ASSESSEMENT OF PARENTAL INFLUENCE ON PEDIATRICS HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART) ADHERENCE IN ADDIS ABABA, ETHIOPIA, May 2010

BY

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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, Faculty of Medicine, School of Public Health

May 2010

Addis Ababa

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AAU-Addis Ababa University

ABC-Abacavir

AIDS-Acquired immune deficiency syndrome

ART-Anti retroviral therapy

ARV-Antiretroviral

AZT/ZDV-Zidovudine

DDI-Didanosine

D4T-Stavudine

EC- Ethiopian calendar

EDHS-Ethiopian demographic health survey

EFV-Efavirenz

Epi-Info-Epidemiological information

ETB-Ethiopian birr

FDC-Fixed drug combination

FGD- Focus group discussion

HAART-Highly active antiretroviral therapy

HAPCO- Human immune deficiency virus acquired immune deficiency syndrome prevention and control office

HIV-Human immune deficiency virus

ICU-Intensive care unit

LPV/r-Lopinavir/Ritonavir/Kaletra

MEMS-medication events monitoring system

MOH-Ministry of Health

NGO-None Government organization

NVP-Nevirapine

PLWHA- People live with human immune deficiency virus acquired immune deficiency syndrome

SPSS-Statistical package for social science

3TC- Lamuvidine

ABSTRACT

Back ground: Ensuring good adherence is critical to the success of highly active anti-retroviral therapy (HAART). Failure to adhere very closely to the regimens results in continued viral replication, treatment failure and the emergence of drug resistant strains of human immune deficiency virus (HIV). Although parents and caregivers may have primary responsibility for their children's medication-taking, there is no single study that examined parents influence on pediatrics highly active anti-retroviral therapy (HAART) adherence in our set up. The result of the study is expected to help device intervention strategies to improving children's adherence on highly active anti-retroviral therapy (HAART).

Objectives: To assess the status, determinants of adherence and identify parental factors influencing pediatrics highly active anti retroviral therapy (HAART) adherence in Addis Ababa.

Methods: An observational: descriptive, cross sectional study was conducted in 9 Health institutions: public, private and Non Governmental Organizations (NGOs) in Addis Ababa. Multi-stage sampling procedure was used to select a total of 586 children: age 0 - 14 years, Human Immune Deficiency Virus (HIV) infected and started anti-retroviral therapy (ART) 12 weeks ago. Primary care givers of the children were enrolled after the nature of the study was explained that allowed informed decision to be made and written consent obtained. Data was collected from February 8- May 10, 2010 on socio demographic, parent factors, clinical markers, care givers to provider relationship and regimen variables. Structured questionnaire and focus group discussion were used. Univariate, bivariate and multivariate analysis was carried out.

Result: The parental factors were strongly associated with non adherence; children who had non biological parents [OR=9.805(95%CI= 2.198, 43.736)], parents who didn't communicate about HIV and ART adherence to their children [OR=3.915 (95%CI= 1.273, 12.036)], and parents who hadn't good relationship with health care providers [OR=29.592(95%CI= 1.326, 660.333)] were more likely non adherent. Children who had more than four siblings [OR= 5.676 (95% CI=2.100, 15.339)] were also significantly associated with non adherence

Conclusion: The parental factors were strongly associated with non adherence. The need for providers to have smooth relation ship with the care givers of the HIV infected children on antiretroviral therapy, support caregivers to communicate with their children about the disease and antiretroviral therapy adherence is critical. Further research is recommended to explore the validation of self report adherence using longitudinal study designs.

1. INTRODUCTION

1.1 Back ground

Acquired immune deficiency syndrome (AIDS) is one of the most destructive pandemic in the history of human kind. According to the 2009 Acquired immune deficiency syndrome (AIDS) epidemic update, the number of People living with Human Immune Deficiency Virus (HIV) globally has reached 33million, of which 2 million were children less than 15 years. Child Acquired immune deficiency syndrome (AIDS) deaths in the same year were 270,000. Africa has 11.6 million Acquired immune deficiency syndrome (AIDS) orphans and 90% of global child deaths were in Sub-Saharan Africa [1].

According to the Ministry of Health (MOH) Ethiopia Single point HIV prevalence estimate, in 2009 estimated about 2.3%. It was projected that it will rise to 2.4% in 2010. In 2009 it was estimated that there were a total of 955,792 of the population of Ethiopia lives with Human Immune Deficiency Virus (HIV) of which 72,945 were children under 15 lives with Human Immune Deficiency Virus (HIV). In Addis Ababa the prevalence of Human Immune Deficiency Virus (HIV) was 8.5% (190,485), of which children contribute 6,545 by the same year [2]. As Ministry of Health (MOH) Ethiopia report up to 2009 there were 7716 children under 15years living with Human Immune Deficiency Virus (HIV) currently on antiretroviral treatment (ART) nationally [3]. Addis Ababa health offices 2009 report had revealed that 2447 children are currently on antiretroviral treatment (ART) [4].

The Human Immune Deficiency Virus (HIV) infection in childhood is different from the infection in adults with regard to transmission, state of the immune system, the natural course of viral dynamics and clinical manifestations. Several factors have to be considered when giving antiviral drugs to children because the pharmacokinetics of the drugs is age dependent and children require special attention to help with adherence [25].

To date few children living with Human Immune Deficiency Virus (HIV) access antiretroviral treatment. Barriers to scaling up pediatrics care remain, limited screening for Human Immune Deficiency Virus (HIV), a lack of affordable simple diagnostic testing technologies, a lack of human capacity and understanding that antiretroviral treatment (ART) is efficacious in children [26, 27].

1.2 Statement of the problem

Antiretroviral treatment for children requires collaboration between the children and parents/caregivers; commitment of the caregivers and cooperation of the children. Antiretroviral treatment for children also complicated by; developmental stage or age of the child, Parent-child interaction, relatively poor palatability of many pediatric formulations, caregiver factors [15, 16, 17, 32].

Adherence means the act or quality of sticking to some thing. Since treatment out come is sensitive to slight changes in adherence, about 95% adherence is recommended for antiretroviral therapy [6]. Getting such high level of adherence may be problematic especially for children as their medication intake rely on parents may be biological or non biological: relatives, house maids, voluntaries, etc. In Addis Ababa, according to EDHS 2005, only 48.5% of children under 18years were found to live with both parents [5].

New York study revealed that non biological care givers associated with non adherent [15]. Studies from USA showed worse parent child communication were strongly associated with non adherence [17] and study from Uganda also strong parent child relation associated with good adherence [21]. Adherence on children may put an enormous strain on the daily lives of parents and caregivers. Some ARVs need to be taken with food, so care givers may have to perform the often difficult task of providing a meal and administering drugs simultaneously [7].

Non adherence can vary widely missing one dose of a medication, missing a single dose of all three or four medication and missing multiple doses or all doses a day or a week. Not observing instructions regarding dietary or fluid intake or not taking medications at prescribed time intervals also constitutes non adherence [6]. A cohort Study in the Netherland had revealed that 47% reported taking all antiretroviral medication on time and according to dietary instructions [14]. Botswana study had showed 56% adherent by physician assessment and 54% by self assessment [31]. Cross sectional study in Addis Ababa had showed that 86.9% on HAART children were adherent to antiretroviral drugs for the past 7 days.

Majority of the literatures tried to examine adherence rate of children on HAART but small proportion of the studies conducted on the predictors of children emphasized on parental factors of children HAART adherence. Most of the studies were from high income countries which are

different from our set up and the research designs were used also different as a result the findings of literatures vary accordingly.

1.3 Rationale of the study

Many studies examined ART adherence and predictors of ART adherence in adults but few studies conducted in children ART adherence and predictors in our set up. Although parents and caregivers may have primary responsibility for their children's medication-taking, no single study has examined caregivers/parents factors influencing children's adherence to antiretroviral therapy in our set up. This study will fill the gap of knowledge about parents influence on pediatrics HAART adherence. In order to facilitate adherence to HAART and to improve out come of HAART in HIV infected children it becomes necessary to know possible and relevant issues in pediatric patients that influence adherence and this study will help as a device for improvement of pediatrics HAART adherence.

2. LITERATURE REVIEW

2.1 Pediatrics HAART and Adherence

Adherence to treatment is critical to obtain the full benefits of HAART, maximal and durable suppression of viral replication, prevention of viral resistance, promotion of immune reconstitution and slowed disease progression [6]. A retrospective cohort study conducted in Spain, Madrid among children vertically infected with HIV-1 showed a significant clinical and immunological improvement, reduction of mortality and delayed progression to AIDS following treatment with HAART over 3 to 5 years compared to those who did not take any treatment and those who did take mono therapy, bi therapy and other forms of treatment [8,9]. In another study in the USA where hospitalization trends among children and youth with prenatal human immunodeficiency virus infection was analyzed, a substantial down ward trend in admission to ICU and hospitalization was observed as evidenced by a decrease from 30.4% in 1990 to 12.9% in 2002 and a further steady decrease after wards. Similar experience had studied in Thailand [10,11].

Sustaining adherence represents a significant challenge for the children. A systemic review of pediatric adherence in low and middle income countries estimates of ART adherence ranged from 49% to 100%, with 76% articles reporting >75% adherence rate [12]. Cross sectional study in Addis Ababa had showed that 86.9% on HAART children were adherent to antiretroviral drugs for the past 7 days and 93% children were adherent for the past 3days before the interview [13]. Another study from Addis Ababa had revealed 93.4% [29]. A cohort study in the Netherland had revealed that 47% reported taking all antiretroviral medication on time and according to dietary instructions [14]. Botswana 56% adherent by physician assessment and 54% by self assessment [31], USA 70% full adherent [30] and similar rate from London and Malawi 72% adherent [32, 19]

2.2 Factors of Pediatrics HAART adherence

Factors that influence adherence: patient factor or care givers factor, treatment regimen, disease characteristics, patient - provider relationship and clinical settings [6]. A cross-sectional study done in USA examined the relationship between caregiver psychosocial characteristics and medication adherence among children with HIV. Caregiver/family factors were strongly

associated with non-adherence, including worse parent-child communication, higher caregiver stress and less disclosure to others [15, 16, 17].

A patient or care givers knowledge about medication regimen and a patients understanding of the relation between non adherence and resistance to medication also were predictors of better adherence. A patient's belief and confidence in therapy and self efficacy also has influence to adherence [6]. A study done in Belgium examined three main factors influenced adherence: Adherent patients; were found to internalize the medical information to a stronger extent than less-adherent patients, showed stronger motivation to stick to the medical regimen and developed greater problem-solving capacities. Furthermore, the interviews revealed a fourth component: knowledge, motivation, and capacities evolved in a progressive way, related to individual stages of coping with human immunodeficiency virus [18].

Numerous variables were found to be significantly associated with adherence study in Addis Ababa, where children whose parents did not pay a fee for treatment and children who had ever received any nutritional support from the clinic were less likely to adhere whereas children who took co-trimoxazole medication/syrup besides ARVs, children who did not know their sero-status and children who were not aware of their caregiver's health problem were more likely to adhere than their counterparts [13]. Study in Malawi assessed caregivers understanding of ART and perceived barriers and enablers for adherence. Positive visual and physical changes were as the key-motivating factor to adhere to ART. Other barriers included multiple responsibilities of patient or care givers and giving responsibility to someone else to give the drugs if the main caregiver is away. This is further complicated by stigma and fear of disclosure. Besides, death of caregiver was highlighted as a particular challenge to adherence [19].

An exploratory study had examined, from the perspectives of both HIV-infected children and such children's primary care givers, the barriers children face in adhering to combination antiretroviral therapies. Results showed that children faced main barriers to adherence related to family daily routines; medication side effects: medication taste, size and shape; the stigma of HIV/AIDS; medications as a reminder of HIV/AIDS and child dishonesty [20].

Disclosure about the HIV status to the child and to others was also determinant factor for adherence. Assessment study conducted in Uganda, the result showed that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good

adherence. However, Structural factors including poverty and stigma were barriers to adherence even for children who had had complete disclosure and a supportive relationship with a parent [21].

2.3 Helpful Adherence Measuring Tools

Measuring adherence is problematic as there is no single method to assess adherence accurately. Therefore, multiple approaches are used to assess adherence, but these have advantages and disadvantages. Some of the currently used measures are client self report or care givers report, electronic monitoring devices, pill counts, provider estimation and measurement of medications in the blood stream [6].

Self–report when patients or care givers get asked to report their and their child adherence with in different periods of recall. Although patients or care givers response over estimate their adherence several studies have found that the self report assessment correlates with the actual medication intake. Meta-analysis study of self reported adherence to HAART, the result showed distinct study characteristics were significantly associated with the relation between adherence and virology response [22]. In contrast another systemic review assessed different strategies of adherence and measurement the result revealed that the self or proxy adherence employed few validation and care givers report was higher than self report estimate [23].

Pill counts when health care worker conduct during scheduled clinic visits the main disadvantage of this method is that patients can manipulate pills, pill dumping prior to scheduled visits leading to an over estimation of adherence and pill count may also hinder patient-care giver relation. In case of children it is infeasible because their medication preparation is commonly in suspension form [6].

Electronic devices like medication events monitoring system (MEMS) and biological markers like monitoring viral load are very expensive for resource limited settings[6]. In a comparison of adherence assessment methods under taken in USA MEMS had provided the most detailed adherence information and good reliability was indicated by significant correlations with medical markers. Pill counts provided similar adherence rates, while patients and caregivers reported nearly perfect adherence in interviews. Nevertheless problems were experienced with each method: MEMS as expensive, had cap malfunctions, and lacked a consistent guiding principle

for data interpretation. With pill counts, families forgot to bring all medication bottles to clinic, and interviews were compromised by social desirability [24].

2.4 Unique Features of Pediatrics HAART Adherence

Children's developmental stages have significant impact on adherence to HAART. The children's cognitive stage, ability to communicate, and their social status determine the effectiveness of achieving adherence to HAART. In addition, the care givers comfort level, understanding of AIDS and beliefs determine the success of pediatric HAART adherence [28].

3. OBJECTIVE

3.1 General objective

1-To assess parental influence on pediatrics highly active antiretroviral therapy (HAART) adherence in Addis Ababa, Ethiopia, 2010 (2002EC)

3.2 Specific objectives

1- To determine the status of pediatrics highly active antiretroviral therapy (HAART) adherence in Addis Ababa, Ethiopia, 2010 (2002EC).

2- To describe factors influencing pediatrics highly active antiretroviral therapy (HAART) adherence on in Addis Ababa, Ethiopia, 2010 (2002EC).

3- To identify the relationship between parental factors and pediatrics highly active antiretroviral therapy (HAART) adherence in Addis Ababa, Ethiopia, 2010 (2002EC).

4. METHEDOLOGY

4.1 Study design

Institution based, cross-sectional study with internal comparison qualitative methods was conducted at pediatrics ART units of public, private, and NGO: Hospitals, Health centers and clinics found in Addis Ababa Ethiopia.

