanding of HIV disclosure process in adolescents in order to tailor age-adequate interventions.

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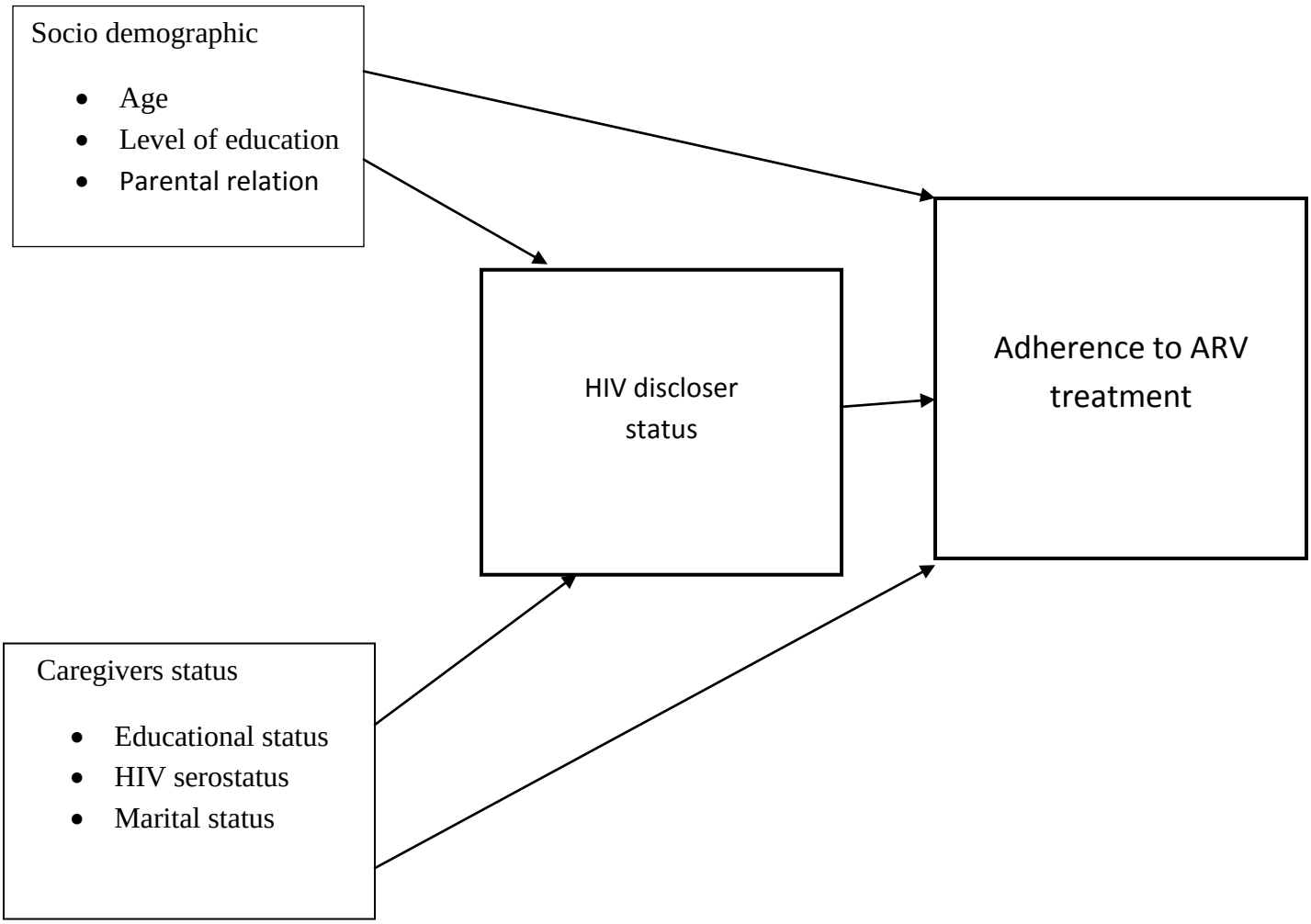
13. ANNEX

13.1 ANNEX I Conceptual framework



Conceptual frame work of HIV serostatus discloser and its effect on ARV treatment adherence developed by principal investigator.

