ADHERENCE TO HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AND ASSOCIATED FACTORS AMONG HIV POSITIVE ADOLESCENTS IN MURANGA COUNTY HOSPITAL, KENYA

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JOMO KENYATTA UNIVERSITY OF

AGRICULTURE AND TECHNOLOGY

2020

Adherence to Highly Active Antiretroviral Therapy and Associated Factors Among HIV Positive Adolescents in Muranga County Hospital, Kenya

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A Thesis Submitted In Partial Fulfillment for the Degree of Master of Science in Public Health in the Jomo Kenyatta University of Agriculture and Technology

2020

DECLARATION

This thesis is my original work and has never been presented for the award of a degree in any other University.

Signature……………………………………….. Date…………………………

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This thesis is submitted for examination with our approval as the university supervisors.

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ACKNOWLEDGEMENT

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

ABSTRACT

The introduction of Highly Active Antiretroviral Therapy (HAART) in the management of HIV infection has led to a significant decline in HIV-related morbidity and mortality. This chronic condition has now become a manageable disease. However, the treatment outcomes may get hindered by suboptimal adherence to ART. The fact that a nearly perfect adherence is required in HAART has remained a major task to people living with HIV (PLWHIV). HIV treatment extends beyond knowledge advancement among PLHIV as strong collaboration between them and healthcare providers is required, with the HIV-infected person assuming the chief responsibility of self-care that will result in adherence and a good clinical outcome. Adolescent HIV/AIDS epidemic needs to be handled and followed keenly as they face problems in accepting their HIV status, undergo behavioural experimentation, identity formation, face difficult choices on sexual behaviour,alcohol and recreational drugs. They also face a big question mark in their future regarding health, education, carrier development and their social life. With all these challenges they are at high risk of having low adherence to HAART as compared to children and adults. This descriptive cross sectional study sought to assess the proportion of adolescents adhering to HAART and identify individual and health system factors associated with adherence at Murang'a County Hospital Comprehensive Care Center. A total of 85 adolescents were consecutively interviewed during their clinal visitsat the CCC. Interviews were conducted using an interviewer-administered semi-structured questionnaire. Ethical approval was sought from Kenyatta National Hospital-University of Nairobi Ethical Review Committee. Quantitative data from questionnaires was entered and analysed using IBM SPSS 22.0. The findings were presented in form of narratives, tables, charts and graphs. The study found 75% of the adolescent adhered to HAART with 24.7% being non-adherent (95% confidence interval (CI) 16.8% to 34.8%). Individual factors such as having supportive parents or care givers, disclosure of HIV status at early stage and being in a day school was associated with HAART adherence whereas early (10-13yrs) and mid (14-17yrs) adolescence, being a student in a boarding school, alcohol and other substance abuse (OR 10.500 (95% CI 1.157-95.254), p = 0.024) was associated with HAART non adherence. Health system factors such as lower pill burden(1 or 2 pills daily) was associated with 87% lower odds of being non-adherent to ART (OR 0.127 (95% CI 0.027-0.591), p = 0.003), having caring and listen health providers was found to have about 80% lower odds of having ever missed their medications (odds ratio (OR) 0.212 (95% CI 0.057-0.789), p=0.023),convenient clinic working hours and having age specific psychosocial support groups were also associated with HAART adherence whereas very far distances from the health facility was associated with HAART non adherence. This study found that a notable proportion of self-reported suboptimal ART adherence among adolescent living with HIV,this is likely to place this cohort at an increased risk of HAART failure, disease progression as well as increased risk of HIV transmission and increased mortality.Based on the findings of this study,there is need to design strategies to address the barriers to HAART adherence in adolescent. The study indicates an urgent need for interventions that will assist adolescent HAART adherence, strategies to support early disclosure, psychological support by the caregivers both at home and school will address some of the individual factors hindering adherence.

ABBREVIATIONS AND ACCRONYMS

AIDS   Acquired Immune-Deficiency Syndrome.

ALWHIV   Adplescents living with HIV.

ART   Antiretroviral Therapy.

AYA   Adolescents and Young Adults.

CCC   Comprehensive Care Clinic.

CDC   Center for Disease Control.

CD4   Cluster Differentiation 4.

HAART   Highly Active Antiretroviral Therapy.

HIV   Human Immune-deficiency syndrome.

KAIS   Kenya AIDS Indicator Survey.

NASCOP   National AIDS and STI Control Programme.

NACC   National   AIDS Control Council.

PLWHIV   People Living With HIV/AIDS.

STI   Sexually Transmitted Infection.

UNAIDS   Joint United   Nations Programme on HIV/AIDS.

WHO   World Health   Organization .

NRTI   Nucleoside Reverse Transcriptase Inhibitors.

NNRTI   Non-nucleoside Reverse Transcriptase Inhibitors.

PI   Protease Inhibitors.

OPERATIONAL DEFINATION OF TERMS

Adherence:. The extent to which a person's behavior taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (WHO;2003)

Adolescents: World Health Organization (WHO) defines an adolescent as any person between ages 10 and 19 (WHO,2010)

Factors Associated: Something or anything that affects client adherence to the HAART regimen.

Non-adherence: Active process whereby the patient chooses to deviate from treatment regimen OR passive process in which the patient may forgetful adhering to treatment regimen.

Opportunistic infections: Infections in an immune-compromised individual caused by pathogens that usually do not cause disease in a healthy immune system.

Virologic Failure: Plasma viral load above 1000 copies/ml based on two consecutive viral load measurements after three months, with adherence support (WHO, 2013).

Immunological Failure: For adults and adolescents cell differentiation 4 (CD4) count below 100 cells/mm3 while children younger than five years persistent CD4 levels below 200 cells/mm3 or <10% (WHO, 2013).

Clinical Failure: For adults and adolescents its defined as new or recurrent clinical event indicating severe immunodeficiency (WHO clinical stage 4 condition) after 6 months of effective treatment, for children defined as new or recurrent clinical event indicating advanced or severe immunodeficiency (WHO clinical stage3 and 4 clinical condition with exception of TB) after 6 months of effective treatment (WHO, 2013).

Self-Report: Assessment method for adherence where a patient reports to the healthcare provider the number of pills per regimen missed over a given period. For this study this period was 7, 14 and 30 days

CHAPTER ONE

INTRODUCTION

1.1 Background Information

By the end of 2019 about 38 million people were living with HIV/AIDS in the world, of this 25.7 million were living in Sub Saharan Africa (WHO, 2018). About 1.8 million adolescents were living with HIV/AIDS all over the world with an estimate of 85% living in Sub Saharan Africa and about 2.1 million new HIV infections were reported (UNAIDS, 2015). Adolescent and young adults (10-24) have been shown to be at high risk of contracting HIV with about two thirds of HIV infected young persons living in Sub-Sahara Africa. Adolescents and young adults accounts for about half of all new HIV infection worldwide. In 2015 alone, 670,000 young people between the ages of 15 to 24 were newly infected with HIV, of whom 250,000 were adolescents between the ages of 15 and 19 (UNICEF, 2016).

AIDS is the leading cause of death and morbidity among adolescents and young people in Kenya (NACC, 2015). About 51% of all new HIV infections in Kenya are among adolescents and youth. The Kenya AIDS Strategic Framework identifies adolescents and young people as a priority population for the HIV response. It is estimated that about 133,455 adolescents are living with HIV in Kenya with an estimate of 18,004 new infections and 2,797 deaths among adolescents 10-19 years annually (Kenya county HIV Profile, 2016).

In 2015 there was about 1,160 adolescent living with HIV in Murang'a County with an annual new HIV infection of 135 among adolescents and 22 HIV/AIDS related mortalities reported in the same year (Kenya County HIV profile, 2016). Majority of adolescent who die from AIDS related illnesses were infected with HIV as infants at a time when fewer pregnant women with HIV received HAART to prevent mother to child transmission, many of them have survived into their teenage sometimes without knowing their HIV status, hence spreading the virus. Though the number of people on treatment has increased, treatment adherence continues to pose significant challenges. WHO defines treatment adherence as "the extent to

which a person's behavior taking medications, following a diet and/or executing lifestyle changes corresponds with agreed recommendations from a healthcare provider" (WHO, 2003). Adherence to ART has been shown to be among the major predictors of complete viral suppression, disease progression, and death (Nachega. J *et al*., 2007).