4.2 Study area

The study was conducted in Addis Ababa; the Capital City of the Federal Democratic Republic of Ethiopia. In Addis Ababa there are 9 Government Hospitals, 24 Government Health centers, 13 private Hospitals and 3 NGO clinics providing ART service for PLWHA. From the above mentioned Health Institutions; 6 Government Hospitals, 24 Government Health centers, 2 Private Hospitals and 3 NGO clinics do render Pediatrics Antiretroviral Treatment service to date. A total of 9 Health Institutions were selected; 3 public Hospitals and 3 public Health Centers (Alert Hospital, Zewditu Hospital, Yekatit 12 Hospital, Kolfe Health Center, Arada Health Center and Addis Ketema Health Center) governed by Addis Ababa regional Health Office, except Alert Hospital which is governed by Federal Ministry of Health, 1 Private Hospital (Betezata Hospital) and 2 NGO Clinics (Missionary of charity Clinic and World wide family health clinic (WWO-AHF) selected.

4.3 The source population

The source populations were all children age 0-14years who are taking HAART, and were on follow up in the ART units of Addis Ababa.

4.4 Study population

The study population; the care givers of children HIV infected, age 0-14years, 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 9 Health Institutions were sampled.

4.5 Inclusion criteria

Care givers of HIV infected children on HAART

- Age 0-14years
- Receiving HAART 12 weeks ago before study in the selected health institutions for the reason children started treatment recently would not missed doses.
- Who has been counseled on the importance of drug adherence and adverse drug reactions associated with antiretroviral drugs were included.

Where the care giver was not available on the first visit of the interview date, appointment was set for the second visit and for those was not presented for the second appointment; we had interviewed the second responsible person for child medication intake when primary care giver moved away.

For qualitative data, care givers of children who were enrolled on the quantitative study in selected pediatrics ART units were included.

4.6 Exclusion criteria

- Started HAART with in the last 12 weeks before study in the selected health institutions for the reason children started treatment recently would not missed doses.
- Children who got sick during the interview date.

4.7 Sample size

To determine the sample size for the quantitative survey a single proportion sample size formula was used.

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

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

Assumptions:

Z α/2= 1.96, standard normal distribution value for the 95% confidence interval

d=0.04 degree of margin of error to increase the power

N=the number of children on HAART to be enrolled in the study i.e. sample size of the study.

p=Adherence rate among children on ART in Addis Ababa.

A design effect of 2: because Multi stage sampling technique was used to select the sample size to over come the short coming of this technique, to increase the sample size and representativeness.

The sample size was calculated using single proportion sample size formula by using Epi Info 6.04 statistical package. The following assumptions were used to calculate the sample size: Proportion of adherence among children on ART in Addis Ababa, the 2008 study had shown 86.9% with in 7 days before the data collection date. 86.9% was used to obtain the sample size 266 and to compute non response rate 10% of the total sample size was added, this gave a total of 293 for design effect multiplied by 2 this gave us 586 children on ART were sampled, care givers of children on ART were responded to the interview questionnaire.

4.8 Sampling procedure

Multi stage sampling technique was conducted. Health institutions providing Pediatrics ART service were stratified by the service categories such as: Public, Private, NGO Pediatrics ART units. The number of Health Institutions enrolled to the study was decided to be 25% of all Pediatrics ART Units; this is because of the limitation of resources. In Addis Ababa there are 9 Government Hospitals, 24 Government Health centers, 13 private Hospitals and 3 NGO clinics providing ART service for PLWHA. From the above mentioned Health Institutions; the 6 Government Hospitals, 24 Government Health centers, 2 Private Hospitals and 3 NGO clinics do render Pediatrics Antiretroviral Treatment service to date. A total of 9 Health Institutions were selected; 3 public Hospitals and 3 public Health Centers, 1 Private Hospital and 2 NGO Clinics selected.

Based on the target group of each selected Pediatrics ART unit, the required sample size was allocated proportionally to size. Simple random sampling technique was employed to identify the study subjects using the ART unique numbers from the registration book in each ART unit and the care givers of the corresponding children were responded to the questionnaire (Figure 1).

In addition a total of 3 Focus Group Discussions (FGD) were conducted. For the qualitative study we purposively recruited individuals for the study by purposive sampling. Primary care givers were participated in the FGD.

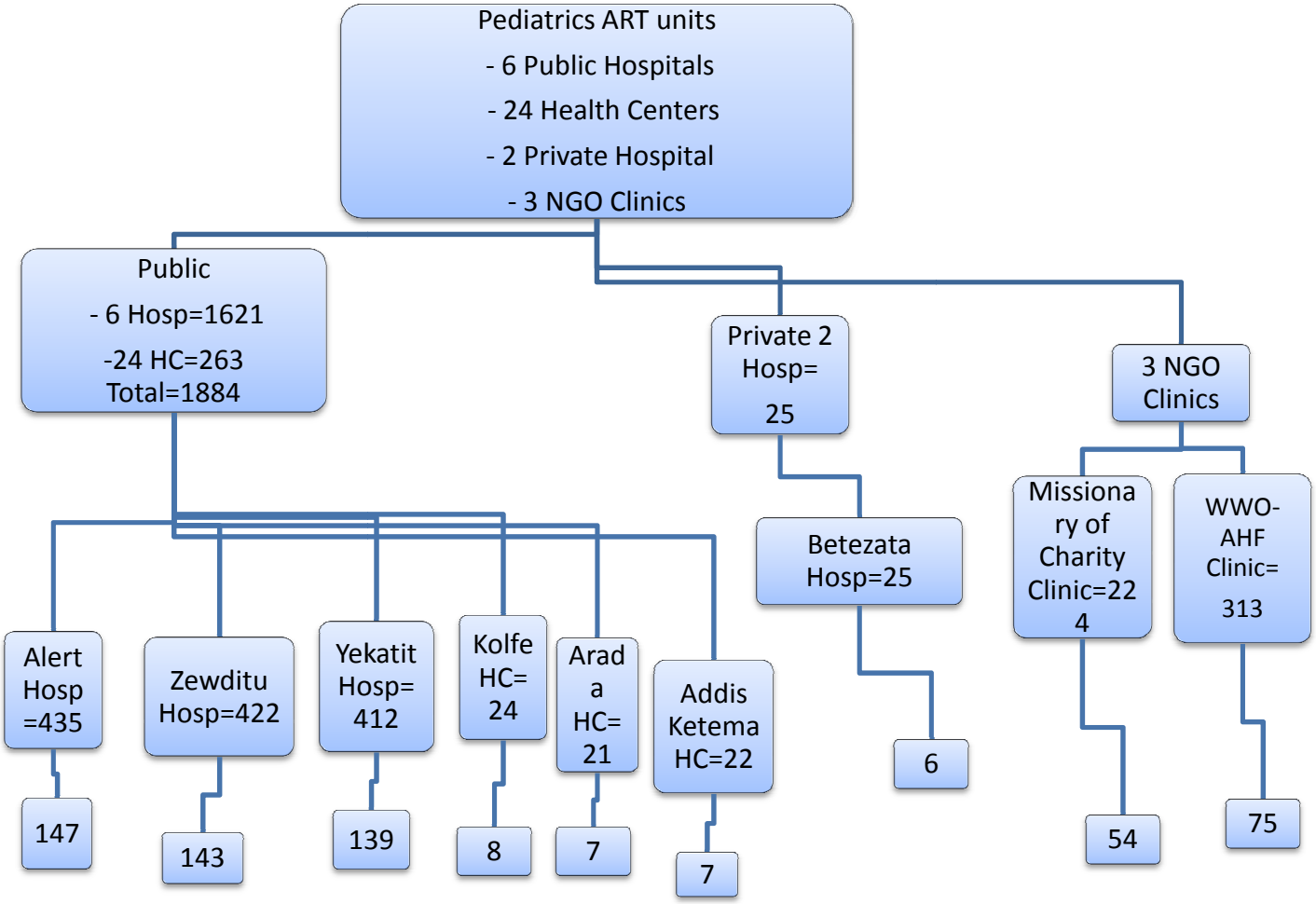

Figure 1 Schematic presentation of sampling procedure

- Stratification based on types of facilities
- Sample size proportionally allocated from the number of children in the facilities
- By Simple random sampling selected 586 children

4.9 Data collection instrument and procedure

The quantitative data was collected from February 8- May 10, 2010 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 9 data collectors and 2 supervisors for 3 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 children for the study before the actual data collection date 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. Continues supervision was arranged to control the data collection procedure by two Health Officers.

Qualitative data was collected by note taker and Tape recording. After data collected; transcribed, translated to English, summarized and manually analyzed.

4.10 Data collectors

The quantitative data was collected by 9 trained nurses. All data collectors participated in pre testing of the questionnaire any unclarity in the questionnaire tried to reach in consensus.

For qualitative data interview was conducted by the Principal Investigator in private room to create an atmosphere of empathy and confidence.

4.11 Variables

The independent variables

- Socio demographic and economic status of the children and parents
- Clinical back ground of the children
- Social condition of the children and parents
- Family factors of the children
- Care giver- health care provider relation and clinical setting conditions

- ART drug administration and adherence status

The dependent variable

- Adherence of HIV infected children to HAART in the past 7 days.

4.12 Data quality assurance

To ensure quality of the data, Pre-testing of the questionnaire was undertaken in 5 percent of the sample size in similar areas with similar characteristics of the study unit before the actual data collection date. This sub sample not included to the actual study participants. The difficulty and ambiguity of the questionnaire was restructured. The final version of the questionnaire was used for the data collection. The over all activity was monitored by the principal investigator. Data was collected by using a pre tested questionnaire by trained health care providers whilst continues supervision was arranged to ensure quality data collection procedure through out.

Training was conducted for the data collectors and supervisors for the consecutive 3days on the data collection procedure, technique and related issues. The collected data was checked for the completeness, for accuracy and clarity by the principal investigator and supervisors.

The collected data was edited, random and spot check was arranged and data cleaning was conducted.

4.13 Data processing and analysis

Data entry and analyses were carried out using Epi-info version 6.04 statistical package and SPSS version 12.0.1 statistical packages, respectively. First, descriptive statistics was carried out to explore the socio-demographic characteristics of the respondents and the children, the adherence rate and clinical characteristics of the children. Cronbach's alpha test was implemented to find the reliability of knowledge questions. To find association between the exposure variables and adherence, bivariate analysis was done. To control the effect of confounding variables, multivariate logistics regression was done. Variables, which were showing statistical significant association ($P< 0.05$) in the bivariate analysis were included in the final model.

4.14 Operational definitions

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

Adherence will be considered good if the patient has taken >95 % of the prescribed doses correctly[6].

Dose- one time intake of the professionally prescribed amount of a given medication

Parent- A person who has consistently assumed responsibility for the regular care, including housing, food, health, safety, and related with essential of fulfillments of the child and which can be through biological or non biological form of standing relationship.

Primary care- giver- an individual who administers medication for the child daily and bringing the child for clinic appointments

Knowledge of adherence- was measured using responses to 10 statements on a five point Liker scale ranging from 1(strongly disagree) to 5(strongly agree). Scores for all 10 items will be totaled, forming a scale with good reliability (Cronbach's $\alpha = 0.708$). Respondents who were answered don't know were excluded from the analyses. Possible values were ranged from 10-50.

Knowledge scores were analyzed as:

Good knowledge of adherence values greater than or equal to 43

Poor knowledge of adherence values less than 43

The cut off value decided to be 43 was the mean value of knowledge questions was 43.

4.15 Ethical consideration

Ethical clearance was obtained from Addis Ababa University, Faculty of Medicine, School of Public Health, from the Institutional Review Board of the College of Health Sciences of AAU and Addis Ababa Health Beauro. Official letter of co-operation from the above organizations and Federal Ministry of Health (FMOH) was given to respective Hospitals, Health Centers and Clinics in Addis Ababa. The primary care giver was enrolled as a study participant since children 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.

The information sheet contained adequate information about the objectives of the study to assess the rate of adherence, describe factors of adherence and identify the relationship of parental factors and pediatrics highly active anti-retroviral therapy (HAART) adherence. The benefits of the study will fill the knowledge gap on parental influence on pediatrics HAART adherence by shedding light on intervention strategies to improve pediatrics HAART adherence.

Equitability on selection was ensured by random selection. Anonymous questionnaire was used to ensure confidentiality and only an identity number was used on each questionnaire. The respondents were told that they have the right to be involved or not to be involved in the study and could skip questions that respondents didn't want to answer. Respondents' right was reserved to interrupt the study at any time; their refusal was not having any effect on services that the respondents and respondents' families received. Invasive procedures were not carried out during the course of the study that could harm the child and study participants. Data was collected through interview and reviewed of registration. When indicated additionally pertinent information was provided to the caregivers of children.

4.16 Dissemination of the result

The finding of this study will be disseminated to the Addis Ababa University, Faculty of Medicine, School of Public Health as a partial fulfillment of Master of Public Health and to the Federal Ministry of Health, Federal HIV/AIDS Prevention and Control Office and Addis Ababa Regional Health Beauru for program improvement and designing. The finding will be presented through publication and distributing to the concerned body.

5. RESULT

5.1 Socio-demographic and economic characteristics

A total of 586 children respondents were included in the study with response rate of 100%.
The majority, 255 (43.5%), respondents had children with HAART of above 9 years. The mean (SD) and median age of the children were 8.60 ±3.24 and 9 years respectively. Fifty percent of the children were females. As to the educational status of the children, 337 (57.5%) of the children were between grade 1-3, 158 (23.5%) were between grade 4-6 and 71(12%) didn't learn. Concerning last year rank of the children 128(21.8%) were greater than 15 and 86(14.7%) were less than 5.

A total of 475 (81.1%) female and 111 (18.9%) male primary care givers of children responded for the structured questionnaire. The age of care givers ranges from 18 years to 80 years, of which 254 (43.4%) were between 30-39 years. The mean (SD) and the median age of the primary care- givers were 36.43 ± 10.35 and 35.00, respectively.

Most of the study participants were belonging to Amhara 314 (53.6%), Oromo 127(21.7%) and Gurage 76 (13.0%) by ethnicity. The majority of care givers 475 (81.1%) were Orthodox. As to the marital status of the care givers 292 (49.9%) were married. Concerning the educational status of the caregiver, the majority 199 (34.0%) have attended secondary school education (9-12). Regarding their occupation, 238 (40.6%) were house wives (Table 1).

Two hundred and thirty five (40.1%) of the participants had house hold income 400-1000.00Eth.Birr, 228 (38.99%) of them had less than 400.00Eth.Birr and 81(13.8%) of them had greater than 1000.00Eth.Birr house hold income. Three hundred and nine (53.1%) of care givers had family size of 4-6 whilst 218(37.5%) had 1-3. The living arrangement of the children (Figure 2).