13.2 ANNEX II

PATIENT INFORMATION AND CONSENT FORM

Addis Ababa University, school of medicine and college of health sciences, Department of public health consent form for a study on HIV serostatus discloser and its effect on adherence to ARV treatment in HIV-infected adolescents in Addis Ababa health institutions.

Greeting!

Hello! My name is _____ I am working in the research team of Addis Ababa University, college of health sciences, school of public health. This is a study to be conducted with the objective of assessment of HIV serostatus discloser and its effect on adherence to ARV treatment in HIV-infected adolescents in health institutions of Addis Ababa.

We believe this study would help to increase your awareness towards HIV serostatus disclosure and its effect on adherence. Therefore, you are kindly requested to participate in this study and provide information required from you.

I am going to ask you some questions and your participation in this study is completely on voluntary bases and you have the right to refuse, to take part or to interrupt the interview at any time. But the information that you will give us is quite useful to take supportive action 0n the ART treatment outcome success. If you participate it will not take as more than 25 minutes.

We would like to assure you, your name will not be mentioned in anywhere. The information that you will give us will be kept confidential and only be used for the research purpose.

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

Name Fikrte Fikadu

Tell 0911365786 Email medykayes@yahoo.com

Consent form

I, the selected participant, heard the information in the study information sheet and understudy the purpose, benefit and what is required from me and what will happen on me if I take part in the study. I understood that all the information regarding my child and me, like name and all answers given by me must not be transferred to the third party .I also understood that I can decide whether or not to take parts in the study or even with draw from the study at any time.

Are you willing to participate in this study?

1. Yes Signature _____
2. No Signature _____

Interviewer name _____

Sign._____

Supervisor name_____

Sign._____

13.3 ANNEX III QUESTIONNAIRE (ENGLISH VERSION)

Addis Ababa University, school of medicine and college of health

Sciences, Department of public health

Assessment of adolescents HIV status disclosure and adherence to ART treatment

Health facility code_____ Time interview started_____

Questionnaire code ---------- completed_____

Date of interview ----------

Part 1; Socio demographic character

NO.	Questions	Classification	Remark
101	What is age of the child	_____age in complete years	
102	What is sex of the child	1. Male 2. Female	
103	What is the respondents age	_____age in complete years	
104	What is the respondents sex	1. Male 2.Femal	
105	What is the respondents ethnicity	1.Amhara 2.Oromo 3.Gurage 4.Tigray 5.Dont know 6.Other_____	
106	What is the respondents current marital status	1.Never married 2.Married 3.Divorced 4.Separated 5.Widowed 6.Other_____	
107	What is the respondents religion	1.Ortodox 2.Protestant 3.Muslim 4.Catolic 5.Other(specify)_____	
108	What is the respondents education status	1.Unabl to read and write 2.Able to read & write 3.Primary(1-8) 4.Secondary(9-12) 5.Diploma & above	
109	What is the respondents occupation	1.Merchant 2.House wife 3.Student 4.Gvt employee 5.Dayly laborer 6.Praivat employee 7.Other(specify)_____	
110	How much is family income	_____ETB	
111	How many family member respondents have	_____	
112	What is the educational status of the adolescent?	1._____ 2.Not learning 3.other _____	

Part 2; Caregiver and adolescents relationship

201	Types of parents/caregiver the child have	1.Biological 2.Non biological 3.Other_____	
202	If non biological what is their relationship	1.With relatives 2. Adaptive 3. Foster care institution 4. Other_____	
203	Who is primary care giver	1.Father 2.Mather 3.Relatives 4.Adopteriv parents 5.Foster care parents 6.House made 7.Neighbor 8.Health workers 9.Other_____	
204	When the primary care giver away who is responsible for child's medication	1.The child 2.From the family 3.House maid 4.Neighbor 5.Health worker 6.Other_____	
205	How many siblings are alive	1.---------brothers 2.----------sisters 3.Other_____4.None	
206	How many siblings are HIV +ve	1.both 2.one of them 3.more than one 4. Not known 5.other 6.none	
207	Are the child's parent alive	1.both alive 2.both died 3.one of them alive	If 3 go to 208
208	Who is died	1.Mother 2.Father 3.Both	