Despite the dramatic improvement in survival and marked reduction in transmission through HAART a sustained effect depends on high adherence (>95%) to daily oral dosing. Poor HAART adherence increases the risk of viral drug resistance, limits treatment efficacy, leading to disease progression, and reduces future therapeutic options as well as increasing the risk of transmission due to unsuppressed viral replication. The current paradigm shift in HIV prevention approaches to using HAART strategically for all people living with HIV to significantly reduce the risk of onward viral transmission, successful viral suppression amongst core risk-taking groups, which include adolescent living with HIV, has a renewed focus. Mathematical models have explored the potential elimination of HIV transmission with a universal HIV testing approach accompanied by immediate HAART for all HIV-positive individuals; this must include adolescents if it is to confer a population level effect. The few studies on adherence show that access to antiretroviral and adherence is lower in adolescents than in the adult population (Kim. S *et al.*, 2014).

This strongly indicates the need to come up with strategies to maximize long-term HAART adherence to ensure success as Kenya scales up HAART programs countrywide. There are many factors which have been suggested to affect HAART adherence, either negatively or positively thus it's important to identify factors that contribute to inability of patient adhering to HAART as expected so that measures can be put in place to counter this challenges.

1.2 Problem Statement

HAART adherence is the primary determinant to the efficacy of this treatment on chronic management of HIV/AIDS. Above 95% adherence to HAART is required in

order to achive HIV viral load suppression which prevents the emergence of resistant HIV strains, reduces destruction of CD4 cells and improve quality of life.

Poor HAART adherence is a public health concern since it limits the effectiveness of available HIV treatments and is associated with poor clinical,virological and immunological response which may leads to increased hospitalization rates resulting to financial constrains, reduced productivity and increase in morbidity and mortality.

First line regimen failure due to poor adherence leads to regimen switch to second-line HAART regimens that can be up to six times more expensive than first-line regimens and this has financial implication to the goverment and international bodies that fund procurement of HAART.

As some HIV positive adolescents have poor HAART adherence achiving viral load suppression will remain a challenge and this is a major obstacle in the fight against HIV/AIDS since adolescent and young adults account for almost two thirds of new HIV infection   annually. This will also hinder the realization of ending the HIV pandemic by the year 2030..

1.3 Justification

Strict adherence to HAART is key to sustain HIV suppression, reduce risk of drug resistance, and improve overall health,quality of life as well as decreased risk of HIV transmission thus reducing HIV related morbidities and mortality.

Although the annual number of AIDS-related deaths worldwide fell by 35% from 2005 to 2012, deaths among adolescents (ages 10-19) living with HIV have sharply risen, increasing by 50% from 2005 to 2012 (UNAIDS, 2015). In the era of antiretroviral therapy, AIDS remains the second leading cause of death among adolescents globally and the leading cause of death among adolescents in sub-Saharan Africa. AIDS related deaths among adolescent have increased over the past decade while decreasing among all other age groups (UNAIDS, 2015).,

In 2015, a total of 1,160 adolescent aged 10-19 years in Murang'a County were living with HIV/AIDS, in the same year there was an annual estimate of about 135 new infection and 22 reported AIDS related deaths in the same cohort (Kenya County HIV profile, 2016). These figures can be greatly reduced if good HAART adherence among HIV adolescent is strengthened through implemetation and provision of factors that are associated with HAART adherence.

1.4 Research Questions

1) What proportion of HIV positive adolescents adheres to HAART at Murang'a County Hospital?

2) What factors are the Individual factors associated with HAART adherence among HIV positive adolescents at Murang'a County Hospital?

3) What are the health system factors associated with HAART adherence among HIV positive adolescent at Murang'a County Hospital?

1.5 General Objective

To determine HAART adherence and associated factors among HIV positive adolescent at Murang'a County Hospital.

1.5.1 Specific Objectives

1) To determine proportion of HIV positive adolescents adhering to HAART at Murang'a County Hospital.

2) To determine the Individual factors associated with HAART adherence among HIV positive adolescents at Murang'a County Hospital.

3) To determine the health system factors associated with HAART adherence among HIV positive adolescent at Murang'a County Hospital.

1.6 Study Limitation

This study was not without limitations which may limit the generalizability of the study findings. The study utilized descriptive cross-sectional study design. Stronger and definitive conclusions on the associations between various factors and adherence to HAART would be possible with a longitudinal cohort study. The findings from this study are not generalizable to all HIV positive adolescents in Kenya. The study population was majorly drawn from a rural area. Observations may be different in an urban set-up.

Another potential limitation of the present study is that adherence was assessed only through adolescent self-report. Incorporating the viral load data would be very helpful in providing insights on the clinical relevance of self-reported adherence. A major challenge with self-report is potential over estimation of adherence due to social desirability bias. Nevertheless, in this study, self-reporting of HAART adherence was done anonymously thus potentially reducing the attendant bias. Moreover, self-reporting of medication adherence by adolescents has been found to be relatively accurate and rates of non-adherence reported in studies using laboratory assays are consistent with rates reported in studies using self-report (Millis. E *et al.,* 2011).

1.7 Significance of the study

The use of HAART is a major way of preventing the occurrence of opportunistic infections and ensuring improved quality of life among PLHIV. Efforts need to be focused on strengthening HAART adherence especialy to adolescents living with HIV due to the special need required by this population.This study conceptualized HAART adherence among adolescent and described individual and health system factors associated with adolescent HAART adherence so that necessary intervention can be put in place so as to strengthen and support adherence among adolescent. This will be of great help to the ministry of health both at national and county levels, HIV Programme implementers and other stake holders in that the finding will help in coming up with policies that can be used to strengthen HAART adherence among

adolescents and contribute towards realization global goal of eradicating HIV by 2030.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In 2019, about 1.7 million adolescents between the ages of 10 and 19 were living with HIV worldwide of which adolescents accounted for about 5% of all people living with HIV with about 1.5 million 88% live in sub-Saharan Africa (UNICEF, 2019). Adolescents represent a growing share of people living with HIV worldwide, in 2019 alone, 460,000 young people between the ages of 10 to 24 were newly infected with HIV, of whom 170,000 were adolescents between the ages of 10 and 19 (UNICEF, 2019).

Adolescence is a critical stage of mental, physical and emotional maturation where they undergo behavioral experimentation, identity formation, risk taking and face difficult choices on sexual behaviour, alcohol and drug abuse. They often have poorly developed life skills, are lacking in knowledge and face financial challenges which limit their access to health facilities. Adolescent have been described as the 'Centre of the epidemic' with approximate 42% of new HIV infections occurring in this age group in 2010 (Kim.S *et al.,* 2014).

For all of these reasons, adolescents have been frequently recognized as a highly vulnerable group to HIV infection and likely to be marginalized from mainstream healthcare provisions.