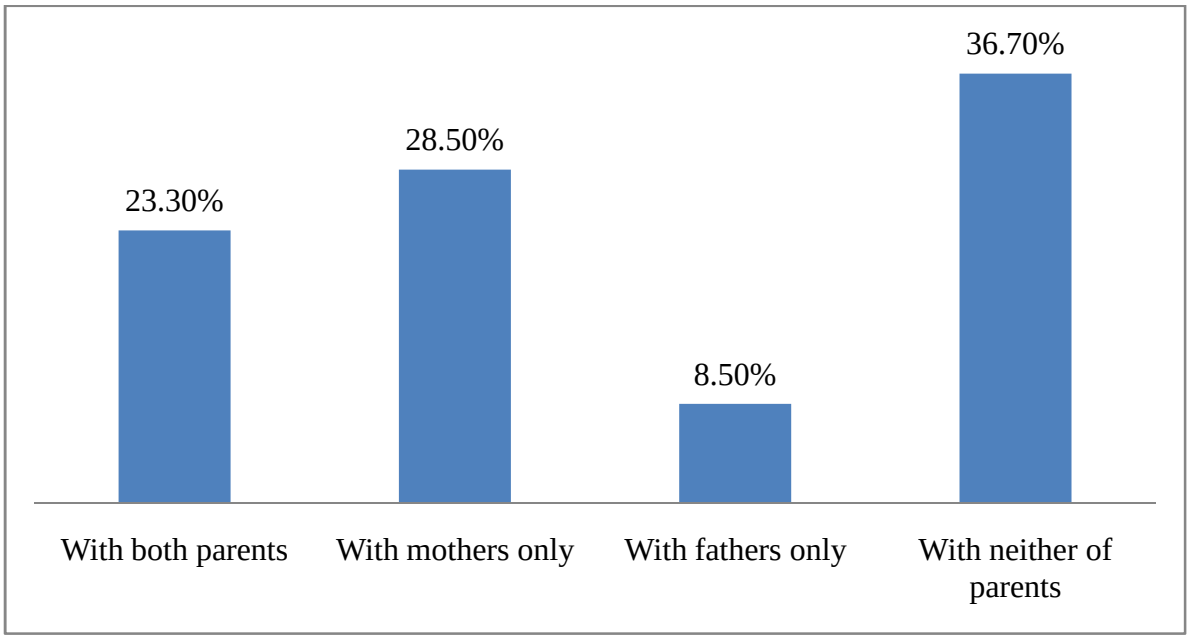

Figure 2-Livining arrangement of the HIV infected children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

Table 1-Demographic and social characteristics of caregiver and children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

Variables	Frequency (%)
Age of the child (years)	
<4	74(12.6)
4-6	88(15.0)
7-9	169(28.8)
>9	255(43.5)
Respondent's age (years)	
18-29	149(25.5)
30-39	254(43.4)
40_49	110(18.8)
≥50	72(12.3)
Religion of the caregiver	
Orthodox	475(81.1)
Catholic	8(1.4)
Protestant	56(9.6)
Muslim	46(7.9)
Others #	1(0.2)
Marital status of the caregiver	
Single	84(14.3)
Married	292(49.9)
Divorced	47(8.0)
Separated	13(2.2)
Widowed	150(25.6)
Occupational status of the caregiver	
Merchant	46(4.8)
House wife	238(40.6)
Student	11(1.9)
Governmental employee	86(14.7)
Private employee	107(18.3)
NGO employee	49(8.4)
Day laborer	49(8.4)
Educational status of the caregiver	
Unable to read and write	88(15.0)
Able to read and write	55(9.4)
Primary (1-8)	175(29.9)
Secondary (9-12)	199(34.0)
Diploma and above	69(11.8)

Others # = Jehovah

5.2 Clinical back ground of the children on HAART

Most of the children 345(58.9%) were in stage III based on WHO classification when children started treatment and 288(48.0%) of the children were currently in stage II (see figure 3 and 4). The mean and median CD4 counts, respectively were 286.67 cells/mm3 and 207.00 cells/mm3 before ART started where as the mean and median of the current CD4 counts were 664.37 cells/mm3 and 580.50 cells/mm3, respectively. Two hundred eighty five (48.6%) of the children had CD4 count of less than 200 cells/mm3 at the start of the treatment. Two hundred seventy eight (47.4%) of the children had CD4 count of greater than 600 cells/mm^3 currently (Figure 5 and 6).

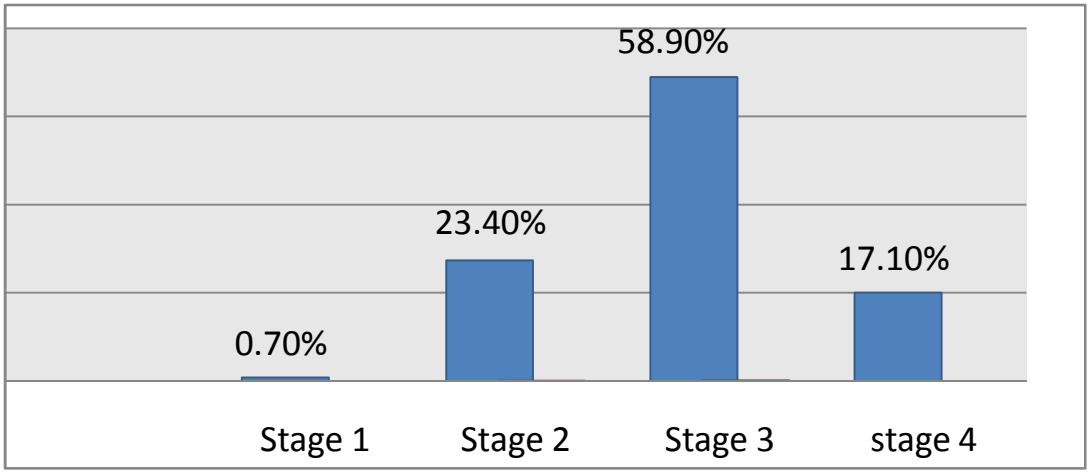

Figure 3- The stage of HIV disease at start of Antiretroviral treatment based on WHO classification for the HIV infected children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

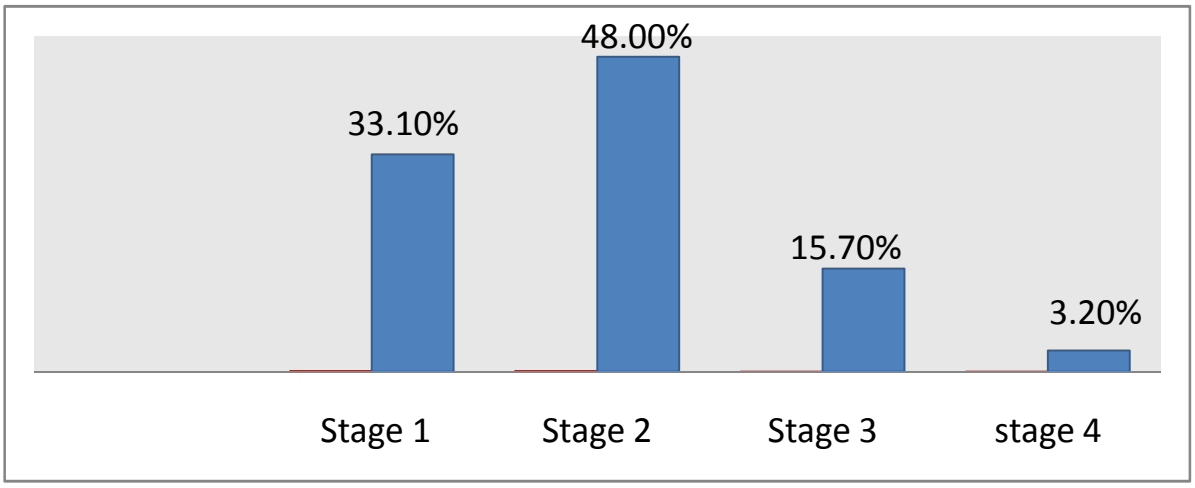

Figure 4- Current stage of HIV disease based on WHO classification for HIV infected children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

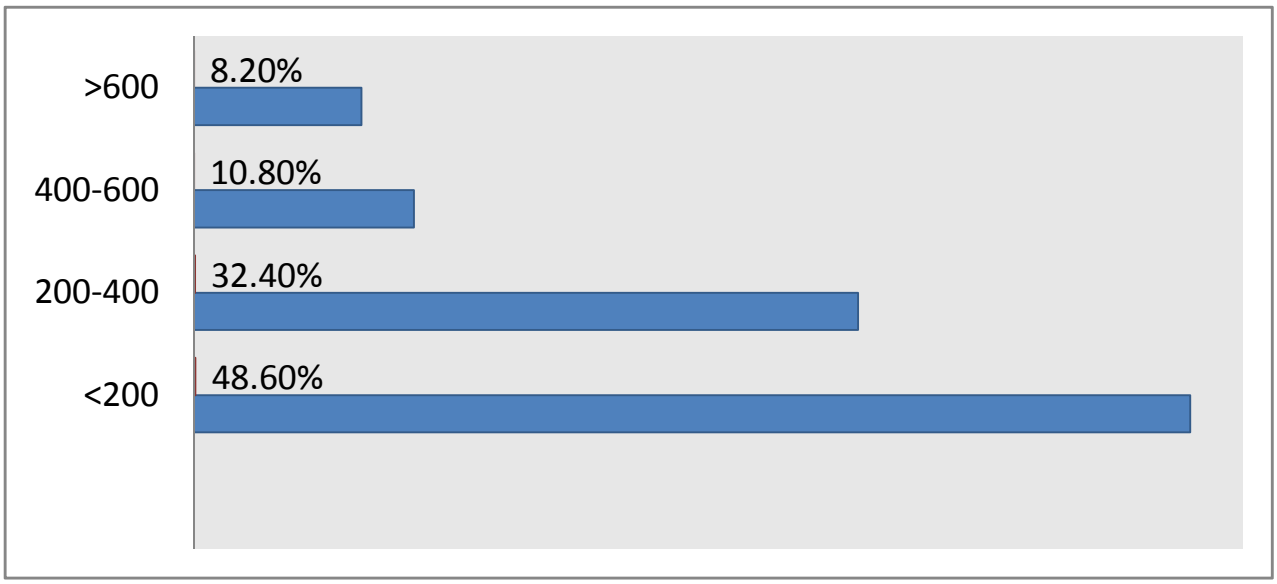

Figure 5- CD4 count at start of Antiretroviral treatment for the HIV infected children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

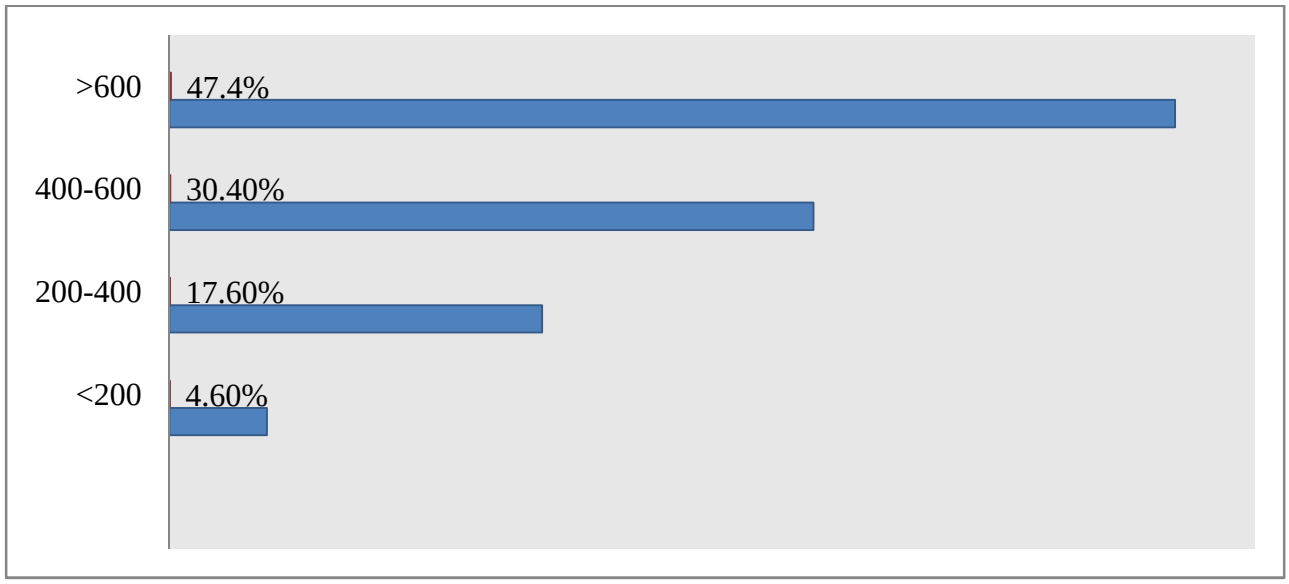

Figure 6- Current CD4 count of HIV infected children on HAART in the sampled Addis Ababa Health Facilities, Addis Ababa, Ethiopia [N=586], May 2010

5.3 Assessment of ART drug administration and adherence

Caregivers used different mechanisms as reminders to administer medications on time; the most common reminder was wall watch 240(41.0%), hand watches/clocks 199(34.0%) and watch bell 99 (16.9%).

Two hundred eighty eight children (49.1%) had been taking D4T/3TC/NVP base regimen (Figure 7). Five hundred twenty eight (90.1%) children took the ART drugs in the form of pill and 58(9.9%) were in the form of syrup. Four hundred ninety four (84.3%) children took Cotrimexazole prophylaxis with ART drugs.

A total of 71 children (12.1%) missed at least one doses of antiretroviral drugs in the past 7 days before the survey, 43(7.3%) children missed doses last month an increase trend of missed dose as recall period increase (See Figure 8).

During group discussion, majority of the respondents had admitted that their children never missed either a morning or night dose within the last seven days or before however; some of the care givers of children have been confirmed to have missed night or morning dose before 7 days, according to the respondents. A small proportion of participants confirmed missed doses within the last seven days. A minority of them also suggested that misunderstanding of administering medication lead the children for over dose.

"*Misunderstanding is a serious issue. I remember her grand mother giving her double dose as a result the medication supposed to be for one month was consumed in a matter of 18 days.*"
An uncle of 13 years of age girl stated.