Part 3; Disclosure status of the child

301	Dose the child knew his/her sero-status	1.disclosed 2.Not disclosed 3.Don't known 4.others____	If 1 go to 305
302	Why not disclosed	1.too young to tell 2.fear of stigma 3.fear of stress 4.waiting till health provider tolled to do 5other----------	

303	For what illness, do you tell him/her, is the medications for	1.TB 2.Headach 3.Weakness 4-skin rash 5.Other_____	
304	When do you think the child should tolled his/her HIV status	_____age in yrs	
305	When did the child told his HIV status	1.Before ART started 2.After ART started 3.on starting treatment 4.Not known	
306	How was the child told his HIV status	1.Planned 2.Not planned 3.Not known	
307	Who was involved in the discloser process	1.Mother involved in disclosure 2.Father involved in disclosure 3.Physician involved in disclosure 4.Psychologist involved in disclosure 5.Social worker/counselor involved in disclosure 6.Other_____	
308	What was the reaction of the child after discloser	1 Nothing happens. 2.Depresed 3.Irretable 4.Crys a lot 5.shoced 6.Other_____	
309	Was the child's HIV sero-status disclosed to others?	1.Yes 2.No 3.Others_____	If No go to 311
310	For whom it is disclosed	1.Family 2.Fiends 3.Organization 4.Community 5.Other_____	
311	Is the sero-status of the parent known by the child	1.Yes 2.No 3.Other____	
312	Did the child get sick before treatment started?	1.Yes 2.No 3.Other___	
313	Is he/she sick now	1.Yes 2.No 3.Other___	

Part 4; Child adherence assessment

401	Did the child take yesterday's ART medication	1.Yes 2.No 3.Others_____	
402	Did the child missed a dose in last 3 days	1.Yes 2.No 3.Others_____	
403	Did the child missed a dose in last 7 days	1.Yes 2.No 3.Others_____	
404	How many days did the chilled miss his medication in the last month	----------days	
405	When dose the last time child missed a dose of any ART medications	1.Never 2.During the previous 2 wks 3.During the last month 4.Over a month ago 5.Don't remember 6.Other_____	
406	What are the reasons that make it hard to give child take every dose of medication every day?	1.Drug completed 2.Child felt sick 3.I forgot 4.Drug stock out 5.Child refused to take 6.I thought the drug had no value 7.Confused about the dose 8.Were to busy 9.Bing away from home 10.Too many pills to take 11.Other_____	
407	What remainder used to give the child medication	1.Hand watch 2.Wall watch 3.Watch bell 4.Tablet box 5.Family remember 6.Other--------	
408	Is the child take any other medication now with ART	1.Yes 2.No 3.Other_____	If No go to 409
409	What are the medications	1.TB 2.Epelphetic 3.scaicatrec 4.DM 5.other---------	
410	Do you communicate about HIV and ART medication adherence	1.Yes 2.No 3.Other____	

Part 5; Caregivers and health facility interaction

501	What type of interaction do you have with the health care provider	1.Good 2.Not good 3.Other_____	
502	Do you have open communication with health care provider?	1.Yes 2.No 3.Other_____	
503	Did the child get food support from the facility	1.Yes 2.No 3.Other____	
504	How frequent do you visit health care provider	1.Every 2 weeks 2.Every month 3.Every 3 month 4.As I will 5.Other_____	
505	Do you get integrated service during your visit	1.Yes 2.No 3.Other____	
506	How many birr do you spend for transportation to reach the health facility	1._____ 2.Don't spend any 3. Don't know	