Although the annual number of AIDS-related deaths worldwide fell by 35% from 2005 to 2012, deaths among adolescents (ages 10-19) living with HIV have sharply risen, increasing by 50% from 2005 to 2012 (UNAIDS, 2015). In the era of antiretroviral therapy, AIDS remains the second leading cause of death among adolescents globally and the leading cause of death among adolescents in sub-Saharan Africa. AIDS related deaths among adolescent have increased over the past decade while decreasing among all other age groups (UNAIDS, 2015).
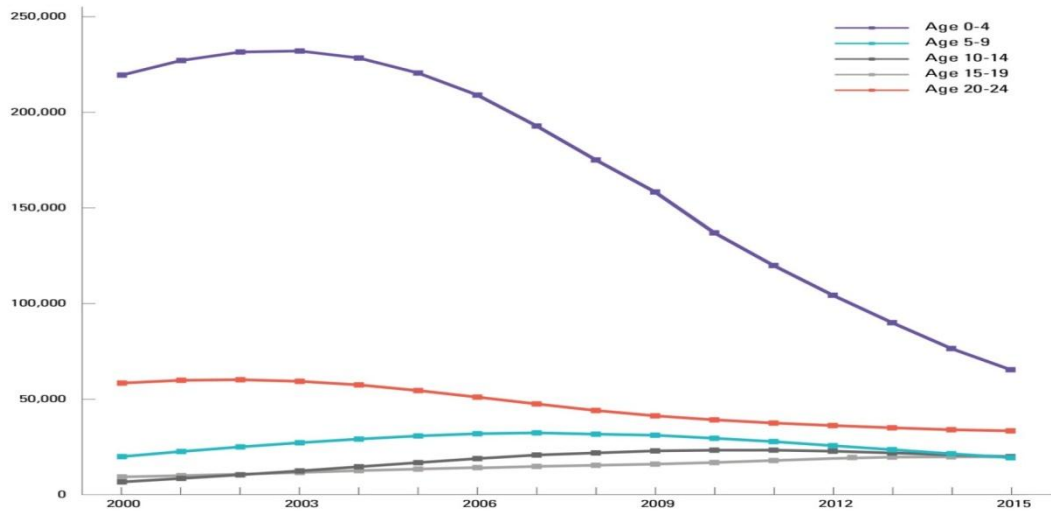
Figure 2.1: AIDS related deaths UNAIDS 2016

Kenya noted an encouraging decline in the HIV prevalence from 2012 to 2019 (5.6% to 4.9%% (KENPHIA, 2019). The prevalence has however stabilized over the last decade due to the scale up of antiretroviral therapy and reduction in the number of new infection, currently the prevalence has decreased to 4.5% among people aged 15 to 49 years; 3.1 % for male and for 6.2% % females (KENPHIA, 2019). Of the 1.3 million people living with HIV, 12 % are children below 15 years. Of concern is that Adolescents and Young Adults (AYA) represented 40 % of new HIV infections globally and, in contrast to the overall decrease in AIDS related deaths between 2005 and 2012. The AIDS related deaths in adolescents aged 10 – 19 years more than doubled in Sub-Saharan Africa. In Kenya, there are approximately 190,000 HIV-infected children and adolescents, of whom only 38% are on antiretroviral therapy (UNAIDS, 2017). Although HIV prevalence seems to have stabilized, new infections have been estimated at 166 000 annually with approximately 50% of these new HIV infections occurring among 15-24 year age group (UNAIDS, 2018),with such a large and young population and with increasingly more and more living with HIV, adherence to ARVs is of utmost importance if the people are to realize any meaningful life free from disease.

Adolescence is the period between 10 and 19 years of age with about one-fifth of the world's population belonging to this age group (Fantahun M *et al*., 2015). In the sub-

Saharan Africa, a third of the total population is aged between 10 to 24 years (world population prospects, 2019). Adolescence is a period characterized by dynamic changes representing the transition from childhood to adulthood, rapid changes in physical, emotional, cognitive and social characteristics take place (Fantahun M *et al*., 2015). By the end of 2012, eighty-two percent of the estimated 2.1 million adolescents aged 10-19 years living with HIV were in sub-Saharan Africa (Idele P *et al*., 2014).

Most adolescents have poorly developed life skills, lack knowledge and financial autonomy in addition to limitation in accessing health facilities and are prone to sexual coercion and peer pressure (Napierala M *et al*., 2018). Adolescents have been described as the 'fulcrum' and the 'centre of the epidemic' (UNAID, 2012), with 42% of new HIV infections occurring in this age group in 2010 (UNICEF, 2011). For these reasons, adolescents have been recognized as a vulnerable group to becoming infected and to being marginalized from mainstream healthcare provisions (WHO, 2016).

With the current paradigm shift in HIV prevention approaches to using ART strategically for all people living with HIV to significantly reduce the risk of onward viral transmission, successful viral suppression amongst core risk-taking groups, which include Adolescent and young adult (AYA) living with HIV, has a renewed focus (Cohen.M *et al*., 2011).

Mathematical models have explored the potential elimination of HIV transmission with a universal HIV testing approach accompanied by immediate HAART for all HIV-positive individuals, but this must include adolescent if it is to confer a population-level effect (Kim .S *et al*., 2014)

2.2 Adherence to Highly Active Antiretroviral Therapy among adolescent

Adherence is defined as the extent to which a person's behaviour on taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (WHO, 2013). Adherence is a multifactorial phenomenon that can be influenced by various factors which can be

social and economic factors, therapy-related factors, disease-related factors, patient-related factors and health care system-related factors (Sabate.E *et al*., 2018, Schefer.C *et al*., 2017).

In the last decade there has been great improvements in access to Highly antiretroviral therapy (HAART) to PLHIV and global HAART coverage has increased by more than two folds between 2010 to 2015 (UNAIDS; 2016). To ensure positive health outcomes, these efforts must be synergized by patients adherent to HAART regimens in order to achieve viral suppression and reduce risk of HIV-related mortality, regimen failure and secondary HIV transmission (Lisa.S *et al*., 2018).

Research from resource-poor settings documents how adolescents and youth have lower HAART adherence than adults (Hudelson.C *et al*., 2015). A comprehensive review of studies done in 2015 focused on adolescents in sub-Saharan Africa (SSA) identified multiple levels of barriers impacting ART adherence (Adejumo.O *et al*., 2015). These included sociodemographic factors (e.g., poorer adherence among older adolescents as well as those living in spaces with less privacy such as foster care or orphanages); structural and economic factors (e.g., limited access to food, high cost of transportation, political instability further limiting access to HIV care); psychosocial factors (e.g., limited caregiver supervision, small support networks); individual factors (e.g., forgetfulness); treatment-related factors (e.g., high pill burden, negative side effects, challenging transition between pediatric and adult HIV treatment services); and individual resilience factors (e.g., good adaptive skills and positive expectations for their future were associated with better adherence).

A systematic review of studies done in 2018 focused on adolescents in SSA reported similar findings, identifying stigma, HAART side-effects, lack of assistance, and forgetfulness as important barriers; facilitators included caregiver and peer support, and youth having knowledge of their HIV status (Ammon.N et al., 2018). Studies done in Uganda noted some barriers to HAART adherence which included treatment holidays (i.e., breaks in ART adherence); delays in disclosure of HIV status by

caretakers; stigma, especially in boarding schools; diminishing or lack of clinical support (Inzaule.S *et al*., 2016) and living in rural areas (Nabukeera.N *et al*., 2015).

Studies both locally and globally have shown poor adherence to HAART in adolescents compared to adults and children (Nachega *et al*., 2010) A study done in South Africa showed the number of adolescents achieving 100% adherence estimated by pharmacy refills, was lower than that for adults, with 20.7% at 6 months, 14.3% at 12 months, 6.6% at 24 months compared to 100% adherence in adults in 40.5%, 27.9%, and 20.6% at each time point, respectively (Nachega *et al*., 2010)

Adherence has been shown to decrease as children grow into adolescence and less in older adolescents (Mutwa. P *et al*., 2013) with adolescents above 15 years of age having a greater risk of non-adherence compared to younger adolescents. Level of adherence to HAART in adolescents varies in different parts of the world. In a systematic review and Meta-analysis (Kim.S *et al.,* 2014) studies in Africa and Asia indicated that more than 70% of HIV infected adolescents and young adults receiving ART were adherent to therapy, lower rates of adherence were shown in Europe and North America at 50 – 60% (Kim.S *et al*., 2014). This was attributed to many factors such as differences between focused and generalized epidemics, access to health care and funding. In a three-year cohort study that followed-up 120 adolescents, only 24% were able to reach and maintain an undetectable viral load.

A cross-sectional study in Brazil conducted among 102 adolescents 10 - 19 years who had been on ART for at least 2 months with adherence determined by self report for the 3 days prior to the interview and viral load done before the interview used to validate results. Adherence defined as taking 95% and above of the prescribed ART showed that 94% of the adolescents in this study were adherent, a rate higher than expected. Factors associated with non-adherence in this study were identified as adolescent not been concerned about treatment, failure to carry an extra dose while away from home and lack of education by the health –care provider (Tang. G *et al.,* 2010).