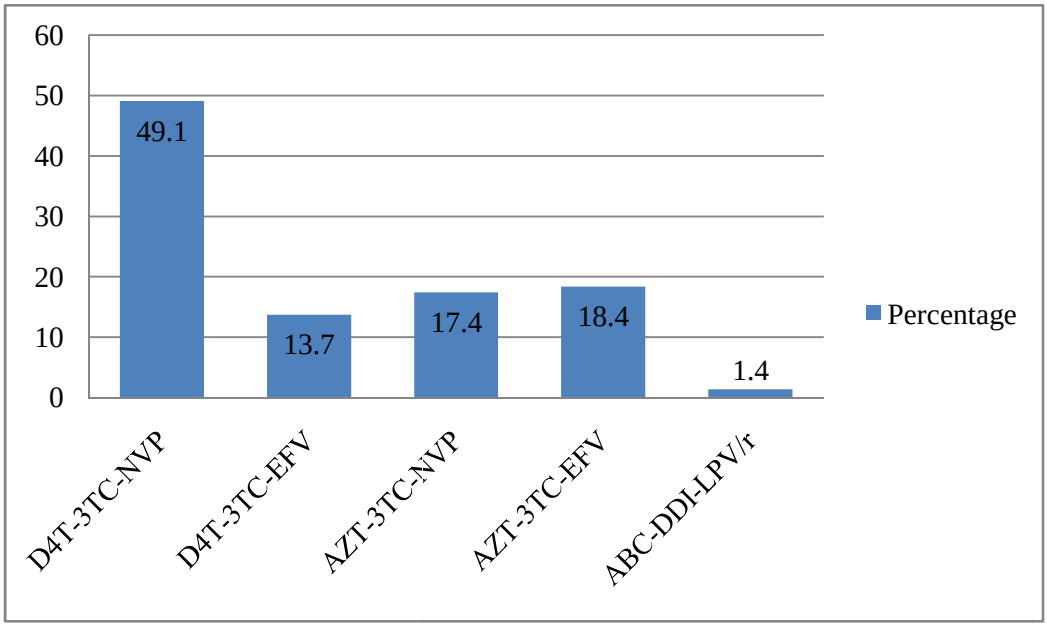

Figure 7. Recommended drug regimens for children on HAART in Addis Ababa, Ethiopia, May 2010

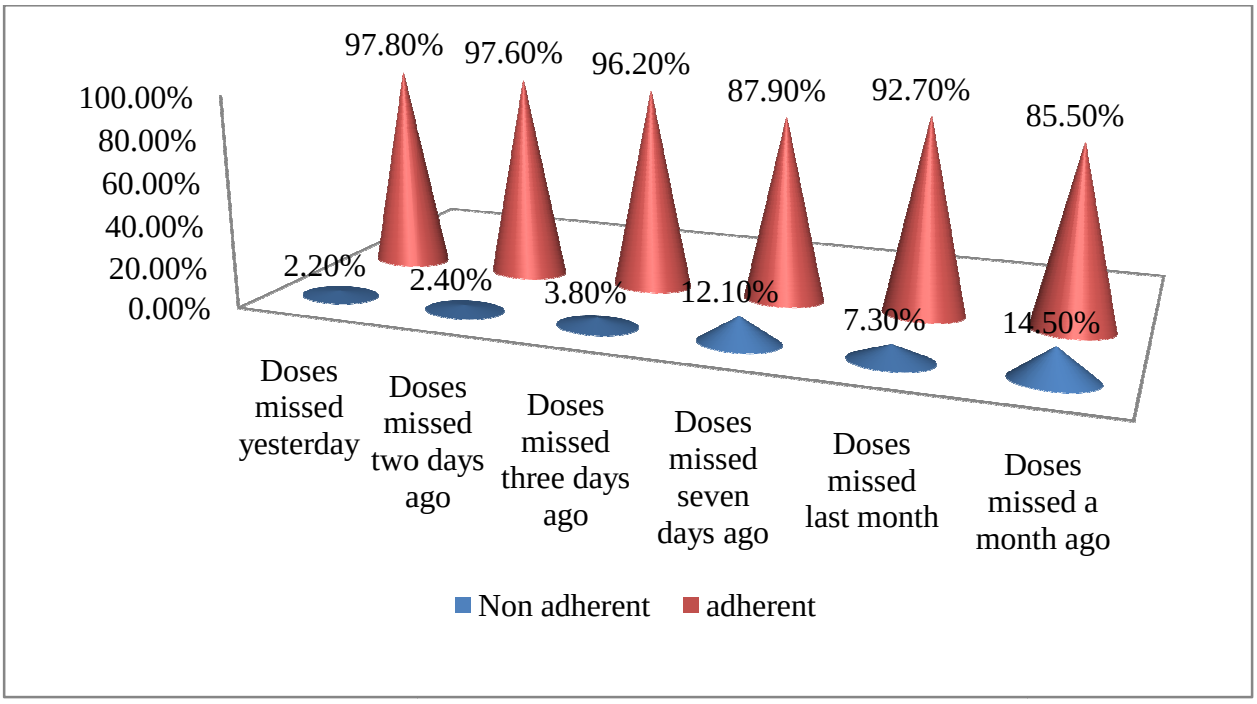

Figure 8- Shows the pattern of missed doses over time among children on HAART in Addis Ababa, Ethiopia, May 2010.

5.4 Reasons, problems or situations that make difficult to give a child medication

For those who had missed a dose or more in the last 7 days, the common reasons were being away from home 37(21%), drug finished 30(17%), child slept 30 (17%), were too busy 27(15%), forgetfulness to give the drugs 18(10%), child felt sick 15 (8.5%), confused about the dosage 5(2.9%) and drug stocked out 5(2.9%) (Figure 9).

During focus group discussion, majority of the respondents reiterated of the difficult task that they had faced when it comes to providing medication to their children as many of them spend much of their time at work place making it difficult for them to be able to stick to timely medication provision. According to them such led to missed doses even.

"I am a daily laborer. One day I came back home very late and my child ended up sleeping with a neighbor. I wanted to wake him up but was too late that is why my neighbor resisted. Because I did not disclose I just let it goes that way leaving my child missing the night dose with in the last four days."

A mother of 10years boy suggested.

Equally important, was that majority of the respondents explained fear of discrimination as a barrier to give medication in front of others.

"He had missed morning dose yesterday, more over; there was also a day when he missed night dose before two weeks; he left early with his classmates before I had managed to get hold of him besides, if he is by chance with his class mates, I don't usually dare to give him in front of them lest he should be discriminated."

A five years male child mother replied.

A significant portion of the respondents complained of the syrup formulation as unpleasant to children. Its multiple frequencies unlike the tablets were also noted as a barrier.

A small proportion indicated that recurrent illness and lack of adequate food were mentioned as problems furthermore; disclosure of HIV status to a renting land lord was described as a risky venture that could lead to being kicked off rented house.

"I did not disclose to the house owners where I had rented because it carries a risk of being rejected and probably driven out of the house. One day my child spent the night with the land lords which I found it difficult to wake him believing that they might know if they saw me while administering the drugs."

A 10 years male child mother suggested.

Minority of them suggested that shortage of medication also was a great problem in adherence.

"There is occasional intake of especially night dose late furthermore; there was one day I remember where she fell short of one full dose perhaps owing to incomplete dose brought from the hospital or dropped off somewhere along the way."

A 9years girl mother explained.

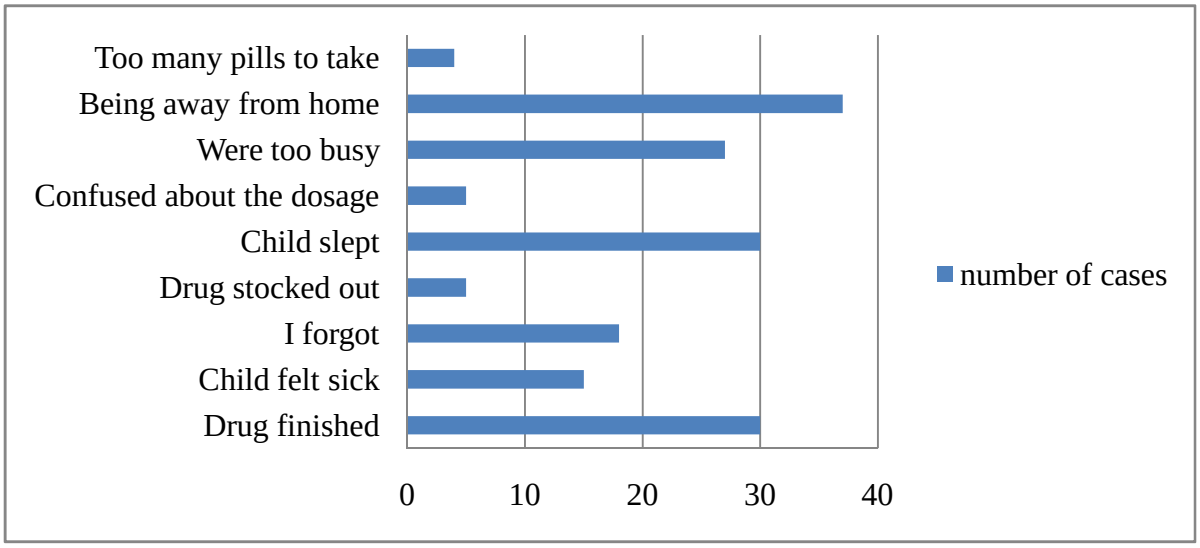

Figure 9- Reasons for missing dose among children who were on HAART in Addis Ababa, Ethiopia, May 2010

5.5- Social conditions of the children on children's HAART adherence

Only 160 (27.3%) of the children knew their HIV serostatus, but 426(72.7) didn't. Children didn't know their HIV serostatus had not significant association with non adherence, but most adherent children knew their HIV serostatus than non adherent children (90% versus 10%). Among all care givers 452 (77.1%) who had disclosed children's HIV serostatus was; to the family (82.3%), for friends (6.3%), organization (22.5%) and community (1.1%). Children who had more than four siblings had significantly associated with non adherent than those who hadn't siblings [Adjusted OR=5.676 (95% CI=2.100, 15.339)].

Two hundred and fifty eight (44.0%) of the children didn't get any kind of support, while the rest had different support from different sources: The number (percent) of children who got support from family, community, and non-governmental organization were 29 (11.2%), 2(.8%) and 205 (78.8%), respectively. The support included financial support 123 (47. 3%), food 180 (69.2%), care emotion 49 (18.8%) and in remedies of medication 56(21.5). Five hundred and thirty one children (90.6%) got sick before ART treatment started (Table 2).

During focus group discussion, an over whelming majority of the respondents said, have already disclosed to the children, family, close relatives and neighbors which according to them would help them be responsible, know the nature of the disease, importance of taking medication and gives as well a chance for family and neighbors to take precautionary measures while dealing with the children.

"A ten years elderly son is informed because that made him even responsible. He takes medicine himself even in my absence. Disclosure actually benefited my sons to a great deal. I have told neighbors so that they can take precautionary measures."

A 10years and 6years boys mother stated.

"She has been told. She was suddenly told without our prior consent in the hospital. She has changed quite a lot since then. She frequently cries and shows sign of despair and frustration. We did not tell to neighbors as this usually leads to discrimination and children could decline to play with her however; we have told to people inside our house."

A 9years female ankle commented.

A small proportion said however; did not disclose to the children or family either. According to them this would lead to psychological trauma and discrimination of many forms.

"He has not been told yet. He saw on television advertisement regarding HIV and its drug package where he took notice of it. He begun to say that the drug he has been taking is exactly the same, since then he lost appetite for he imagined/knew what he has been taking is HIV drugs."

A 12years boy mother suggested.

Table 2. The relationship of social conditions with adherence of the HAART receiving children in Addis Ababa, Ethiopia [N=586], May 2010

Variables	Non adherence (n, %)	Adherence (n, %)	Crude OR(95% CI)	Adjusted OR(95% CI)
Does the child Knows his/her HIV sero-status				
Yes	16(10.0)	144(90.0)	1.00	
No	55(12.9)	371(87.1)	1.334(0.740, 2.405)	
Was the child's sero-status disclosed to others				
Yes	50(11.1)	402(88.9)	1.00	
No	21(15.7)	113(84.3)	1.147(0.849, 2.560)	
Number of child siblings				
No siblings	27(13.4)	174(86.6)	1.00	1.00
<2 siblings	22(7.7)	265(92.3)	0.535(0.295, 0.970)*	0.666(0.235, 1.892)
2-4 siblings	3(21.4)	11(78.6)	1.758(0.460, 6.708)	1.457(0.087, 24.338)
>4 siblings	19(22.6)	65(77.4)	1.884(0.981, 3.617)	5.676(2.100, 15.339)*
Did the child get sick before child treatment started				
Yes	70(13.2)	461(86.8)	1.00	1.00
No	1(1.9)	52(98.1)	0.127(0.017, 0.931)*	0 .251(0.25, 2.498)
Child started treatment				
<12months before	30(42.9)	127(25.6)	1.00	1.00 1
12-23months before	5(7.1)	49(9.9)	0.432(0.159, 1.177)	0.582(0.104, 3.263)
24-48months before	28(40.0)	242(48.8)	0.490(0.280, 0.856)*	0.510(0.202, 1.286)
>48months Before	7(10)	78(15.7)	0.380(0.159, 0.907)*	0.345(0.098, 1.218)

* = Statistically significant

5.6- Health care giver and clinical setting conditions

Almost all 579 (98.8%) of the care givers felt they had good relation ship with health care givers, but care givers who had poor relationship had statistical significant association with non adherent [Adjusted OR=29.592(95%CI= 1.326, 660.333)].

Eighty eight (15.0%) of them reportedly have been practicing follow up every month, 310 (52.9%) every two months, 168(28.7%) of them every three months. Five hundred and thirty one (90.6%) respondents replied as they got integrated services in the facilities. Three hundred and three (51.7%) participants took less than 30minutes for drug refill. Two hundred and thirteen participants (36.3%) had less than 5birr transport cost to reach the treatment units (Table 3).

During group discussion, the majority of the respondents expressed the relationship with health professionals as quite good. Most of the health workers are cooperative and advise on a number of issues like adherence, regular follow up and nutrition. A small proportion however complained of frequent change of doctors and service rendered late usually at 9:00 A: M and beyond which has caused problem for them to go to work on time.

"Though the relationship is good, however; there is frequent change of doctors whenever we come to see them. It would have been good had one or two doctors had been assigned for us. There is incredibly long waiting time. If we arrive at late 9:00 A: M we are subjected to collect our medicine usually in the afternoon at about 1:00 P: M this subjects us for unnecessary expenses."

A 5years boy mother stated.

A substantial segment of the respondents suggested, assignment of same doctors for a reasonable period of time, separate waiting room, a small quarter playing ground for children equipped with simple entertainment means like toys. Leaving at home apparently healthy children during the time of medicine collection was also suggested.

"When the children are virtually healthy what is the importance for them to come out of school just to collect medicine? That could have actually been done by us the parents or care- takers alone."

A 12years boy mother suggested.

"I have the same feeling that if there is a way for them perhaps to be served on the weekends instead of them missing school."

A 9years girl ankle suggested.

A minority group also suggested the importance of having comprehensive health care free of charge for the children in particular and HIV/AIDs infected in general.