Part 6; Review of charts

601	When did adolescent start ART treatment	_____	
602	Type of ARV medication	1.AZT/3TC/NVP 2. AZT/3TC/EFV 3.d4T/3TC/NVP 4.d4T/3TC/EFV 5.TDF/3TC/NVP 6.TDF/3TC/EFV 7.Other_____	
603	The stage of the disease when started treatment	1.Stage 1 2.Stage 2 3.Stage 3 4.Stage 4	
604	The current stage of the disease	1.Stage 1 2.Stage 2 3.Stage 3 4.Stage 4	
605	CD4 count when the child start treatment	_____	
606	Current CD4 count	_____	
607	The functional status of the	1.Working	

	child when started treatment	2.Anbulatory 3.Bed redden	
608	Current functional status of the child	1.Working 2.Anbulatory 3.Bed redden	
609	Did the adolescent disclosed (registered)	1.yes 2.no 3.not registered	
610	Stage of discloser	1.on process 2.disclosed 3.other---------	
611	Adherence of the adolescent when started treatment	1.Good 2.Fair 3.Poor	
612	Current Adherence of the adolescent	1.Good 2.Fair 3.Poor	
613	Last month appointment date missed	1.Yes 2.No 3.Not recorded	Pharmacy refill
614	Last 3 months appointment date missed	1.Yes 2.No 3.Not recorded	Pharmacy refill

13.4 ANNEX IV

PATIENT INFORMATION AND CONSENT FORM (AMHARIC VERSION)

በአዲስ አበባ ዩኒቨርስቲ በህክምና ጠፍ ሳይንስ ኮለጅ የሚበረሰብ ጠፍ አጠበበቅ ዲፓርትመንት የሚደረግ የታዳጊን የ ኤችአይቪ ምርመራ ወጠት ስለማህወቅ እና ፀረ ኤችአይቪ መድኀኒት የመወሰድ ልምድን ለመምህም በአዲስ አበባ ከተማ በሚኙ የጠፍ ተቐማሙ ላይ ለፀረ ኤችአይቪ ተጠቃሚ ልጆች ወላጆች የተዘጋጀ የፈቃድ ማጠየቂያ ፎርም

እኔ ስሜ ----------የምህራወም በአዲስ አበባ ዩኒቨርሰቲ በህክምና ፋኩልቲ የሚበረሰብ ጠፍ አጠበበቅ ትምህርት ቤት ጥናት አድራጊ ቡድን ወስጥ ነው፡፡

የዚህ ጥናት ዓላማ የታዳጊዎችን የኤችአይቪ ምርመራ ወጠት ስለማህወቅ እና ፀረ ኤችአይቪ መድኀኒት የመወሰድ ልምድን ለመምህም በአዲስ አበባ ከተማ በሚኙ የጠፍ ተቐማሙ ስር ባሉ ፀረ ኤችአይቪ ተጠቃሚ ልጆች ላይ ለማጥናት ነው፡፡ ይህ ጥናት የእወቀት ደረጃዎትን ለሚጨመር ይረዳል ብለን እናምናለን ስለሆነም የዚህ ጥናት ተሳታፊ እንዲሆኑና አስፈላጊወን መረጃ እንዲሰጠን በትህትና እንጠይቃለን፡፡

በመሆኑም አንዳንድ ጥያቄዎችን አቀርብልዎታለሁ፡፡ በዚህ ጥናት ወስጥ መካፈልዎ ሙሉ በሙሉ በፈቃደኝነት ላይ የተመሰረተ ሲሆን ላለመሳተፍም ሆነ መረጃ መስጠትዎን በማኛወም ሰአት ለሜቋረጥ መቦትዎ የተጠበቀ ነው፡፡ ነገር ግን የሚሰጠን ማንኛወም አይነት መረጃ የህፃናትን የህፃናትን የኤችአይቪ ምርመራ ወጠት ስለማህወቅ እና ፀረ ኤችአይቪ መድኀኒት ወጠቃማ እንዲሆን ምን መደረግ እንዳለበት እቅድ ለመንደፍ ያስችለናል፡፡