A study done in India found that by using the method of self-reporting of adherence to HAART, 84% of patients on HAART were reaching optimal adherence levels (Sarna *et al.,* 2012). While a meta-analysis of studies done in several sub-Saharan African has shown that HAART adherence in early treatment programs are favorable whereby 77% of patients were reaching optimal adherence levels (Mills. E *et al.,* 2011). In Africa studies have shown varying but suboptimal adherence levels to HAART by adolescents (Ndiaye. M *et al*., 2013).

A cross-sectional study among 262 adolescents aged 10 – 19 years, who had been on ART and aware of their status in two clinics in Zimbabwe where adherence was determined by self reports showed that 61% of these adolescents were adherent. Common factors among the adherent adolescents in this study were; living with family, good client-health provider relationship, confident in their ability to take medication and satisfied about their care (Mavhu. W *et al*., 2013).

In Kenyatta National Hospital a study on HAART adherence among 158 adolescents aged 10 –19 years who had been on ART for at least 6 months prior to the study showed 93.7% of the adolescents had good self-reported adherence, 96.8% kept their scheduled clinic appointment and 95.6% refilled their drugs on time. Commonest reasons given for missing doses by the adolescents included forgetting to take medication,being away from home and a school schedule that did not allow them time to take medications. Stigma and lack of social support were identified assignificant barriers to adherence in these adolescents in both the qualitative and quantitative methods. Promoters of adherence were extensive counseling before treatment initiation as well as during treatment, peer counseling and supportgroups (Gatuguta.A *et al.,* 2012).

A major concern with HAART is the emergence of viral resistance, which is mainly due to poor adherence Studies have indicated that at least 95% adherence to HAART regimens is optimal (WHO, 2016). With 95% adherence, viral suppression to below detectable levels occurs in 80% of individuals. However, a fall in adherence to 70% drastically decreases viral suppression to 33%. Also, it has been demonstrated that a 10% higher level of adherence results in a 21% reduction in disease progression

(Anuradha.S *et al.,* 2013). Implications of suboptimal adherence include failure of the regimen, increase in morbidity and mortality and emergence of resistant strains of virus. For example for non nucleus reverse transcriptase inhibitors(NNRTIs), studies have shown that 69% of individuals using them had resistance at 0 - 48% adherence while resistance was significantly reduced to 13% at 95-100% adherence (Parienti.J *et al.,*2010). For Proteus Inhibitors(PIs), virologic failures of 22% have been documented in patients with adherence of 95% or more and of 80% in patients with adherence of 80% or less (Paterson. D *et al.,* 2000). This finding indicates that achieving adherence level of 95% or more is even more important for PIs than NNRTIs based regimens.

For NNRTIs which have been shown to have less probability of virologic rebound even with moderate adherence levels, continuous and sustained treatment interruptions pose a high risk for virologic rebound than interspersed missed doses. Therefore, near perfect adherence leading to sustained virologic suppression remains the goal of HAART, sustained NNRTIs treatment interruptions have to be limited in patients with incomplete adherence (Parienti. J *et al.,* 2010)

2.3 Individual Factors associated with HAART adherence among adolescents

Maintaining medication adherence is vital to ensuring that adolescents living with HIV/AIDS receive the benefits of HAART, although adolescents faces unique challenges on HAART adherence, knowledge on the factors influencing adherence among people during this unique developmental period is needed to develop more targeted and effective adherence-promoting strategies. Previous studies in Kenya have shown that adolescent populations are the least adherent to HAART (Kabogo.J *et al.*, 2018). A national survey in Kenya revealed higher levels of suboptimal adherence among persons aged 15–29 (Mukui.I *et al.*, 2012). Similar findings were noted with data from across sub-Saharan Africa found that HAART adherence by adolescents is infuenced by disclosure (Aderomilehin.O *et al.*, 2016), financial status, treatment burnouts, peer stigmatization and close support by the caregivers (Bermudez. L *et al.*, 2016).

13

Adolescents under the care of guardians were found to have low adherence rates (Kabogo.J *et al.,* 2018) and other previous studies have showed that ALWHIV and under the care of their guardians are at greater risk of poor adherence and HAART failure (Thurman .T *et al.,* 2012, Popoola T *et al.,* 2016). A study done in Zambia found higher HAART adherence levels where the mother was the primary caregiver and improved further if the adolescent had multiple caregivers (Haberer. J *et al.,* 2011).

In a similar study done in Rwanda found that adolescents under the care of guardians or relatives had the lower adherence rates to HAART with a similar finding with other studies in the region that found that non-biological caregivers are less keen to monitor how their adolescents are adhering to HAART as compared to biological parents (Kikuchi.K *et al.,* 2014).

A study done in Malawi found that stigma and discrimination among peers and realatives coupled with family pressure, frequent changes in areas of resisdencs and religious beliefs influenced HAART adherence among adolescent (Chirambo *et al*., 2019)

Forgetting to take HAART due to alcohol and substance abuse has been has been attributed to poor HAART (Jones. D *et al*.,2015). Non-adherence to HAART in the context of alcohol and other substance use is influenced by individuals need to keep one's HIV status private which leads to missing taking HAART while one is taking alcohol (Scholl. I *et al*.,2014). In addition to the fear of HAART adverse effects that may resulting from drug toxicity and alcohol results in defaulting.

Individual experiences with drugs may either prompt clients to take HAART timely or abandon the regimen. (Chirambo *et al*., 2019) found that a bad experience with HAART adverse effects influenced defaulting from treatment.

A systematic review reported that adolescent with compromised immune system with recurent illnesses and opportunistic infections would interfere with clinic appointments leading to them missing their HAART refill and subsequent poor adherence as compared to those who were stable (Kelsey.B *et al*., 2016).

Other studies found that participants would default from HAART after been initiated on alternative medicines such as traditional or herbal medicine (Azia.I *et al.,* 2016). Disclosure of one's HIV status was found to be another individual factor associated with poor adherence, a study in Malawi reported that most clients deny their HIV status which results in a poor understanding of the benefits of HAART (Wasti.S *et al.*, 2012). The same study found that lack of adequate information on HAART affected clients adherence.

Studies in Uganda, Botswana and Tanzania found that non-disclosure among HIV positive adolescents on HAART contributes to poor taking of medications or missed medications hence defaulting from HAART (Wasti.S *et al.*, 2012). On the contrary,a study done by (Musumari.P *et al.*, 2014) found that early disclosure of one's HIV positive status been associated with improved adherence to HAART. A study by (Mutngwa.L *et al.,* 2016) proposed promotion of age appropriate adolescent disclosure of one's HIV status and strengthening interventions that overcome stigma and discrimination. Integration of mental health services within comprehensive care clinics would assist the clients in navigating through acceptance of their results (Schneider.M.,*et al* 2016).

In Europe factors associated with HAART adherence vary from those related to the patient, the treatment regimen, the doctor-patient relationship, and the system of medical care. Depression, active alcohol/substance abuse, self-efficacy, belief that medications can fit into one's day schedule, understanding the relationship of viral resistance and adherence, and history of adherence have been found to be strongly associated. Sex, race, age, stage of disease (Wenger.J *et al.,*2011) are inconsistently associated. Education, income, employment, HIV risk factors and belief that medications will improve health have not been found to be always associated. Studies in Spain, Italy and France; countries with highest epidemic in Western Europe, showed that even where therapy is accessible, injection drug users, immigrants or people with low income and education levels are less likely to adhere to treatment (Carballo.E *et al.,* 2014). This may be due to poor understanding of treatment regimen, failure in communication with clinicians or poor social support.

Studies in US have associated heavy alcohol and drug use with non-adherence (Wenger.J *et al.* 2011). Where drug regimens fitted well into patient's daily schedules or patients perceived ARTs as effective and understood that non-adherence to therapy leads to viral resistance, adherence was good. Low income and education levels; complexity of HAART regimens due to pill number, dosing frequency, meal restrictions or side effects were associated with non-adherence (Nieuwkerk *et al*, 2011)).