Table 3. The relationship of Health care giver and clinical setting conditions with adherence of the HAART receiving children in Addis Ababa, Ethiopia [N=586], May 2010

Variables	Non adherent (n, %)	Adherent (n, %)	Crude OR (95% CI)	Adjusted OR (95% CI)
Relationship with health workers				
Good	68(11.7)	511(88.3)	1.00	1.00
Not good	3(42.9)	4(57.1)	5.636(1.235, 25.722)*	29.592(1.326, 660.333)*
Do you get integrated services?				
Yes	64(12.1)	467(87.9)	1.00	
NO	7(12.7)	48(87.3)	1.064(0.462, 2.452)	
Drug refill time				
<30minutes	34(11.2)	269(88.8)	1.00	
30-59minutes	7(13.5)	45(86.5)	1.231(0.514, 2.945)	
60-90minutes	12(9.1)	120(90.9)	0.791(0.396, 1.581)	
>90minutes	18(18.2)	81(81.8)	1.758(0.943, 3.278)	
How frequent child visit Health care provider?				
Every month	17(16.7)	85(83.3)	1.00	1.00
Every two month	29(9.2)	285(90.8)	0.509(0.267, 0.971)*	0.682(0.259, 1.796)
Every three month	25(14.7)	145(83.3)	0.862 (0.440, 1.688)	0.646(0.199, 2.096)
Transport cost				
<5 Birr	30(14.1)	183(85.9)	1.00	
5-9Birr	25(12.4)	177(87.6)	0.862(0.478, 1.523)	
9-15Birr	13(10.2)	155(89.8)	0.690(0.345, 1.377)	
>15Birr	3(7.0)	40(93.0)	0.458(0.133, 1.573)	

Adjusted for variables: marital status of care giver, did the child get sick before treatment started, when does child started treatment, relationship with health workers, how frequent child visit Health care provider, types of parents the children have, responsible person for child's drug administration when primary care giver away, number of child siblings, do you communicate with the child about HIV and ART adherence, Who is died.

5.7 Relationship of parental conditions with children's HAART adherence

As shown in the table 4, after controlling for other variables, children who had non biological parents were significantly associated with non adherent than who had biological parents [Adjusted OR=9.805 ((95% CI= 2.198, 43.736)]. Over all 297 (50.8%) of primary care givers of children were their biological mothers, 159(27.2%) were relatives, 66(11.3%) their fathers.

About 441 (55.8%) parents did not communicate at all with their children about HIV/AIDS and ART adherence. Children where their parents didn't communicate about HIV and ART adherence to their children had significant association with non adherent than those communicated [Adjusted OR=3.915 (95%CI= 1.273, 12.036)].

From the total children, 153 (43.6%) lost their both parents by death, 111 (31.6%) lost their fathers, 87(24.8%) lost their mothers. Death of both parents and their mothers were higher proportion in non adherent when compared to children with death of fathers (57.8% versus 13.3%) and (28.9% versus 13.3%) respectively. Knowledge of parents on HIV/AIDS and ART adherence hadn't significant association with adherence (Table 4).

During focus group discussion, majority of the respondents had explained the fact that they themselves are HIV positive and on treatment that helped them care properly and positively for the children undergoing treatment. About the same respondents also stated about the positive cooperation when both children are positive and taking medication during which time the elderly helping the younger to take medication regularly and on time even though the parents are away at work.

"The fact that I have two HIV positive sons already on treatment, one of them is elderly that helped a lot in terms of providing his younger brother with medicine while he takes for himself which actually contributes to a greater extent as far as adherence is concerned."
A mother of 10 years and 6years old boys' had explained.

" *I have two daughters on ART that helps them to adhere properly because I work in a shift bases so that they can take care of themselves as far as taking medicine is concerned it was difficult to give the treatment by me timely."*
A mother of 10years and 8years girls stated.

A small segment of the respondents expressed lack of awareness as reflected by misapprehension of spiritual holy water to cure and shortage of food resulted in family negligence with the resultant poor adherence.

"My mother is completely against me and my son taking medicine. She is very much into holy water and other traditional options. I and my son used to miss some doses as she used to hide the medicines but now I am on my own and hence I and my son are strictly sticking to medication."
A mother of 7years girl mother stated.
A very minority group had unveiled the effect HIV/AIDS brought about in terms of the number of deaths within the same family that led to psychological trauma and despair resulting in failure to properly take care of the children as manifested by poor adherence.

"Our family is overwhelmed with HIV. I myself am HIV infected, my husband deceased because of HIV and my sister is positive as well. Our family is infected and affected by HIV more than any one I would say and this led to a bit of despair that resulted in less optimal care of the child."

A five year male child mother explained.

Table 4 Relationship of parental conditions and HAART adherence of children on HAART in Addis Ababa, Ethiopia [N=586], May 2010

Variables	Non adherent (n, %)	Adherent (n, %)	Crude OR (95% CI)	Adjusted OR (95% CI)
Types of parents the children have				
Biological parents	32(45.1)	334(64.9)	1.00	1.00
Non biological parents	39(54.9)	18(35.1)	2.249(1.362, 3.712)*	9.805 (2.198, 43.736)*
Marital status of care giver				
Single	13(18.3)	71(13.8)	1.00	1.00
Married	39(54.9)	253(49.1)	0.842(0.426, 1.663)	0.468(0.181, 1.211)
Divorced	5(7.0)	42(8.2)	0.650(0.216, 1.953)	0.158(0,011, 2.318)
Separated	5(7.0)	8(1.6)	3.413(0.964, 12.084)	0.448(0.043, 4.616)
Widowed	9(12.7)	141(27.4)	0.349(0.142, 0.885)*	0.356(0.101, 1.255)
Responsible person for child's drug administration when primary care giver away				
The child	20(14.6)	117(85.4)	3.9073(0.873, 10.781)	
From the family	41(11.5)	317(88.5)	2.325(6.696, 7.772)	
House maid	1(6.7)	14(93.3)	1.285(0.124, 13.305)	
Neighbor	6(31.6)	13(68.4)	8.298(1.830, 37.636)*	
Health worker	3(5.3)	54(94.7)	1.00	
Do you communicate with the child about HIV and ART adherence?				
Yes	7(5.0)	133(95.0)	1.00	1.00
No	64(14.3)	382(85.7)	3.178(1.422, 7.104)*	3.915(1.273, 12.036)*

Cont'd

Who is died?				
Fathers died	6(13.3)	105(34.3)	1.00	1.00
Mothers died	13(28.9)	74(24.2)	3.071(1.11, 8.447)*	1.958(0.415, 9.234)
Both died	26(57.8)	127(41.5)	3.579(1.420, 9.019)*	0.526(0.101, 2.744)
Knowledge of HIV and ART adherence				
Good knowledge	32(12.9)	216(87.1)	1.00	
Poor knowledge	39(11.5)	299(88.5)	0.880(0.534, 1.450)	

5.8 Encouraging factors to give the child medicine timely in the face of challenges

A significant portion of the respondents mentioned the positive drastic change (dramatic improvement in health) encouraged them to carry on treatment nearly as it should be while a small fraction of them mentioned fear of going back to ill health and optimistic view that at some point in the future there might be new developments that could radically cure HIV/AIDS as encouraging factors. A very minority stated that complying with treatment prevents opportunistic infection.

"As a matter fact I decided to give him treatment one year after the doctors advised me. Even though he was put on treatment one year later, I witnessed a dramatic change in terms of weight gain, improved appetite and positive mind set up. Before it was unthinkable for him to play with peer friends and was physically weak but nowadays he is quite healthy and this has encouraged me to keep on adhering to treatment substantially."

A five year male child mother replied.

"Before he started the ART he suffered a lot. He even was affected by tuberculosis during which time he really was crippled by ill health but soon after he started HIV treatment he begun to improve significantly and has enjoyed a good health ever since. This gave me the morale and hopes to properly and timely give the medicine to my child. Right now he runs, jumps up and down. This really gives me emotional satisfaction and sense of relief."

A 10years boy mother stated.

"Many have lost their lives before the advent of ART but now thanks to God we are in a unique opportunity where we have effective drugs that prolong life and this motivates us quite a lot. I have also witnessed the fact that someone almost terminally ill and unable to walk by himself turned in to a complete and full state of health which enabled him to go to school to study."

A nine years boy mother suggested.

"I know what he went through. I am fearful and cognizant of the possibility that he would suffer again badly if discontinued. This encourages me to carry on as he has been relieved quite significantly ever since he has started treatment."

A father of 12years boy stated.

"We believe and hope that some time in the future something may come by that could radically cure HIV/AIDs and this motivates us to keep on giving medication."

A 7years of girl mother replied.

6. DISCUSION

This study tried to examine the rate of adherence, different factors related to adherence; like socio demographic, parental, social and environmental, Health care givers, clinical setting, medication related and clinical marker variables and the relationship of parental factor with adherence for HIV infected children on highly active antiretroviral therapy in Addis Ababa, Ethiopia. Adherence is challenging especially for children as their medication intake rely on parents may be biological or non biological: relatives, house maids, voluntaries, etc [7].

The study revealed adherence rate of 515(87.9%) with in the last seven days of the interview. In accordance with the earlier studies, a systemic review of pediatric adherence in low and middle income countries estimates of ART adherence ranged from 49% to 100%, with 76% articles reporting greater than 75% adherence rate [12] and a systemic review study in Spanish also revealed 50% to 80% [33]. Study in Addis Ababa had showed that 86.9% on HAART children were adherent to antiretroviral drugs for the past 7 days and 93% children were adherent for the past 3days before the interview [13]. The rate of reported adherence was higher than from Netherland cohort 47% reported taking all antiretroviral medication on time and according to dietary instructions [14], Botswana [56%] adherent by physician assessment and [54%] by self assessment [31], USA 70% full adherent [30] and similar rate from London and Malawi 72% adherent [32,19] but lower than from Addis Ababa 93.4% reported [29]. The Possible explanations for the greater adherence in our study might be as the majority of the child start ART recently, children were taking medication with a twice-daily dosing schedule and half of the drugs started fixed drug combination, and children and caregivers were given strict adherence counseling sessions before starting ART in the hospitals and majority of caregivers 216(87.1%) had a good knowledge of HIV/AIDS and ART adherence. The qualitative survey also revealed they were fearful and cognizant of the possibility that they would suffer again badly if discontinued and they motivated by their physical mental changes to the greatest extent.

Concerning the predictors of adherent in this study parental factors having non biological parents were statistically associated with non adherent similar studies showed in New York non biological care givers associated with non adherent [15]. Bivariate analysis of the study showed

widowed care givers were less likely to became none adherent but other studies revealed socio demography factors of care givers had no association with adherence [13, 29, 34].

Interestingly at the time primary care givers away when neighbors responsible for children drug in take were significantly associated with non adherent. In contrast with this study other study showed when children them selves were responsible for drug intake significantly associated with non adherence [16, 24, 29, 34].

Children who had poor communication with their parents about HIV/AIDS and ART adherence had statistically significant association with non adherence. Similar studies from USA showed worse parent child communication were strongly associated with non adherence [17] and study from Uganda also strong parent child relation associated with good adherence [21].

Number of child siblings also strongly associated with non adherence in this study having greater than 4 siblings had strong association with non adherence in this study. Similarly cohort study in USA revealed each additional child reported living in the household was associated with a 6% decrease in the odds of > or = 95% adherence. Possible explanation for this is the care givers with high number of children siblings might be responsible in taking care of large family got busy and neglected the child on treatment.

Care giver and health care provider relation had strong association with non adherence bad relation of children care givers and health care providers had statistically significance association with non adherence in this study similar study in New York examined Factors associated with the process leading to adherence were: changing attitudes towards HIV medication, finding the right health care provider, creating the right support system, getting control of life [34].

Parents knowledge on HIV/AIDS and ART adherence unlike many studies had no significant association with adherence in this study. In contrast to the study good care givers knowledge had significant association with good adherence [17, 34] and study from Belgium revealed adherent children care givers were found having good knowledge, motivation, and capacities evolved in a progressive way, related to individual stages of coping with human immunodeficiency virus (HIV) [18].

Disclosure of the HIV status to the child and others were not associated with adherent in the present study but study from Uganda revealed parents disclosure about HIV status of the child to the child were significantly associated with adherence [21] consistently another study from USA also showed that less disclosure to others were significantly associated with non adherence [17]. In contrary, Study from Addis also revealed that children who did not know their sero-status and children who were not aware of their caregiver's health problem were more likely to adhere than their counterparts [13] and another study from New York also showed that not disclosed to the child were associated with adherence [15]. Co-trimoxazole prophylaxis hadn’t significant association in the present study but study from Addis revealed that children who took co-trimoxazole medication/syrup besides ARVs were more likely became adherent.

7. STRENGTH AND LIMITATION OF THE STUDY

The limitation of this 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.
- ✓ 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 (only allows us to evaluate the association between adherence and other factors, rather than the variability and consistency of adherence over time).
- ✓ Caregivers might be prone to social desirability bias and recall bias.
- ✓ Caretakers of the child may respond inappropriately to the counselors as if they were the one in near by to them and might mask some important information pertaining to the adherence.
- ✓ Adherence classification cut off points may not be perfect in different set up to compare and contrast the finding.

The strength of the study

- ✓ Use of both qualitative and qualitative methods for triangulation
- ✓ Large sample size
- ✓ Inclusion of several sites and
- ✓ Inclusion of several variables

8. CONCLUSION

Form this research finding, it is concluded that adherence to HAART in children in Addis Ababa were 515(87.9%) in the past 7 days before interview.

The parental factors were strongly associated with non adherence to the prescribed medication; children who had non biological parents [Adjusted OR=9.805(95%CI= 2.198, 43.736)], parents who didn't communicate about HIV and ART adherence to their children [Adjusted OR=3.915 (95%CI= 1.273, 12.036)] and Children's care giver who hadn't good relationship with health professionals [Adjusted OR=29.592(95%CI= 1.326, 660.333)] were more likely became non adherent. Other variables like children who had more than four siblings had significantly associated with non adherent than those who hadn't siblings [Adjusted OR=5.676 (95% CI=2.100, 15.339)].

Socio demographic variables, disclosure status to the child and others, knowledge of parents about HIV/AIDS and ART adherence and Co-trimexazole prophylaxis hadn't significant association with adherent in the present study.

9. RECOMMENDATION

Our data suggest that efforts to improve children's adherence to complex antiretroviral regimens requires addressing family factors and to ensure adherence to life-extending medications, our findings also underscore the need for providers:

- To have smooth relation ship with the care givers of the HIV infected children on HAART.
- To support caregivers to communicate with their children about the disease and ART adherence provide on-going support and maintain open communication with HIV-infected children taking HAART.
- Further research is recommended to explore the validation of self report adherence using longitudinal study designs.

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ANNEX-ONE: ENGLISH STRUCTURED QUESTIONNNAIRE

Addis Ababa University, Faculty of Medicine, Department of Community Health

Assessment of Parental influence on pediatrics HAART adherence in Addis Ababa, Ethiopia.

1. Information sheet and Consent form

1.1 Information sheet

My name is_____. I represent the study team coordinated by the Department of Community Health, Faculty of Medicine, AAU and interview of caregivers of children on ART at _____service center to assess their children's adherence to the ARV drug and parental influence toward child's HAART adherence.

Back ground of the study: - Adherence to treatment is critical to obtain the full benefits of HAART; maximal and durable suppression of viral replication, prevention of viral resistance, promotion of immune reconstitution and slowed disease progression.