በዚህ ጥናት ሲሳተፉ ስምዎ በማኛወም ቦታ እንደሜጠቀስ የሚሰጠንም መረጃዎች በሚስጥር እንደሜያዙና ለጥናቱ ስራ ብቻ እንደሜወል ልናረጋግጥልዎ እንወዳለን፡፡

በዚህ ጥናት ላይ ማንኛወም አይነት ጥያቄ ካለዎት 0911365786

¾ðnÅ˜ƒ SÓLÝ ö`U

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በዚህ ጥናት ላይ ለማሳተፍ ፍቃደኛ ነዎት?

1. አዎ ----------ፊርማ

2. አይደለሁም -------ፊርማ

¾Ø'~ ¦"ðÃ ò`T ----------

S[Í cwdu= eU ----------

ò`T ----------

ANNEX IV QUESTIONNAIRE (Amharic)

በአዲስ አበባ ዩኒቨርስቲ በህክምና ጠፍ ሳይንስ ኮለጅ የሚሀበረሰብ ጠፍ አጠባበቅ ዲፓርትመንት የሚደረግ የታዳጊን የ ኤችአይቪ ምርመራ ውጤት ስለማሳወቅ እና ፀረ ኤችአይቪ መድኀኒት የመሰድ ልምድን ለማ ምም በአዲስ አበባ ከተማ በሚ ኙ የጠፍ ተቐማት ላይ ለፀረ ኤችአይቪ ተጠቃሚ ልጆች ወላጆች የተዘጋጀ ማጠየቂያ

መጂው የተሰበሰበበት ቀን ----------

መጂው የተሰበሰበበት ሰዓት የተጀመረበት ----------

የተጠቀቀበት ----------

¡õM ›”É : ›ÖnLÃ ¾ÓKcw S[Í

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104	¾}ÖÁm¨< ë U”É” ’¨< ;	ı. ¨”É 2. c?ƒ	
105	wN?`-ƒ U”É ’¬ ;	ı. ›T^ 2. *aV 3. Ñ<^Ñ@ 4. ƒÓ_ 5. K?L ÃØkc<	
106	¾}ÖÁm¨< ¾ƒÇ` G<’@ U”É ’¨< ;	ı. ÁLÑv 2. ÁÑv 3. ¾}ó 4. ¾}KÁÂ 5. ¾V}uƒ 6. K?L ÃØkc<	
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¡õM G<Kƒ : ¾u?¦cw G<’@

201	ÇÑ>¨< U” ¯Ã’ƒ u?¦cv© G<’@ ›K¨<	1. ¨LÐ‡ ¨<’¦— 2. ÁM¨KÆƒ /›dÇÑ> 3. ¾eÒ ²SÊ‹ 4. ¾Ñ<Ç=ð‰ ›dÅÑ> 5. ›dÇÑ> É‘Ïƒ 6. w‰¨<” 7. K?L ÃØkc< ----------	
202	u¾k’< ¾ì[›?‹ ›Ã y= SÉH’>~” ¾T>cÖ¨< T” ’¨< ;	1. ›vƒ 2. “ƒ 3. ²SÉ 4. ›dÇ²Ñ> 5. ¾É‘Ïƒ ¦”Ÿv"u= 6. ¾u?ƒ W^¦— 7. Ô[u?ƒ 8. ¾Ö?“ vKS<Á 9. K?L ÃØkc<	
203	G<MÑ>²? SÉH’>ƒ ¾T>cÖ¨< c¨< uK?K Ñ>²? SÉH’>~” ¾T>cÖ¨< T’¨< ;	1. ÇÑ>¬ ^c< 2. ¾u?¦cw ›vM 3. ¾u?ƒ W^¦— 4. Ô[u?ƒ 5. ¾Ö?“ vKS<Á 6. K?L ÃØkc<	
204	lé’< e”ƒ ¨”ÉUV‹ “ l„‹ ›K<ƒ ;	1. ---------- 2. ›Ã¨pU 3. K?L ÃØkc<	
205	e”ƒ ¾lé’< ¨”ÉUV‡ “ l„^ ¾›?‹ ›Ã y= ¾ÅU ¨<Ö?†¨< zÃ[c< uÅT†¨< ›K ;	1. G<K<U 2. ›”Æ w‰ 3. Ÿ›”É uLÃ 4. ›Ã¨pU 5. K?L ÃØkc<	
206	G<K~U ¾lé’< ¨LÐ‹ ul¨Ãƒ ›K< ¨Ã ;	1.›K< 2.¾K<U 3.K?L ÃØkc<	SMc<lŸJ’ ¨ÅØÁo209 Ã K ñ
207	uQ¨Ãƒ ¾K?L¨< T”¨< ;	1. “ƒ 2. ›vƒ 3. G<K~U	