(Byakika *et al.,* 2015) in a study to assess level of adherence and associated factors in Uganda found lack of money, forgetfulness, drug inaccessibility, adverse effects of the drug, traveling away from home, unclear instructions by the health provider, being too busy, regimen too complex, fear of wasting drug and presence of other disease conditions as reasons for non-adherence. Age, gender, education, religion, treatment duration, dosing interval, pill burden, drug and alcohol consumption, confidence in HAART, distance from treatment center, cost of medications, depression, social support and number of concurrent conditions did not predict adherence.

A meta-analysis of studies done found that African adolescents have adherence rates similar to those of their adult counterparts, and significantly higher than European or North-American adolescents (Gross.R *et al.,* 2015). A possible explanation for this might be that access to HAART is still one of the biggest limiting factors to adherence in Sub Saharan Africa. It must also be taken in consideration that the complexity in medication regimes greatly differs between Sub Saharan Africa and industrialized countries, and thus confounding the difference in adherence rate(Kim.S *et al*., 2014)

A study investigating possible barriers to access and HAART adherence in resource limited settings,the most commonly cited were lack of knowledge of HIV status, treatment options, fear of stigma and discrimination and poor access through lack of health care infrastructure and resources.The most important barrier that was reported was unintended disclosure of the HIV status(Kim.S *et al*., 2014). Adolescents often felt that they had to choose between taking their medication and keeping their HIV

status a secret. In a study by (Chuleeporn.C *et al.,* 2010) on Antiretroviral Therapy Adherence among Patients living with HIV/AIDS in Thailand it was noted that HIV disclosure was a significant predictor of increased adherence to HAART. This was in consistent with previous studies showing that HIV disclosure is a necessary facilitator to HAART adherenceForgetfulness due to other preoccupations was also frequently mentioned as a barrier to adherence in recent studies. Facilitating factors include clinical youth support groups,support from family and health care providers, disease knowledge, self-motivation and perceived treatment outcome.

In Kenya, reasons and factors associated with adherence are not well understood and documented. Action Aid Kenya attributed non-adherence to treatment in Western Kenya to poor nutrition and poor access to correct information; treatment literacy is not only low among patients, but also among health workers reported more than half (54%) of patients switched at least one drug 41% of those who switched, was because of clinical toxicity reported lack of food and clean water, stress, and financial problems to be barriers to adherence in Kibera slums (Jennings. L *et al*., 2017) These findings suggest that adolescents could benefit greatly from interventions that support their adherence, as they gradually become more independent and parents/caregivers withdraw their supervision of their medication adherence.

2.4 Health Systems Factors associated with HAART Adherence among adolescents

Inefficiency in health services provided such as inadequate counseling on importance of HAART compromised confidentiality due to inadequate clinical rooms, long waiting times, inadequate supply and stock outs of HAART and dissatisfaction with the care provided are some of the health system factors associated with HAART non adhrenece (Watis.S *et al*., 2017, Holtzman.C *et al*., 2015). Other studies have found that provision of HIV education and counseling adequately builds adolescents adhere to HAART treatment through intensive education and counseling that focuses on recepient of care feedback, problem solving, self-monitoring and patient education which are also premises of patient centeredness (De Man.J *et al*., 2016).

Health systems should create structures that are aimed at supporting adolescents who are on HAART to ensure they have good adherence,(Chirambo.L *et al.*, 2019) suggest that health facilities should have mechanisms to trace those adolescent who miss their clinic appointments and follow up visits made to establish the problems leading to non adherence and provide adherence counseling sessions.

Good relationship between health providers and adolescents was found to contribute to better HAART adherence (Kranzer.K *et al.*, 2010) .Health facility should strive to provide client centered services to meet their needs which improves quality of services provides and intensifies HAART adherence among PLHIV (Scholl.L *et al.*, 2014). Adolescent centered care promotes active involvement in their own care creating responsibility to their own health and makes them knowledgeable on issues to do with HAART adherence and its importance (De Man.J *et al.*, 2016). In addition, good relationships between adolescents and health care providers builds good rapport which creates a platform for sharing information and enhances counseling for the provider and the participants (Rackal.J *et al.*, 2011).

Inadequate staffing was identified as a contributor to poor HAART adherence as PLHIV usually get suboptimal counselling about the disease and the importance of HAART adherence (Wasti.S *et al.*, 2017). Studies in some African countries reported a huge gap in health providers staffing which usually results to suboptimal counselling on HIV and HAART benefits which thereafter affects retention and adhrenece (Wasti.S *et al.*, 2017).

Despite provision of HIV services in most public facilities in Africa as they are mostly donor supported PLWHIV still incur some financial burden to access this services (Chirambo. L *et al.*, 2019). Other studies in Nepal and Africa found that recepients of care incurred cost in terms of transport to reach the health facilities and this means that incase they don't have money during their clinic appointment they would most likely miss the appointment and thus miss their HAART refill which would affect their adherence to HAART (Shubber.Z *et al.*, 2015).

Residing very long distances from the health facility has been incriminated as hinderance to un interrupted access to HIV services. A study done in Malawi showed

that geographical accessibility led to defaulting from HAART and other treatments, this is in agreement with findings other previous studies that reported that PLHIV residing far from the health facility usually defaulted from HAART treatment because of the long distances ((Shubber.Z *et al*., 2015).

According to (Bijker.R *et al*., 2017) psychosocial support to PLHIV enhances HAART adherence. This support could be from health service providers,peers, Guardians or relatives and community members (Chen.W *et al*., 2013). Adolescent who received psychological support reported to have felt non-discriminated, accepted and were motivated which promoted adherence to HAART (Wang.K *et al*., 2016).

2.5 Theoretical Framework

The Information, Motivation and Behavioural (IBM) model, proposed by Fisher and Fisher in1992) to explain HIV-related behaviors, recognizes three constructs; information, motivation, and behavioral skills that are required to support a given health behavior as specific individual determinants of behavior and behavioral change (Fisher & Fisher; Norton, 2013). Based on the IMB model, "well-informed, well-motivated patients with adequate knowledge and skills for enacting complex patterns of adherence related behaviour will adhere to their HAART regimen optimally over time" (Norton.W *et al*., 2013).

Adherence information is one the intervention that the patient receives during the clinical encounter with the health provider, this information relates to the regimen, correct use of HAART and the importance of adequate adherence, additional information such as side effects of the medication and possible drug interactions (Mukumbang. C *et al*., 2017). This information can be a source of motivation for the patient in the psychological sense basing on this model.Social support is based on how the patient perceives the support of his or her significant others such as realtives, spouses,parent or guardian. The patient's motivation (psychological or social) and self-efficacy are moderated by actor-related elements such as the psychological health of the patient, unstable living situation, poor access to medical care services and substance use.

According to the IMB model, adherence behavioural skills including objective ability and perceived efficacy for performing critical skills such as acquiring self administering HAART play a vital role in determining whether a patient adheres to their medication or not. The IMB model also specifies that adherence information and adherence motivation may be directly related to ART adherence in cases where medication-taking behaviours are not complex or demanding (Barta.A *et al*., 2014). This study was based on this model where individual and health system factors associated with HAART was assessed among the study population.