Objectives of the study: - To assess the rate of adherence in pediatrics receiving Highly Active Anti-retroviral Therapy, to determine the factors that affects adherence in pediatrics receiving Highly Active Anti-retroviral Therapy and to identify the relationship between parental factors and adherence in pediatrics receiving Highly Active Anti-retroviral Therapy.

Methodology of the study: - Institution based, cross sectional study in 9 selected public, private and NGO Health Institutions providing pediatrics antiretroviral therapy in Addis Ababa will be conducted. A total of 586 children aged 0-14year started Anti-retroviral therapy 12 weeks ago will be selected. Their primary care givers will participate in the study. Participants are randomly selected to be one of the participants in the study. A structured questionnaire will be used for data collection and data will be collected by interviewing and reviewing registration. The study will be conducted from September, 2009 – June, 2010. The data collection will be conducted for consecutive 3 months from Dec, 2009-Feb, 2010.

Benefits of the study: - Has no direct benefit right at the moment but in the long run it will help to fill the gap of knowledge about parental influence on Pediatrics HAART adherence and program design to improving children adherence on HAART. This will decrease drug resistance, decrease viral load, increase CD4 cells and decrease morbidity and mortality of children receiving HAART in Addis Ababa and others of a similar setting.

Disadvantages or Risk of the study: - There is no invasive procedure that can harm the child or the participant since data collection is by interview. The participant will spend 40-50minutes for the interview. They may have psychosocial discomfort for the participant and for the child knowing the child HIV sero-status by others. We will try to minimize this disadvantage by securing confidentiality.

Confidentiality: - Participant's name is not going to be registered and the information you give us should be kept confidential and will be used only for the study purpose and designing policies, strategies and programs; a code number will identify every participant and isolated room will be used for interview.

Freedom to withdrawal: - The interview is voluntary; you have the right to either participate or not, to interrupt and not to answer some questions you don't like to answer at any time during the course of the interview. Your refusal will not have any effect on services that you or any member of your family receives. However, your participation is important to fulfill the study and in order to help design appropriate intervention to increase adherence rate of children who are on HAART in Addis Ababa and other similar setups. It will take you 40-50 minutes to complete the whole questionnaire. Would you be willing to participate in the study?

Disagree ☐ **Agree** ☐

For further explanation contact the investigator at any time by the following address;

Name of the investigator Frie Hailu

Mobile: 0913224121

E-mail: hailufrie@yahoo.com

1.2 Consent Form

I have been informed in the language that I can understand about the study that aims to assess parents' influence on children's HAART adherence in Addis Ababa. I have been requested to participate in this study after I am fully informed about the entire study and agreed to act voluntarily. I have been informed that all information I will give to the data collector will be kept confidential and interview will be under taken in private room. I have understood the benefits of the study has no direct benefit right at the moment but in the long run will help the designing of program strategies for the improvement of children adherence. I also know that I have the right to skip questions that I don't want to respond and I can with draw from the study any time and no body will ask me to explain the reason of withdrawal. My withdrawal will not have effect on the services that I and my family will get.

I have read this consent form or has been read to me in the language I can understand the condition stated above and hereby agree to take part in the study.

Name of the participant _____

Signature _____

Interviewer name _____

Signature _____

Date of interview _____

Questionnaire for the Assessment of Parental influence on Pediatrics HAART adherence in Addis Ababa, Ethiopia.

Q1.Questionnaire identification number_____

Q 2. Pediatrics ART unit _____

Q 3. Respondent available on — First visit ☐

—Secondvisit ☐

Q 4. Result of interview: 1. Completed 2. Respondent not available

3. Refused 4. Partially completed

5. Others Specify_____

Interviewer name _____

Signature _____

Supervisor name _____

Signature _____

Time started_____ Time completed _____

Part one:- Socio-demographic characteristics

No.	Questions	Classification	Remark
101	What is age of the child?	----------(Age in complete year)	
102	What is sex of the child?	1.Male 2. Female	
103	What is the respondent's age?	----------(Age in complete year)	
104	What is the respondent's sex?	1.Male 2. Female	
105	What is the respondent's ethnicity?	1. Amhara 2. Oromo 3. Gurage 4. Tigray 5. Don't know 66. Other(specify)	

106	What is the respondent's current marital status?	1. Single 2. Married 3. Divorced 4. Separated 5. Widowed 66. Other(specify)	
107	What is the respondent's religion?	1. Orthodox 3. Protestant 2. Muslim 4. Catholic 66. Other (Specify)	
108	What is the respondent's educational status?	1. Unable to read and write 2. Able to read and write 3. Primary (1-8) 4. secondary(9-12) 5.Diploma and above	
109	What is the respondent's occupation?	1. Merchant 6. NGO employee 2. House wife 3. Student 7. Daily laborer 4. Government employee 66. Other 5.Private employee (Specify)	
110	How much is family's monthly income (ETB)?	----------	
111	How many family member respondent's have?	----------	
112	What is the educational status of a child?	1. ---------- 2. He didn't learn 66. Others (Specify)	If 2 skip to114
113	What was child's last year rank in the class?	1. ---------- 2. Don't know 66. Others (specify)	

Part two: Parental factors

201	What types of parents the child has?	1. Biological parent 2. Non biological parent	
202	What is the living arrangement of the child?	1. With both parents 2. With mother 3. With father 4. With neither parents	If 1,2,3 skip to 204
203	With whom the child lives?	1.With relatives 2. Adoptive 3. Foster care institution 4. Lonely 66. Other (specify)----------	
204	Who is primary care giver of the child?	1. Father 2. Mother 3. Relatives 4. Adoptive parent 5. Foster care parent 6. House maid 7. Neighbor 8. Health workers 66. Other(specify)----------	
205	When the primary care giver moves away who is responsible for medication intake?	1. The child 2. From the family 3. House maid 4. Neighbor 5. Health workers 66. Others specify----------	
206	Is the sero status of parents known by the child?	1. Yes 2. No 66. Others (specify	
207	How many siblings have the child?	1. _____ 2. Not known 66. Others (specify)	

208	What is HIV status of child siblings?	1. Negative 2. 1 3. 2 4. 3 66. Others (specify)	
209	Do you communicate with the child about HIV and ART adherence?	1- Yes 2- No 66. Others (specify)	
210	Are the child's both parents alive?	1. Yes 2. No 66. Others (specify)	If yes skip to 301
211	Who is died?	1. Mother died 2. Father died 3. Both died	

Part three: Social variables

No	**Question**	**Classification**	**Remark**
301	Does the child knows his/her HIV sero status?	1. Yes 2. No 66. Do not know 67. Others (specify)	
302	Was the child HIV sero status disclosed to others?	1. Yes 2. No 66. Others (specify)	If response is no skip to 304
303	For whom it is disclosed?	1. Family 2. Friends 3. Organization 4. Community 66. Other(specify)-------	

304	Does the child get any kind of support?	1. yes 2. No 66. Other(specify)-------	If response is no skip to 401
305	Who supports the child? Can answer more than one answer.	1. Family 4. Community 2. Friends 5. Organization 3. Peer 66. Other (specify)	
306	What types of supports did the child get from supporters? Can answer more than one answer.	1.Financial Support 2. Care & Emotion 3. Food 4. In remedies of medication 66. Other (specify)	
307	Did the child get food support from the health facility?	1. Yes 2. No 66. Other (specify)	
308	Did the child get sick before treatment started?	1. Yes 2. No 66. Other (specify)	
309	Is he currently sick?	1. Yes 2. No 66. Other (specify)	

Part four: Knowledge about HAART and adherence

Please tick only one box that best describes respondents feeling.

No.	Questions	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know
		1	**2**	**3**	**4**	**5**	**6**
401	Taking ART drugs as prescribed prevent drug resistance.						
402	When one takes ART, the daily doses should not escape.						
403	ART will delay AIDS.						
404	A person taking ART will not be cured from AIDS.						
405	When taking ART, an HIV-infected will live longer than when it is no.						
406	All HIV- infected people can not take ART any time they want.						
407	Only when the body's defense system extreme low (Very low WBC) is a person entitled to receive ART.						
408	When one takes ART, has to take at specific time.						
409	Child should take pills the rest of his / her life to delay AIDS.						
410	I feel comfortable when child taking ART in front of others.						

Part five: Patient/care giver-health care provider relationship and Clinical setting variables

No	Questions	Classification	
501	What types of interaction (relationships) do you have with the health care provider?	1. good 2. not good 66. Other (specify)	
502	Do you have open communication with health care provider?	1. Yes 2. No 66. Other (specify)	
503	How frequent do you visit for the child's health care provider?	1. Every 2 weeks 2. Every month 3. Every 2 month 4. Every 3 month 5. As I want 66. Other (specify)	
504	Do you get integrated services during your visit?	1. Yes 2. No 66. Other (specify)	
505	What time did you wait to refill the drug? By minute	1.---------- 2. don't know 66. Other (specify)	
506	How money birr do you expend for transportation to reach the Health Facility?	**1.**---------- 2. don't know	

		66. Other (specify)	

Part six Pediatrics adherence assessments

Q. 601. Are to be completed by the study nurse

Complete prior to the interview				Complete during the interview				
S.no	Drug names	Drug type syrup/pill	Expected number of doses per 24 hours (1,2,3,4)	Reported number of doses per 24hours (1,2,3,4)	Doses missed			
					Yesterday	2 days ago	3days ago	7 days ago
1								
2								
3								

No.	Questions	Classification	Remark
602	When was the last time child missed a dose of any of these medications?	1-Never 2-During the previous 2 weeks 3. During the last month 4-Over a month ago 5-Don't remember 66- Others (specify)	If Never, go to question 604.
603	What are the reasons, problems or situations 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 stocked out 5. Child slept 6. I thought the drug had no value 7. Transport problem 8. Confused about the dosage 9. Were too busy 10. being away from home 11. Too many pills to take	

		. 66. Others (specify)--------	
604	What reminder use to give the child's medication?	1. Hand watch 2. Wall watch 3. Watch bell 4. Tablet box 5. Family remember 66. Other(specify)----------	
605	When a child did start treatment (ART)?	1.---------- 2. don't know 66. Other(specify)----------	
606	Are you convinced to start the treatment before the Child starts ART?	1.Yes 2 No 66. Other(specify)----------	
607	Is a child take any others medication now with ART?	1. Yes 2. No 66. Other(specify)----------	If 2 skip to 701
608	What are the medications?	----------	

Part seven: Clinical markers

Are to be completed by the study nurse

701	The stage of the disease when he/she started treatment	1. Stage I 2. Stage II 3. Stage III 4. Stage IV	
702	The current stage of the disease	1. Stage I 3. Stage III 2. Stage II 4. Stage IV	
703	CD4 count when the child started treatment	----------	
704	Current CD4 count	----------	

11.1. English Focus Group Discussion Guide

Addis Ababa University, Faculty of medicine, Department of community health.

Assessment of Parental influence on pediatrics HAART adherence in Addis Ababa, Ethiopia.

My name is ----------and I come from Addis Ababa University, Faculty of medicine, School of Public Health. We are here to discuss about antiretroviral drug adherence among children. This is voluntary based discussion. There is no right and wrong answer. All comments, positive and negative, are all welcome. We would like to have many points of view. I would like this to be open discussion, so feel free to express your opinion honestly and openly. In order not to miss any points in this discussion, I will use a tape recorder. I will like to confirm you that all your comments are confidential and used for research purpose only. Your name will not be recorded to keep its confidentiality.

Thank you for your willingness; and these will be the questions:

1. Doses missed in the last seven days and before?

2. What are the reasons, problems or situations that make difficult to give a child each dose of medication every day?

3. What things reinforce you to give the child medicine timely in the face of challenges?
4. How Family influences on child medication adherence?
5. Do you disclose the HIV status of the child to the child and others? Why? Why not?

6. How is your Relationship with health professionals and quality of service?

7. Suggest solutions from service user's perspective?

ANNEX TWO:- የአማርኛ መጠይቅ ክፍል ሁለት

1. የጥናቱ መረጃና የውል ስምምነት

1.1 የጥናቱ መረጃ

አዲስ አበባ ዩኒበርሲቲ የህክምና ፋካልቲ የህብረተሰብ ጤና ክፍል

በአዲስ አበባ ህፃናት ኤች አይቪ መድሀኒት ክትትል እና የቤተሰብ ተፅእኖ ስላለ ችግሮች በተመለከተ ለሚደረግ የዳሰሳ ጥናት የቀረበ መጠይቅ

ስሜ ፡- _____ ይባላል፡፡

እኔ የአዲስ አበባ ዩንቨርስቲ ሕክምና ፋካልቲ የጤና አጠባበቅ ክፍል ወክዬ እዚህ የተገኘሁት የሕፃናትን ተንከባካቢዎች የፀረ ኤች አይቪ ኤድስ መድሐኒት በመውሰድ ላይ ያሉ ከ _____ _____ ጤና ጣቢያ ፣ሆስፒታል፣ ክሊኒክ

የቤትሰብ ተፅእኖ የሕፃናት የፀረ ኤች አይቪ መድሐኒት በታዘዘው መሠረት ላለመውሰድ የሚዳርጉትን ምክንያቶች ለማወቅ የተደረገ ጥናት ነው፡፡

መግቢያ ፡- የፀረ ኤች አይቪ መድሐኒትን ጥቅም ለማግኘት መድሐኒቱን በታዘዘው መሠረት መውሰድ ግዴታ ነው፡፡ ይህ ደግሞ ቫይረሱን ይቀንሳል ፣መድሐኒቱ ከቫይረሱ ጋር እንዳይላመድ እና የማዳን አቅሙን እንዳይቀንስ ያደርጋል፣ የሰውነት የመካላከያ አቅምን ይጨምራል፣ በሽታው እንዳይባባስ ያደርጋል፡፡

የጥናቱ ዓላማ፡- ምን ያህል ልጆች መድሐኒቱን በታዘዘው መሠረት እየወሰዱ እንደሆነ ለማወቅ ፣መድሐኒትን በታዘዘው መሠረት እንዳይወስዱ የሚያደርጋቸውን ተፅኖዎች ለማወቅ ፣የቤተሰብ ተፅኖ መድሐኒቲን በታዘዘው መሠረት እንዳይወስዱ የሚያደርጋቸውን ተፅኖ ለማወቅ ፡፡

የጥናቱ አካሄድ፡- በጤና ተቋማት የደሰሳ ጥናት በ9 የጤና ተቋማት በመንግስት ፣ በግል እና በመንግስታዊ ያልሆነ ድርጅት የሕፃናት የፀረ ኤች አይቪ መድሐኒት በመስጠት ላይ የሚገኙ የጤና ተቋማት ውስጥ በ 586 ሕፃናት እድሜአቸው በ 0-14 የሆኑ መድሐኒቱን ከጀመሩ ከ 3 ወር በላይ የሆናቸውን ሕፃናት ተንከባካቢዎች በእጣ ሳይንሳዊ በሆነ መንገድ የመረጣሉ፡፡ በተዘጋጀ መጠየቅ በቃለ መጠየቅ እና ከመዝገብ በሚገኙ መረጃዎች መረጃ ይሰበሰባል፡፡ ጥናቱ