¡õM feƒ : ¾›?‹ ›Ã y= ¾U‘S^ ¨<Ö?ƒ ¾Td¨p G<’@

301	ÇÑ>¨< ¾›?‹ ›Ã y= ¾ÅU U‘S^ ¨<Ö?~” Á¨<nM ;	1.›-” 2. ›Á¨<pU	

		3. ›Ã?¨pU 4. K?L "K ÃØkc<	
302	¾T>¨eÅ¨< SÉH'>ƒ ¾U" SÉH'>ƒ ¨< }wKA }'Ñ[¨< ;	1. ¾+u= 2. ¾^e U?ƒ 3. ¾JÉ ISU 4. K?L "K ÃØkc<	
303	?ÅÑ>¨< ¾›?‹ ›Ã y= U`S^ ¨<Ö?~" SŠ"¨< T¨p ÁKuƒ wK¨< ÁevK< ;	-------- ?ÉT@ c=J"¨<	
304	?ÅÑ>¨< ¾›?‹ ›Ã y= ¾U`S^ ¨<Ö?~ SŠ }'Ñ[¨< ;	1.SÉH'>ƒ ŸSËS\ uòƒ 2. SÉH'>ƒ ŸËS[u%EL 3. ›Ã?¨pU	
305	¾›?‹ ›Ã y= U`S^ ¬Ö?ƒ ?"Èƒ }'Ñ[¨<	1.?pÊ 2. dÃ?kÉ 3. ›Ã?¨pU	
306	¾ÅU U`S^ ¨<Ö?~" uS"Ñ` T" }dƒóM ;	1.?"ƒ 2. ›vƒ 3. ¾Ö?" vKS<Á 4. ¾e'- Mx" vKS<Á 5. ¾Tlu[cw vKS<Á 6. K?L "K ÃØkc<	
307	?ÅÑ>¨< ¾U`S^ ¨<Ö?~" c=cT U" ›Ã'ƒ ul`Ã ›d¾ ;		
308	¾?ÅÑ>¨< ¾U`S^ ¨<Ö?ƒ KK?L c¨< }'Ó^M ¨Ã ;	1.›- 2. ›M}'Ñ[U 3.K?L "K ÃØkc<	
309	KT" }'Ñ[	1.Ku?}cw 2.KÕÅ— 3.KÉ`Ïƒ 4.Klw[}cu 5.K?L "K ÃØkc<	
310	?ÅÑ>¨< ¾¨ĸÐ‡" ¾U`S^ ¨<Ö?ƒ Á¨<nM ;	1. ›-" 2. ›Á¨<pU 3. K?L "K ÃØkc<	
311	?ÅÑ>¨< ¾é[›?‹ ›Ã y= SÉH'>ƒ ŸSËS\ uòƒ u}ÅÒÒT> Ã?SU 'u` ;	1. ›-" 2. ›Ã?SU 3. K?L "K ÃØkc<	
312	›G<" u}ÅÒÒT> ÁSªM ;	1. ›-" 2. ›ÁS¨<U 3. K?L "K ÃØkc<	