Independent Variables   **Depenedent Variable**

Individual Factors
▪ Age
▪ Sex
▪ Education
▪ Religion
▪ Parent/Guardian support
▪ Alcohol and Drug abuse

HAART ADHERANCE AMONG ADOLESCENT

Health System Factors
▪ HAART regimen frequency
▪ Facility accessibility
▪ Convient clinic hours
▪ Availability of psychosocial groups
▪ Friendly and Caring Health workers
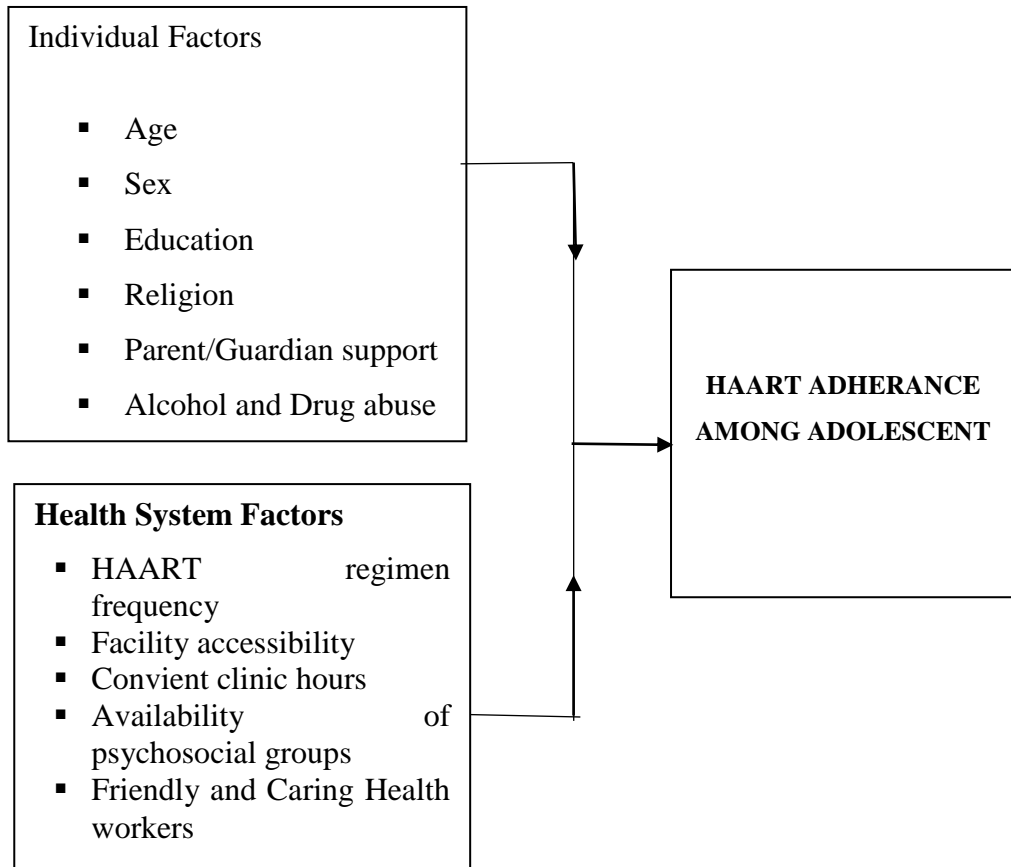
Figure 1.2: Conceptual Framework

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study Area

The study was carried out at the Comprehensive care clinic, Murang'a County Hospital which is in Central Kenya. A cosmopolitan town home to people with diverse cultures but mainly inhabited by Kikuyu community. It is the main referral hospital in the county being a tier four health facility. Murang'a County has a population of 1,063,721, comprising of 522,970 males (49%) and 540,751 females (51%). Children below 15 years constitute 36% of the population, while youth aged 15-24 years constitute 18% of the population (KNBS, 2015). HIV prevalence in Murang'a is lower than the national prevalence at 4.2% (Kenya HIV Estimates, 2015). The HIV prevalence among women in County is higher (6.2%) than that of men (2.2%), indicating that women are more vulnerable to HIV infection than men in the County.

Murang'a County contributed to 1.8% of the total number of people living with HIV in Kenya, and is ranked the seventeenth nationally. By the end of 2015, a total of 27,245 people were living with HIV in the County, with 10% being young people aged 15-24 years and 4% being children under the age of 15 years (NACC, 2016)

3.2 Study Design

A descriptive cross sectional study was carried out to systematically gather information on the unexplored and complex interplay of forces contributing to adolescent adherence to HAART medication at Murang'a County Hospital. The study used quantitative data to explore patient adherence to HAART and describe the demographic profile of respondents and to gain insight into HAART adherence.

3.3 Study population

The study population comprised of 109 HIV positive adolescents (10 to 19 years) seeking services at the CCC in Murang'a County Hospital and had been on HAART for at least six months;

3.3.1 Inclusion criteria

(i). HIV positive adolescents aged 10 -19 years.

(ii). Enrolled for care and treatment at Murang'a County Hospital

(iii). Have been taking HAART for at least six month

(iv). Having assented to participate in the study and consent given by the caregiver or assent/consent from adolescents.

3.3.2 Exclusion criteria

(i). Adolescents who were severely sick.

(ii). Adolescents whose guardian declined to consent.

3.4 Sample size determination

Sample size estimation was calculated using Yamane's formula (Yamane,1967)

$$n = \frac{N}{1} n = \frac{N}{+Ne^2}$$

Where n = sample size

N= total population

e = the error of 5 percentage points

N = Total number of HIV positive adolescents at Murang'a County Hospital was 109.

$$n = \frac{109}{1+109*0.05^2} = 85$$

3.5 Sampling Technique

Consecutive sampling technique was used to recruit the study participants as they sought services at the CCC until the desired sample size was achieved.

Consecutive sampling is as a non-probability sampling technique where samples are picked at the ease of a researcher more like convenience sampling, only with a slight variation. The researcher picks a sample or group of people meeting the criteria of inclusion until the required sample size is achieved (Mathieson *et al.,* 2014). In this sampling method, each consecutive eligible individual seeking health services is approached for enrollment (Setia, 2016). This sampling method included all adolescents seeking health services within the defined study time period as long as they met the inclusion criteria.

3.6 Study Procedure

The questionnaire was pre-tested in Kangema Sub County Hospital among HIV Positive adolescents who met the inclusion criteria a month prior to the study period. Pretest was done to five percent of the proposed sample size after which the questionnaire and the interview process was reviewed in readiness for the survey. The lead investigator trained all the field assistants on the study objectives, study tools that were used and on good research practices. Good research practices such as integrity, confidentiality, clear and accurate documentation of responses was be emphasized.

During the routine clinic visit at the CCC adolescents meeting the inclusion criteria were recruited, the lead investigator and the field assistants then informed the adolescents and their caregiver about the study. The purpose and method of the study was also explained and assent was sought from guardians of participants below 18 years while consent was sought from participants above 18 years. Those who consented and assented were requested to sign a pre-designed consent form. The consent form described the purpose of the study, procedure to be followed, potential benefits and risks of participating in the study. Any questions regarding the study from the caregiver and /or adolescent was answered before signing the consent. The

lead investigator then countersigned all the consent forms and noted the reasons for non-participation of eligible participants. Consenting and assenting was voluntary and free of coercion.Upon recruitment, the study subjects had the questionnaire administered to them, one by one at the comprehensive care clinic board room by the field assistants.

3.7 Data collection

Data was collected using interview administered questionnaires by trained research assistants who had prior hands on experience working in the comprehensive care clinic setting before. Research assistants were trained on ethical issues and how to administer the questionnaires to the respondents prior to the study.

The following data was collected:

a) HAART adherence among adolescent was determined by self-reports, keeping clinical appointments and refill records in the pharmacy. Self-report was obtained during questionnaire administration and missed doses in the previous 7, 14 and 30 days recorded and adherence was calculated as a percentage. Adolescents with adherence of 95% and above and those with adherence of below 95% had their proportions calculated out of all the adolescents interviewed.

b) Individual related factors; such as Age, sex, religion, relation with caregiver (biological parents, relatives or others), level of education of the adolescent, type of school(Boarding or day school), use of alcohol and abuse of other substances.

c) Health system related factors; Frequency of HAART provided, Pill burden, waiting time during clinic appointment, relationship with health care provider , psychosocial groups being helpful, convinent clinic working hours and distance from home to the health facility.

After the face to face interviews, data was abstracted from the Hospital data base on the pharmacy refill appointment records of the interviewed adolescents and also

clinician appointment records. These was assessed retrospectively for a period of 6 months prior to the interview date.

3.8 Data Management, analysis and presentation

Collected data from the study questionnaires was thoroughly checked and validated for accuracy and completeness. Data entry was done in MS Excel and was stored in a secure database and a hand drive for backup before and after analysis. Primary data on the questionnaire was kept under lock and key in a cabinet while electronically stored data was password protected for the entire duration of the study.

Quantitave data from questionnaires was cleaned, entered and analyzed using IBM to SPSS 22.0. Chi square (χ^2) test was used to evaluate the association between the independent variables and the dependent variable. The threshold for statistical significance was set at $p<0.05$. findings from quantitative data analysis are presented as narratives, tables, charts and graphs. The strength of the associations between the independent variables and the dependent variable are presented as odd ratio (OR) and the corresponding 95% confidence intervals(CI).