የሚካሄደው ከመስከረም 2002 ዓ.ም እስከ ሰኔ 2002 ዓ.ም ሲሆን መጠየቁ የሚካሄደው ለ 3 ወር ከታሕሳስ 2002 እስከ የካቲት 2002 ዓ.ም ነው።።

<u>የጥናቱ ጥቅም</u>፡- በአሮጮር ጌዜ በአሁኑ ሰዓት ምንም ጥቅም የለውም ነገረ ግን ጥናቱ ካለቀ በኋላ የሕፃናት የፀረ ኤች አይቪ መድሐኒት እንዳይወስዱ የሚያደረጉትን ችግሮች ለማወቅ ይረዳል፣ ፖሊሲ ፣ እስትራቴጂ፣ ፕሮግራሞች ለመቅረፅ የሕፃናት የፀረ ኤች አይቪ አወሳሰድ በታዘዘው መሠረት እንዳይወስዱ የሚያደርጉትን ችግሮች ለማሻሻል ይረዳል።። ይህ ደግሞ መድሐኒቱ እንዳይላመድ ቫይረሱ እንዲቀንስ ፣ የሰውነት የመከላከያ ሐይል እንዳጨምር እና ሕመምን እና ሞትን ለመቀነስ በአዲስ አበባ እና በተመሳሳይ አገሮች ሕክምናውን ለሚወስዱ ሕፃናት ይረዳል።።

<u>የጥናቱ ጉዳት</u> ፡- ሕፃኑን የሚጎዳ ወይም ተጠያቂውን የሚጎዳ ስልት አንጠቀምም፣ መረጃ የሚሰበሰበው በቃለ መጠየቅ ነው።። ነገር ግን የተጠያቂውን ጊዜ ከ 40 እስከ 50 ደቂቃ ሊወስድ ይችላል።። የሥነ ልቦና ጫና ችግር ሊያመጣ ይችላል የሕፃኑ የኤች አይቪ ውጤት በሌላ ወገን በመታወቁ ነገር ግን ይህንን ጫና ለመቀነስ የተጠቀምንባቸው የሚስጥር አጠባበቅ ዘዴዎች አሉን ።።

<u>ሚስጥር መጠበቅ</u>፡ - የተጠያቂው ስም ሆነ የሕፃኑ ስም አይመዘገብም፣ የሚሰጡን መረጃ በሙሉ በሚስጥር የተጠበቀ ነው።። የሚጠቅመውም ለጥናት ብቻ ነው።። የኮድ ቁጥር ብቻ ነው የሚመዘገበው ።። በተለየ ክፍል ነው መጠየቁ የሚካሄደው ።።

<u>ጥናቱን የማቋረጥ መብት</u>፡- በጥናቱ ለመሳተፍ በፈቃደኝነት ነው ።። ምንም እንኳን የእርሶዎ ተሳትፎ ለዚህ የሕፃናት የፀረ ኤች አይቪ አወሳሰድ ላይ ለሚደረጉ ፖሊሲዎች፣እስትራቴጂዎች ፕሮግራሞች ጠቃሚ ቢሆንም በጥናቱ መሳተፍ ወይም አለመሳተፍ ወይም ማቋረጥ እና የማይፈልጉትን ጥያቄ አለመመለስ መብትዎት ነው።። ባለመሳተፍዎት እርሶዎ ወይም ቤተሰቦችዎ የሚያገኙት የጤና አገልግሎት ላይ ምንም ለውጥ አይኖርም ።። ከ 40 እስከ 50 ደቂቃ መጠየቁ የወስድቦታል ለመሳተፍ ፍቃደኛ ነዎት?

እስማማለሁ ☐ አልስማማም ☐

ለበለጠ መረጃ የአጥኝው አድራሻ

የአጥኚው ስም፡- ፍሬ ሀይሉ

ስልክ ቁጥር፡- 0913 22 41 21

ኢሜል ፡- hailufrie@yahoo.com

1፡2 **የውል ስምምነት**

እኔ በሚገባኝ ቋንቋ አላማውን የቤተሰብ ተዕእኖ በሕፃናት የፀረ ኤች አይቪ አወሳሰድ ላይ ያለውን ተዕእኖ ለማወቅ የተደረገውን የደሰሳ ጥናት ተነግሮኝ በፈቃደኝነት እንድስማማ የተጠየኩ ሲሆን የተነገረኝም ሁሉም እኔ የምስጠውን መረጃ በሚስጥር የተጠበቀ መሆኑን፤ መጠየቁ የሚካሄደው በተለየ ክፍል እንደሆነ ፤ የጥናቱ ጥቅም አሁን በቀጥታ የማገኘው ጥቅም እንደሌለ እና ጥናቱ ካለቀ በኋላ ግን ለሌሎች ጥናት መነሻ እንደሚሆን ፤ የሕፃናት የፀረ ኤች አይቪ አወሳሰድ ለማሻሻል ፖሊሲዎች ፣ፕሮግራሞች ለመቅረፅ እንደሚጠቅም ተረድቼአለሁ፡፡ከጥናቱ ማቋረጥ ፣አለመሳተፍ፣ የማልፈልጋቸውን ጥያቄዎች አለመመለስ ፤ መብት እንዳለኝ እና ምክንያቱንም እንደማልጠየቅ እኔም ሆነ ቤተሰቤ የምናገኘውን የጤና አገልግሎት ላይ ምንም ለውጥ እንደማይኖር ተነግሮኛል፡፡

እኔ የውል ስምምነቱን አንብቤ ወይም በምችለው ቋንቋ ተነግሮኝ በጥናቱ ለመሳተፍ ተስማምቼአለሁ፡፡

የተሳታፊ ስም _____

ፊርማ _____

የመረጀ ሰብሳቢ ስም _____

ፊርማ _____

የመጠይቁ ቀን _____

መጠይቅ

የመጠየቁ መለያ ቁጥር ----------

የጤና ተቋሙ ስም ----------

ተሳታፊው የተገኘው በመጀመሪያ የጉብኝት ወቅት ----------

በሁለተኛ የጉበኝት ወቅት ----------

<u>ውጤት</u>

ለመጠየቁ ምላሽ የሰጡ ----------

ያልተገኙ ----------

ምላሽ መስጠት ያልፈለጉ----------

ሌላ ካለ ይገለፅ ----------

የመጀመሪያ ሰብሳቢ ስም ----------

ፊርማ ----------

የሱፐርቫይዘሩ ስም ----------

ፊርማ ----------

መጠየቁ የተሞላበት ቀን ----------

መጠየቁ የጀመረበት ሰዓት ---------- /ያበቃበት ሰዓት/ ----------

መጠየቁ ---------- ደቂቃ አካባቢ ይፈጃል

<u>የክፍል አንድ አጠቃላይ የግለሰቡ መረጃ</u>

ተ.ቁ	መጠይቅ	መልስ	ምልክት
101	የህፃኑ/ኗ ያለፈው የልደት ቀን ስንት ዓመት ነበር?	----------	
102	የህፃኑ/ኗ ፆታ ምንድን ነው ?	1- <u>ወንድ</u> 2- <u>ሴት</u>	
103	የተጠያቂ ያለፈው የልደት ቀን ስንት ዓመት ነበር?	----------	
104	የተጠያቂ ፆታ ምንድን ነው ?	1- ወንድ 2- ሴት	
105	የየትኛው ብሔረሰብ አካል ኖዎት?	1- አማራ 2- ኦሮሞ 3- ጉራጌ 4- ትግራይ 5- አላውቅም	

		66. ሌላ የጠቀስ----------	
106	የተጠያቂ የትዳር ሆኔታ ምንድን ነው ?	1- ያላገባ/ች 2- ባለትዳር 3- የፈታ/ች 4- የተለያዩ 5- ባል/ሚስት የሞተችበት/ባት 66. ሌላ ይጠቀስ----------	
107	የተጠያቂው ሃይማኖት ምንድን ነው ?	1- ኦርቶዶክስ 2- ሙስሊም 3- ፕሮቴስታንት 4- ካቶሊክ 66. ሌላ ካለ ይጥቀሱ ---- ----------	
108	የተጠያቂው የትምህርት ደረጃ ስንት ነው?	1- ማንበብና መፃፍ የማይችል 2- ማንበብና መፃፍ የሚችል 3- ከ1-8ኛ ክፍል 4- ከ 9-12 ክፍል 5- ዲፕሎማና ከዚያ በላይ	
109	ተጠያቂው በምን አይነት የሥራ ሆኔታ ላይ ይገኛሉ?	1- ነጋዴ 2- የቤት እመቤት 3- ተማሪ 4- የመንግስት ቅጥርኛ 5- የግል ተቀጣሪ 6- መንግስታዊ ያልሆነ ድርጅት 66. ሌላ ካለ ይጥቀሱ ---- ---------- --	
110	የቤተሰቡ የወር ገቢ በብር ስንት ነው?	----------	
111	የተጠያቂው የቤተሰብ ስንት ነው?	----------	
112	የህፃኑ የትምህርት ደረጃ ስንተኛ ክፍል ነው?	1. ---------- 2. አይማርም 66. ሌላ ይጥቀሱ---------- ------	መልሱ 2 ከሆነ ወደ 114 ይለፉ
113	የህፃኑ የባለፈው ዓመት የውጤት ደረጃው ስንት ነው?	1.---------- 2. አላውቅም	

		66. ሌላ ይጥቀሱ----------	

<u>ክፍል ሁለት የህፃኑ የቤተሰብ ሆኔታ</u>

201	ህፃኑ ምን አይነት ቤተሰባዊ ሁኔታ አለው ?	1. ወላጆቹ እውነተኛ 2. ያልወለዱት/አሳዳጊ	
.202	ህፃኑ የሚኖረው ከማን ጋር ነው?	1.ከአባትና እናቱ 2.ከእናቱ ብቻ 3.ከአባት ብቻ 4.ከአባትእና ከእናት ውጪ	መልሱ 1,2,3, ከሆነ ወደ 204 ይለፉ
203	ከአባትና ከእናት ወጭ ከሆነ ያለው የቤተሰብ ግንኙነት ምንድን ነው?	1. የስጋ ዘመዶቹ 2.. የጉዲፈቻ አሳዳጊ 3. አሳዳጊ ድርጅት 4. ብቻውን 66. ሌላ ይጠቀስ----------	
204	በየቀኑ የፀረ ኤች አይቪ መድሃኒቱን ለህፃኑ የሚሰጥ ማን ነው?	1. አባት 2.እናት 3. የስጋ ዘመዶቹ 4. የጉዲፈቻ አሳዳጊ 5. አሳዳጊ ድርጅት 6. ሰራተኛ 7. ጎረቤት 8. ሐኪም 66. ሌላ ይጥቀሱ ----------	
205	ሁልጊዜመድሃኒቱንበየቀኑ የሚሰጠው ሰው በሌለ ጊዜ መድሃኒቱን የሚሰጠው ማነው?	1.ህፃኑ 2. ከቤተሰቡውስጥ 3. ሰራተኛ 4. ጎረቤት 5. ሐኪም 66. ሌላ ይጥቀሱ----------	
206	ህፃኑ የቤተሰቡን የኤች አይ ቪ የደም ውጤት ያውቃል?	1. ያውቃል 2. አያውቅም 66. ሌላ ይጥቀሱ	
207	ህፃኑ ሰንት ወድንሞችና እህቶች አሉት?	1. ---------- 2. አልታወቀም 66. ሌላ ይጥቀሱ----------	
208	ሰንት የህፃኑ ወንድሞቹና እህቶቹ የኤች አይ ቪ የደም ወጤታቸው ፖይረሱ በደማቸው አለ?	1. ፖይረሱ በደማቸው የለም 2. 1 3. 2 4. 3 66. ሌላ ይጥቀሱ----------	

209	ስለ ፀረ ኤች አይቪ መድሃኒት እና ስለ ኤች አይቪ በሽታ ከህፃኑ ጋ ይወያያሉ ወይ?	1. አዎ 2. አንወያይም 66. ሌላ ይጥቀሱ----------	

210	ሁለቱም የህፃኑ ወላጆች በሂወት አሉ ወይ?	1. አሉ 2. የሉም 66. ሌላ ይጥቀሱ----------	መልሱ1 ከሆነ ወደ ጥያቄ ቁጥር 301 ይለፉ
211	በሕይወት የሌለው ማነው?	1. አባት 2. እናት 3. አባትና እናት	

<u>ክፍል ሦስት፡- የህፃኑ ማህበራዊና አካባቢ ሁኔታዎች</u>

ተ.ቁ	መጠይቅ	መልስ	ምልክት
301	ህፃኑ ኤችአይቪ ውጤቱን ያውቃል ወይ?	1. ያውቃል 2. አያውቅም 66. አላውቅም 67. ሌላ ይጥቀሱ----------	
302	የህፃኑን የደም ውጤቱ ለሌሎች ሰዎች ተናግረዋል ወይ?	1. አዎ 2. አልተናገርኩም 66. ሌላይጥቀሱ----------	2 ከሆነ ወደ ቁጥር 304 ይለፉ
303	ለማን ነው የተናገሩት የህፃኑን የደሙን ውጤት?	1. ለቤተሰብ 2. ለጓደኛ 3. ለእርዳታ ድርጅት 4. ለህብረተሰብ 66. ሌላ ይጥቀሱ----------	
304	የሚያገኙት እርዳታ አለ ወይ?	1. አዎ 2. የለም 66. ሌላ ይጥቀሱ----------	2 ከሆነ ወደ ጥያቄ 307 ይለፉ
305	ማነው ህፃኑን የሚረዳው? ከአንድ በላይ መልስ ይሙሉ	1. ቤተሰብ 2. ጓደኛ 3. የህፃኑ ጓደኛ 4. ህብረተሰብ 5. የእርዳታ ድርጅት 66. ሌላ ይጠቀስ----------	

306	ምን አይነት እርዳታ ነው ህፃኑ የሚያገኘው? ከአንድ በላይ መልሰ ይሙሉ	1. በገንዘብ 2. የሀሣብ ድጋፍና እንክብካቤ 3. የምግብ 4. የመድሀኒት 66. ሌላ ይጠቀስ----------	
307	ህፃኑ በጤና ተቻሙ ውስጥ የምግብ እርዳታ ያገኛል ወይ?	1. አዎ 2. የለም 66. ሌላ ይጠቀስ----------	
308	ህፃኑ መድሃኒቱን ከመጀመሩ በፊት በተደጋጋሚ ይታመም ነበር ወይ?	1. አዎ 2. አይታመምም ነበር 66. ሌላ ይጠቀስ----------	
309	አጉንስ በተደጋጋሚ ይታመማል ወይ?	1. አዎ 2. አይታመምም 66. ሌላ ይጠቀስ----------	