¡õM ›^ƒ : ¾SÉH'>ƒ ›¨dcÉ

401	?ÇÑ>¨< ƒL"ƒ" ¾T>¨eÅ¨<" ¾é[›?‹ ›Ã y= SÉH'>ƒ ¨eÊM ;	1. ›- 2. ›M¨cÅU 3. K?L "K ÃØkc<	
402	?ÇÑ>¨< vKñƒ feƒ k"ƒ ¾é[›?‹ ›Ã y= SÉH'>-" [e„ Á¨<nM ;	1. ›- 2. ›M[dU 3. K?L "K ÃØkc<	
403	?ÇÑ>¨< vKñƒ cvƒ k"ƒ ¾é[›?‹	1. ›-	

	›Ã y= SÉH'>~" [e„ Á¨<nM ;	2. ›M[cU 3. K?L "K ÃØkc<	
404	ÇÑ>¨< KSÝ[h Ñ>²? ¾é[›?‹ ›Ã y= SÉH'>~" ¾[d¨< SŠ ’¨< ;	1. [e„ ›Á¨<pU 2. vKñƒ G<Kƒ dU"ƒ 3. vKñƒ ›"É ¨‟ 4. Ÿ›"É ¨‟ uòƒ 5. ›Le?¨<eU 6. K?L "K ÃØkc<	
405	KÇÑ>¨< u³²¨< Sc[ƒ SÉH'>~" KS¨<cÉ ¾TÁe‹K< G<'@-‹ U" 'u\; Ÿ›"É uLÃ SMe SS<Lƒ Ã‰LM	1.SÉH'>~" SÚ[e 2. ÇÑ>¨< uS SS< 3.[eŠ¨< 'u` 4.SÉH'>~ ŸSÉH'>ƒ u?ƒ uTKl 5. ÇÑ> ›M¨eÉU uTK~ 6. ¾SÉH'>~ ØpU eLLS"Ÿ<uƒ 7.›¨dcÆ eLMÑv˜ 8. e^ u′„ w˜ 9.u¨p~ u?ƒ eK›M'u`Ÿ< 10.SÉH'>„‹ uSw³†¨< 11. K?L "K ÃØkc<	
406	SÉH'>~" KS¨<cÉ ¾T>ÖkS<uƒ ¾Te?h ²È U"É¨< ;	1. c¯ƒ 2. Å¨<M 3. Ÿu?¦cw ¾T>Áe?¨<e ›K 4. ¾T>¨eÅ¨<" SÉH'>ƒ SS´Ñw 5. K?L "K ÃØkc<	
407	Ÿç[›?‹ ›Ã y= SÉH'>~ Ò` K?L ¾T>¨eÅ¨< SÉH'>ƒ ›K ;	1. ›–" 2. ¾KU 3. K?L "K ÃØkc<	
408	U"›Ã'ƒ SÉH'>ƒ Ã¨eÅM ;	1. ¾+u= SÉH'>ƒ 2. ¾T>ØM ui SÉH'>ƒ 3. ¾›°Ua ui SÉH'>ƒ 4. ¾Ee"‟ SÉH'>ƒ 5. K?L ŸK ÃØkc<	
409	ŸÇÑ>¨< Ò` eK SÉH'>~ ›¨dcÉ MUÉ uÓMê ƒ¨ÁÁL‹G< ;	1. ›–" 2. ›"¨ÁÃU 3. K?L "K ÃØkc<	