3.9 Ethical Considerations

The study proposal was presented to Kenyatta National Hospital/University of Nairobi Ethical Review Committee where it was approved. Courtesy calls was also made to Murang'a County Hospital Medical superintendent and the hospital administrator. Confidentiality and privacy in accordance with Medical ethics was highly observed and only study participants who assested and consented were allowed to participate in the study. Consenting and assenting was free of coertion.st

CHAPTER FOUR

RESULTS

4.1 Social demographic Characteristics

The age of the study participanants ranged from 10 to 19 years with a mean ± standard deviation age of 16 ± 2.3 years. Respondents who were aged 18 years and above comprised 37% of the study sample. Majority of the study participants were Christians (95%) and were pursuing secondary school education (60%). Additionally, most of the study participants were enrolled in day schools (61%) and were still dependent on their parents (77%). Figure 4.1 and table 4.1 shows the social demeographic characteristics of the study participants.
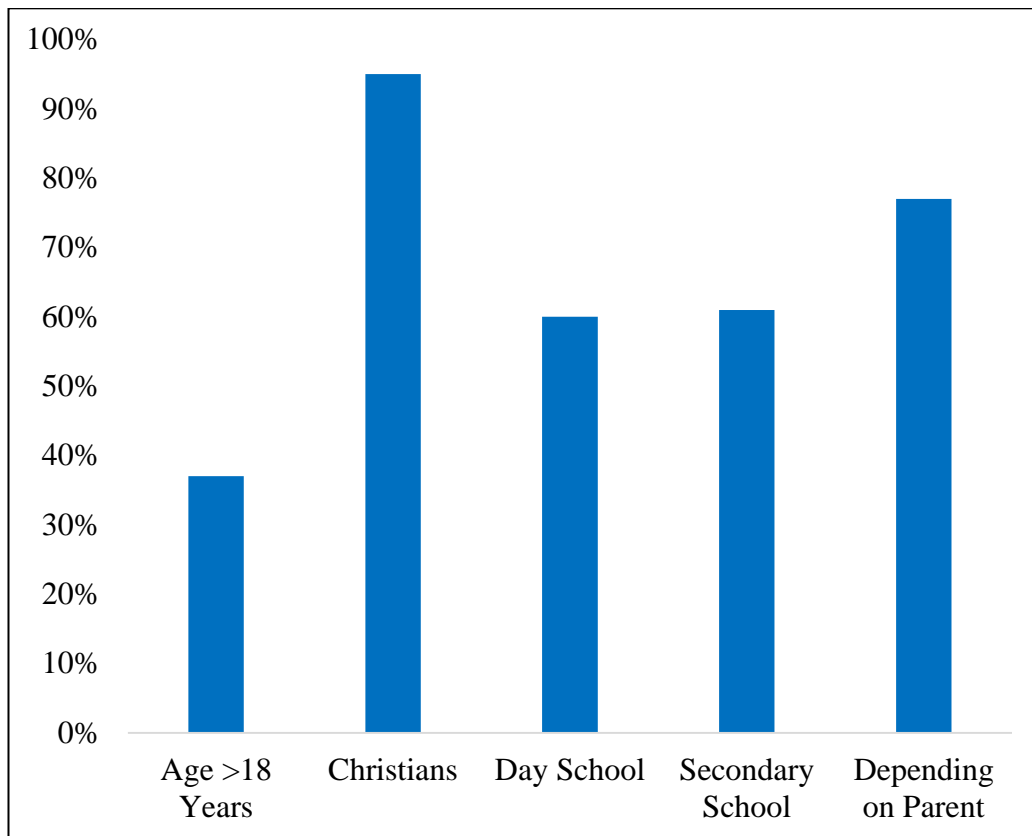
Figure 4.1: social demographic charateristics of the study participants

Table 4.1: Social demographic characteristics of the study participant

Characteristics	Frequency (n=85)	%
Gender		
Female	41	48.2
Male	44	51.8
Age (years)		
10 to 13	18	21.2
14 to 17	36	42.4
18 to 19	31	36.5
Religion		
Christian	81	95.3
Muslim	4	4.7
Education		
Tertiary	9	10.6
Secondary	51	60.0
Primary	25	29.4
Type of school		
Day	49	61.3
Boarding	31	38.8
Source of your livelihood		
Depends on parents	65	76.5
Depends on Relatives	17	20.0
Depends on well wishers	1	1.2
Employed	2	2.4
Rating of the support provide caregiver		
Good	78	91.8
Fair	6	7.1
Poor	1	1.2
Caregiver's support affects how I take medicines		
No	35	41.2
Yes	50	58.8
Knows his/her HIV status		
Yes	82	96.5
No	3	3.5
Ever been treated differently because of the medications		
Yes	9	10.6
No	76	89.4
Drinks alcohol or abuses other substances		
Yes	36	42.4
No	49	57.6

4.2 Social attributes

Most of the adolescents enrolled in the study (93%) reported that their main caregivers were the biological parents (mother and/or father) while, minority mentioned that their caregivers were not related to them biologically (7%). Asked to rate the support provided by caregiver, most of the respondents said it was 'good' (92%). In addition, most of them felt that their caregivers' support affected how they took the prescribed medications (59%).

A vast majority of the adolescents were aware of their HIV status (97%). Inquiries into the disclosure status among those who knew of their HIV status revealed that of the 76% had disclosed their HIV status. The highest proportion had disclosed their HIV status to parents (74%). An equal proportion of the interviewed adolescents had disclosed their status to their cousins and grandparents (10% in both cases).

The proportion of respondents who responded on the affirmative on being asked if they had ever been 'treated differently' because of the medications they were taking was 11%. Of the 36 adolescents who reported that they took alcohol or abused other substances (42%), twenty one (58%) reported to have had missed taking the medicines because of taking alcohol or abusing other substances as shown in Table 4.2.

Table 4.2: Social attributes of the adolescents enrolled in the study

Attribute	Number	%
Relationship with main caregiver (n=82)		
Mother/Father	63	74.1
Grandparent	7	8.2
Relative	6	7.1
Sister	2	2.4
Aunt	1	1.2
Other (no bloody relations)	6	7.1
Rating of the support provide caregiver (n=85)		
Good	78	91.8
Fair	6	7.1
Poor	1	1.2
Caregiver's support affects how I take medicines (n=85)		
No	35	41.2
Yes	50	58.8
Knows his/her HIV status (n=85)		
Yes	82	96.5
No	3	3.5
Disclosed HIV status (n=82)		
Yes	62	75.6
No	20	24.4
Disclosed to: (n=62)		
Parents	46	74.2
Cousins	6	9.7
Grandparents	6	9.7
Sister	1	1.6
Matron	1	1.6
Other/relatives	2	3.2
Ever been treated differently because of the medications (n=85)		
Yes	9	10.6
No	76	89.4
Drink alcohol or abuses other substances (n=85)		
Yes	36	42.4
No	49	57.6
Ever missed taking your medicine because of using alcohol or any other substance (n=36)		
Yes	21	58.3
No	15	41.7

4.3 Health system attribute of the study participants

4.3.1 Health system attributes on HAART regimen among the study participants.

The HAARTrelated attributes of the study participants are outlined in Table 4.3. Those who were on the first line and second line of HAART at the time the study was undertaken constituted 66% and 15% of the respondents. Majority took the drugs two times daily (86%) and reportedly took the medicines at specific times, for instance 8.00 a.m. and 8.00 p.m. were (86%). Minority of the study respondent's had experienced adverse effects from HAART (14%). The coping strategies following adverse effect included stopping taking the medicines, taking the medicines occasionally and consulting the health provider.