ክፍል አራት፡- ስለ መድሀኒት ያላቸውን እውቀት ደሰሳ ከዚህ በታች ስለ ኤችኤይቪ መድሀኒት ጥያቄዎች አሉ ስሜቴን ይገልጻል የሚሉትን ብቻ ምልክት ያድርጉ

ተ.ቁ	መጠይቅ	በጣም አልስማማም	አልስማማም	አልወግንም	እስማማለሁ	በጣም እስማማለሁ	አላውቅም
		1	2	3	4	5	6
401	ህፃኑ መድሃኒቱን በታዘዘው መሰረት ሳይወስድ ቢቀር በሽታው ከመድሀኒቱ ጋር ሊላመድ ይችላል						
402	መድሀኒቱን ጊዜ ማሳለፍ አይቻልም						
403	መድሀኒቱ የኤድስ በሽታን ያዘገያል ወይም በሽታው ቶሎ እንዳይታይ ያደርጋል						
404	መድሀኒቱ ከኤድስ ፍጹም አያድንም						
405	መድሀኒቱን የወሰደ ሰው እድሜው ይረዝማል						
406	ሁሉም ኤች አይ ቪ የያዛቸው						

	ሰዎች በማንኛውም ጊዜ መድሀኒቱን መጀመር አይችሉም						
407	የሰውነት የመከላከያ ሀይል ሲደክም ብቻ ነው የሚጀመረው						
408	መድሀኒቱ ሲወሰድ በሰዓቱ መወሰድ አለበት						
409	ህፃኑ ለተቀረው እድሜው መድሀኒቱን ይወስዳል						
410	መድሀኒቱን በሰው ፊት ሲውጥ ምቾት ይሰማኛል ወይም አልፈራም						

ክፍል አምስት፡- ከጤና ባለሙያ ጋር ያላቸው ግንኙነት ደሰሳ እና የጤና ተቋሙ ሁኔታ

ተ.ቁ	መጠይቅ	መልስ	ምልክት
501	ከጤና ባለሙያ ጋር ያሎት ግንኙነት ምን ይመስላል?	1. ጥሩ 2. ጥሩ ያልሆነ 66. ሌላ ይጥቀሱ----------	
502	ከጤና ባለሙያ ጋር ግልፅ የሆነ ውይይት ታደርጋላች ወይ?	1. አዎ 2. አናደርግም 66. ሌላ ይጥቀሱ----------	
503	በምን ያህል ጊዜ ሐኪምዎን ይጐበኙታል?	1. በሁለት ሳምንት 2. በየወሩ 3. በየሁለት ወሩ 4. በየሶስት ወሩ 5. በፈለኩት ጊዜ 66. ሌላ ይጠቀስ----------	
504	የተሟፈልጉትን ሌሎች ተጉዳኝ አገልግሎቶች ያገኛሉ ወይ?	1. አዎ 2. አይደለም 66. ሌላ ይጥቀሱ	
505	የህፃኑን መድሀኒት ጨርሰው ለመውሰድ ስንት ጊዜ ይወስድብዎታል? በደቂቃ	1._____ 2. አልታወቀም 66. ሌላ ይጥቀሱ----------	
506	ወደ ጤና ተቓሙ ለመድረስ ስንት ብር ያወጣሉ?	1.---------- 2. አልታወቀም 66. ሌላ ይጥቀሱ----------.	

ክፍል ስድስት፡- የህፃናት መድሀኒት አወሳሰድ ደሰሳ

601. በመረጃ ሰብሳቢ የሚሞላ ሰንጠረዥ

ከመጠይቁ በፊት የሚሞላ				በመጠይቁ ጊዜ የሚሞላ				
ተ.ቁ	የመድሃኒቱ ስም	የመድሃኒቱ ዓይነት በሽሮፕ በኪኒና	በ24ሰአት የሚወሰደው የጊዜ ብዛት በባለሙያ የሚሞላ (!፣2፣3፣4)	በ24ሰአት የሚወሰደው የጊዜ ብዛት በተጠያቂ የሚሞላ (!፣2፣3፣4)	መድሃኒቱ ሳይወሰድ የቀረ ጊዜ			
					ትላንትና ለስንት ጊዜ ሳይወስድ ቀረ?	ከ2ቀን በፊት ለስንት ጊዜ ሳይወስድ ቀረ?	ከ3ቀን በፊት ለስንት ጊዜ ሳይወስድ ቀረ?	ከ7ቀን በፊት ለስን ጊዜ ሳይወስድ ቀረ?
1								
2								
3								

ተ.ቁ	መጠይቅ	መልስ	ምልክት
602	ህፃኑ መድሃኒቱን በታዘዘው መሰረት ያልወሰደበት ጊዜ አለወይ?	1. አልነበረም 2. ባለፈው 2ሳምንት 3. ባለፈው ወር 4. ከወር በፊት 5. አላስታውስም 6. ሌላ ይጠቀስ----------	መልሱ 1 ከሆነ ወደ 604 ይለፉ
603	ለህፃኑ በታዘዘው ሁኔታ ለመስጠት የማያስችሉ ችግሮች ምን ነበሩ? ከአንድ በላይ መልሰ ይመለሱ	1. መድሀኒቱን ጨርሸው ነበር 2. ህፃኑ ታሞ ነበር 3. ረስቼው ነው 4. መድሀኒቱ መድሀኒት ቤት አልነበረም 5. ህፃኑ ተኝቶ ነበር 6. መድሀኒቱን አላምንበትም 7. የትራንስፖርት ችግር ነበር 8. አወሳሰዱ ስላልገባኝ ነው 9. የስራ ጫና ነበረኝ 10. በወቅቱ ቤት አልነበርኩም 11. የእንክብል መብዛት 66. ሌላ ይጠቀስ----------	

604	መድሃኒቱን ለመውሰድ የሚጠቀሙበት የማስታወሻ ዘዴ ምንድን ነው?	1. የሰዓት ደወል 2. ታብሌት ቦክስ 3. ከቤተሰብ የሚያስታውሱ አሉ 4. የምወስደውን መድሀኒት እመዘግባለሁ 66. ሌላ ይጠቀስ----------	
605	ህፃኑ የፀረ ኤችአይቪ መድሃኒት ከጀመረ ስንት ጊዜ ሆነው?	1.---------- 2. አልታወቀም 66. ሌላ ይጥቀሱ----------	
606	ህፃኑ መድሀኒቱን ከመጀመሩ በፊት ለመጀመር ተስማምተው ነበር ወይ?	1.አዎ 2.አልተስማማሁም 66. ሌላ ካለ ይጠቀስ----------	
607	ከፀረ ኤችአይቪ መድሃኒት ጋር ሌላ የሚወሰድ መድሃኒት አለው ወይ?	1. አዎ 2. የለውም 66. ሌላ ይጥቀሱ----------	2 ከሆነ ወደ 701 ይለፉ
608	ምን አይነት መድሃኒት ይወስዳል? ይጠቀስ	_____ ----------	

ክፍል ሰባት፡- የበሽታውን ሁኔታ የሚያሳይ መረጃ

በመረጃ ሰብሳቢ የሚሞላ

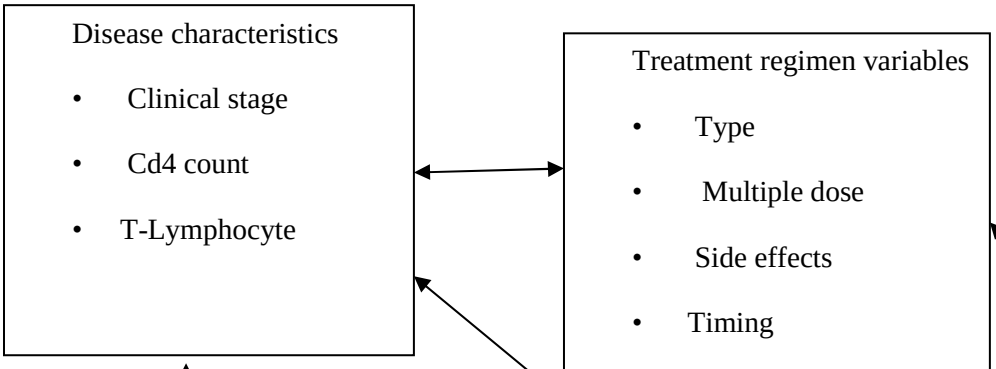
ተ.ቁ	መጠይቅ	መልስ	ምልክት
701	መድሃኒቱን ሲጀምር የህፃኑ የኤችአይቪ ደረጃ ስንት ነበር?	a. ደረጃ I b. ደረጃ II c. ደረጃ III d. ደረጃ IV	
702	በአሁኑ ሰዓት ያለው የኤችአይቪ ደረጃ ስንት ነው?	1. ደረጃ I 2. ደረጃ II 3. ደረጃ III 4. ደረጃ IV	
703	የህፃኑ CD4 ቁጥር መድሃኒቱን ሲጀምር ስንት ነበር?	_____	
704	በአሁኑ ሰዓት CD4 ቁጥር ስንት ነው?	_____	

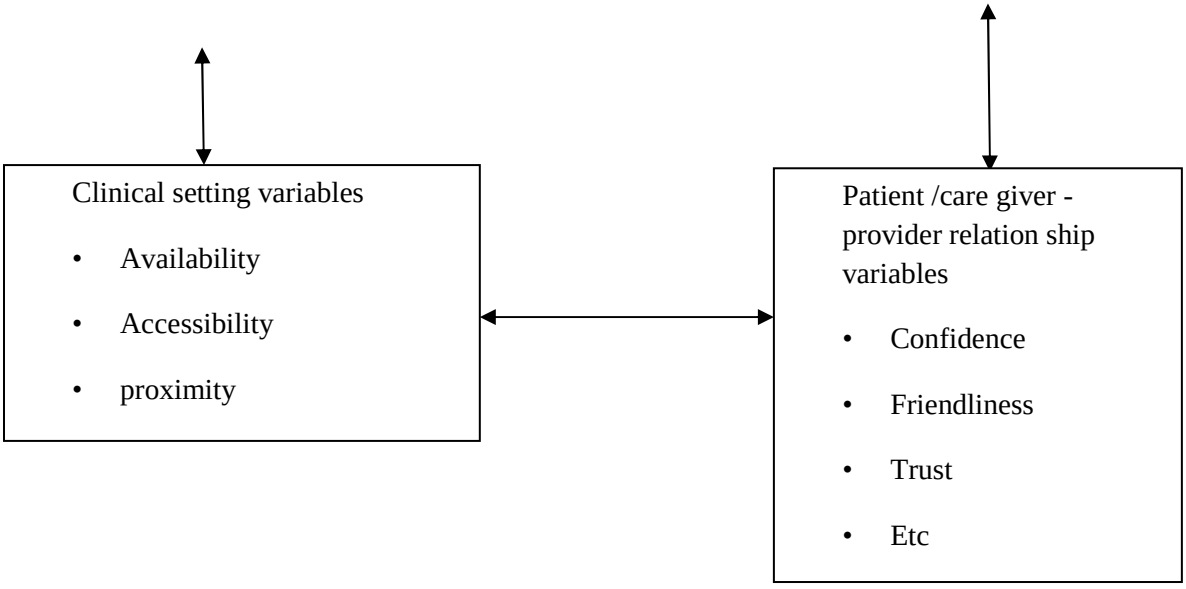
9.1 የአማርኛ ቃለመጠይቅ መመሪያ በአዲስ አበባ ዩኒቨርሲቲ ሜዲካል ፋካሊቲ የህብረተሰብ ጤና ክፍል በህፃናት የፀረ ኤች አይ ቪ መድሃኒት አወሳሰድ የቤተሰብ ተፅእኖ የደሰሳ ጥናት

ስሜ_____ ይባላል የመጣሁት ከአዲስ አበባ ዩኒቨርሲቲ ሜዲካል ፋካሊቲ የህብረተሰብ ጤና ክፍል ነው፡፡ ስለህፃናት የፀረ ኤች አይ ቪ ኤድስ መድሃኒት አወሳሰድ ነው የምንወያየው፡፡ ውይይቱ በፈቃደኝነት ነው፡፡ የማይፈልጉትን ጥያቄ አለመመለስ ይችላሉ፡፡ በውይይቱ እውነትና ሐሰት መልስ የለም ብዙ ሐሳብ ነው ማግኘት የምፈልገው ከርስዎ ነፃ ሆነው የተሰማዎትን ሀሳብ ይግለፁ፡፡ የርስዎን ሀሳብ ሁሉንም ለመውሰድ ቴፕ ሪከርድ እጠቀማለሁ፡፡ እንዳረጋግጥልዎት የምፈልገው ነገር ሁሉም የሰጡኝ ሀሳብ በሚስጥር የሚጠበቅ ይሆናል፡፡ ስምዎት አይቀዳም፡፡ የሰጡት ሀሳብ ለምርምር ስራ ብቻ ነው የምንጠቀምበት፡፡ አመሰግናለሁ፡፡ ለተጠያቂ የተዘጋጀ የቃለመጠይቅ መመሪያ

1. ህጻኑ ባለፉት ሰባት ቀናት መድሀኒት ሳይወስድ የቀረበት ጊዚ አለ ወይ?
2. ህፃኑ መድሀኒት በታዘዘለት መሰረት እንዳይወስድ የሚያደርጉት ችግሮች ቢነግሩን?
3. ለህፃኑ በየጊዜው መድሀኒት እንዲሰጡት የሚያበረታታዎት ነገር ቢነግረን?
4. የቤተሰብ ሁኔታ በምን መልኩ ህፃኑ መድሀኒት በታዘዘለት መሰረት እንዳይወስድ እንደሚያደርግ ቢገልፅሉን?በቤተሰብ ውስጥ ህፃኑ መድሀኒት ሳያቋርጥ እንዲወስድ መወሰድ ያለባቸው መፍትሔዎች ቢጠቅሱልን?
5. ለህፃኑ ስለኤች አይቪ ውጤቱ ተነግሮታል ወይ? ለሌሎች? ለምን ነገሩ? ለምንስ አልተናገሩም?
6. ከጤና ባለሙያ ጋር ያሎት ግንኙነት፣ ከጤና ድርጅቱ የሚያገኙት አገልግሎት፣ የሚሰማዎትንና እንዲሁም መድሀኒት በፈለጉት ጊዜ ማግኘትዎን ይግለፁልን?
7. መድሀኒቱን ለመውሰድ በሚመጡበት ጊዜ ያጋጠሞትን ችግር ቢነግሩን? መፍትሔዎች ሊሆኑ የሚችሉትን ነገሮች ቢጠቅሱልን

ANNEX THREE: CONCEPTUAL FRAME WORK FOR DETERMINANTS OF PEDIATRICS HAART ADHERENCE





DECLARATION

I, the undersigned declare that this thesis is my original work, and has not been presented for a degree in this or another university and that all sources of materials used for the thesis and all people and institutions that gave support for this work have been quoted and acknowledged.

Name: Frie Hailu

Signature: _____

Place: Addis Ababa

Date of Submission June 23, 2010

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

Dr. Mulugeta Betre _____

Advisor's Name signature