¡õM ›Ueƒ & ŸÖ?“ vKS<Á Ò` ÁL†¨<" Ó"'<˜¦ Çcc ¾Ö?“ ¦sU G<'@

501	ŸÖ?“ vKS<Á Ò` ¾K-ƒ Ó"–<'ƒ U" ¾SeLM ;	1. Ø\ 2. Ø\ ¾MJ' 3. K?L ÃØkc<	
502	ŸÖ?“ vKS<Á¨< Ò` ÓMê ¾J' ¨<ÃÃƒ Å`ÒL‹G< ;	1. ›–" 2. ›“Å`ÓU	
503	ÅÑ>¨< ŸÖ?“ ¦sS< ¾UÓw ÉÒõ ÁÑ—M ;	1. ›- 2. ›ÁÑ˜U 3. K?L ÃØkc<	
504	uU" ¾IM Ñ>²? ¾Ö?“ vKS<Á¨<" ÃÔu—K< ;	1. uG<KƒdU"ƒ 2. u¾¨\ 3. u¾G<Kƒ ¨\ 4. u¾feƒ ¨\	

		5. uðKŸ<ƒ Ñ>²?	
505	¾}ðKÑ<ƒ" K?KA‹ }ÕÇ˜ ›ÑMÓKA„‹ ÁÑ—K< ;	1. ›- 2. ›LÑ˜U 3. K?L ÃØkc<	
506	¨Å Ö?" }sU KSÉ[e e"ƒ w` Á¨×K< ;	1. -------- w` 2. U"U ›L¨×U 3. ›Lk¬U	

¡õM eÉeƒ : ŸI¡U" S´Ñw LÃ ¾T>VL

601	ÇÑ>¨< ¾é[›?‹ ›Ã y= SÉH'>ƒ SŠ ËS[;	1. ------	
602	¾T>¨eÅ¨< ¾é[›?‹ ›Ã y= SÉH'>ƒ ¯Ã'ƒ UÉ"¨< ;		
603	SÉH'>ƒ c=ËU` ¾'u[¨< ¾›?‹ ›Ã y= ISU Å[Í e"ƒ 'u` ;	1. Å[Í 1 2. Å[Í 2 3. Å[Í 3 4. Å[Í 4	
604	›G<" ÁK¨< ¾›?‹ ›Ã y= ISU Å[Í e"ƒ "¨< ;	1Å[Í 1 2Å[Í 2 3Å[Í 3 4Å[Í 4	
605	ÅÑ>¨< SÉH'>~" c=ËU` ¾'u[¨< ¾ CD 4 lØ` e"ƒ 'u` ;	1. ------	
606	›G<" ÁK¨< ¾ CD 4 lØ` e"ƒ "¨< ;	1. --------	
607	ÅÑ>¨< SÉH'>ƒ c=ËU` ¾'u[¨< ¾W¨<'ƒ ›sU Å[Í U" 'u` ;	1. Se^ƒ ¾T>‹M 2. Se^ƒ Án}¨< 3. ›MÒ LÃ ¾}—	
608	›G<" ÁK¨< ¾c¨<'ƒ ›sU Å[Í U"É "¨< ;	1.Se^ƒ ¾T>‹M 2.Se^ƒ Án}¨< 3.›MÒ LÃ ¾}—	
609	SÉH'>ƒ c=ËU` ¾'u[¨< ¾SÉH'>ƒ ›¨dcÉ MUÉ "È'ƒ 'u` ;	1.Ø\ 2. S"ŸK— 3. ´p}—	
610	›G<" ÁK¨< ¾SÉH'>ƒ ›¨dcÉ MUÉ "È'ƒ "¨< ;	1. Ø\ 2. S"ŸK— 3. ´p}—	
611	¾vKð¨<" ¨ ¾kÖa Ñ>²? ›dMðªM ;	1. ›- 2. ›LdKðU 3. ›M}S²ÑuU	
612	¾Kñƒ" feƒ ¨^ƒ ¾kÖa Ñ>²? ›dMðªM ;	1. ›- 2. ›LdKðU 3. ›M}S²ÑuU	

Declaration

I, the under signed, declared that this is my original work and has not presented in this or any other University and all sources of materials used for this thesis have been duly acknowledged.

Name: FIKRTE FIKADU

Signature:----------

Date----------

Place: Addis Ababa University, school of public health

This thesis work has been submitted with my approval as university advisor

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Signature:----------

Date----------

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