Table 4.3: HAARTrelated attributes of the study participants

Attribute	Number (n=85)	%
Therapy		
First line	56	65.9
Second line	13	15.3
Not sure	16	18.8
Daily frequency of drugs (HAART)		
Once	8	9.4
Twice	77	90.6
Time of taking medicines		
At specific time e.g. 8.00 a.m. and 8.00 p.m.	73	85.9
Morning and evening without following specific time	3	3.5
Evening	6	7.1
Morning and evening	3	3.5
Ever experienced a bad side effect due to the medicines		
Yes	12	14.1
No	73	85.9
Side effects affect the way I take medicines		
Yes	8	40.0
No	12	60.0

4.3.2 Health-system attributes on facility-home distance, health care providers and clinic operation

Asked to rate the distance from home to the hospital, 45% and 44% of the respondent said it was far and near respectively while 11.8% reported it as very far. Those who rated the healthcare workers as 'good' in terms of being caring, friendly and listening were 87% while 86% stated that the CCC working hours were convenient. Waiting time during clinic appointments was rated as appropriate by 69% of the adolescents in the study. Majority of the respondents found the psychosocial support groups very helpful (94%) and 98% of the respondents reported the medication was counted before refilling during the clinic visit as represented in the table 4.4 below.

Table 4.4: Health-system attributes on facility-home distance, health care providers and clinic operation

Attributes	Frequency (n=85)	Proportions(%)
Distance from home to the hospital		
Very far	10	11.8
Far	38	44.7
Near	37	43.5
Rating healthcare workers (interms of being caring, friendly and listening)		
Good	74	87.1
Average	9	10.6
Poor	2	2.4
CCC working hours convenient		
Yes	73	85.9
No	12	14.1
Waiting time during your clinic appointment		
Appropriate	58	69
Long	26	31
Psychosocial support groups are:		
Very helpful	80	94.1
Not sure	5	5.9
Remaining drugs were counted before refill is done		
Yes	83	97.6
No	2	2.4

4.4 Proportion of HIV positive adhering to HAART among the study participants

Twenty one of the eighty five adolescents in this study reported that they had missed taking the HAART as prescribed by the health providers. The study found a non-adherence level of 24.7% (95% confidence interval (CI) 16.8% to 34.8%). The most frequently reported reason for non-adherence was forgetting (62%) followed by travelling (14%) and running out of drugs (10%) (Figure 4.2)
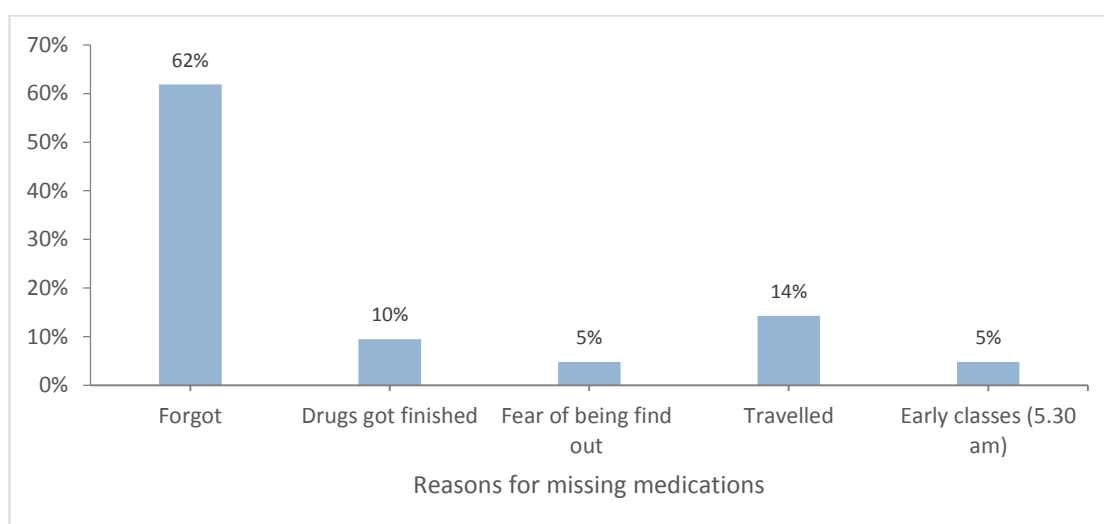
Figure 4.2: Reasons for missing medications

Table 4.5 displays the distribution of the drugs missed by the study participants during the period under study. The absolute adherence to HAART among the study participants in the last 7, 14 and 30 days assessed and was found to be, 100%, 94% and 67% respectively. Achieving an adherence of above 95% varied with regimen that the study participants were taking. Half of the study participants on single regimen failed to achieve an adherence of above 95% in the last 30 days while 22.1% of those on twice daily regimen failed to achieve an adherence of above 95%.

Table 4.5: Distribution of the drugs missed by the study participants during the study period

Dosage	Number missed	Last 7 days		Last 14 days		Last 30 days	
		Adherence	N(%)	Adherence	N(%)	Adherence	N(%)
Once Daily	0	100	8(100.0)	100	8(100.0)	100	4(50)
	1						
	2					<95	2(25)
	3 and Above					<95	2(25)
Twice Daily	0	100	77(100.0)	100	72(93.5)	100	53(68.8)
	1				5(6.4)	>95	5(6.5)
	2					>95	2(2.5)
	4 and Above					<95	17(16.9)

4.5 Individual factors associated with HAART adherence

4.5.1 Individual demographic factors association with HAART adherence

The age of the respondents who had ever missed any of the prescribed medications was not significantly different from that of their counterparts who had never missed the medications (mean ± standard error 15.1±0.46 years and 16.2±0.29 years,respectively, p=0.048). Adolescents aged between 10 and13 years were about seven times more likely to be non-adherent to HAART when compared with their older colleagues of 18 to 19 years (odds ratio (OR) 7.250 (95% CI 1.278-41.139), p=0.039). Similarly,those who were aged between 14 and 17 years had approximately 8 times higher odds of being non-adherent compared to those who were at least 18 years old (OR 8.196 (95% CI1.678 - 40.033), p=0.007). None of the adolescents in the aged between 10 and 12 years reported ever missing medications. Analysis of adherence by sex showed that a higher proportion of boys reported that they had ever missed taking the HAART (37% for boys and 14% for girls, OR 3.654 (95% CI 1.253 - 10.654), p=0.014). A significantly higher proportion of the respondents who were in boarding school reported ever missing their medications compared to those who were in enrolled in day schools (45% versus

14% respectively, OR 0.202 (95% CI 0.070 - 0.589), p=0.002). Other demographic factors assessed in the present survey including education, source of livelihood and religion failed to show any significant relationship with adherence to HAART among the studied adolescents as shown in Table 4.6.

Table 4.6: Association between individual demographic factors and adherence to HAART

Characteristic	Ever missed medications		OR (95% CI)	$\chi2$, df, P-value
	Yes	No		
Age (years)				
10 - 13.	6(33.3)	12(66.7)	7.250(1.278-41.139)	6.024,1,0.039
14 - 17	13(36.1)	23(63.9)	8.196(1.678-40.033)	8.433,1,0.007
18+	2(6.5)	29(93.5)	REF	
Sex				
Male	15 (36.6)	26(63.4)	3.654 (1.253 - 10.654	6.009, 1, 0.014
Female	6(13.6)	38(86.4)	REF	
Education Level				
Tertiary	1(11.1)	8(88.9)	0.396(0.041-3.841)	0.672,1,0.644
Secondary	14(27.5)	37(72.5)	1.198(0.397-3.617)	0.103,1,0.748
Primary	6(24.0)	19(76.0)	REF	
Type of school				
Day	7(14.3)	42(85.7)	0.202(0.070-0.589)	9.350,1,0.002
Boarding	14(45.2)	17(54.8)	REF	
Source of livelihood				
Depends on parents	15(23.1)	50(76.9)	0.300(0.018-5.090)	0.774,1,0.379
Depends on Relatives	5(27.8)	13(72.2)	0.385(0.020-7.404)	0.423,1,0.521
Employed	1(50.0)	1(50.0)	REF	
Religion				
Christian	21(25.9)	60(74.1)	0.741(0.651-0.843)	1.377,1,0.568
Muslim	0(0.0)	4(100.0)	REF	

4.5.2 Association between individual social factors and adherence to HAART

The current survey also assessed the relationship between selected social factors and adherence to HAART. The findings are presented in Table 4.6. Awareness of the HIV status was not significantly predictive of adherence to ART (p=0.086). A significantly lower proportion of non-adherence was observed among those who had disclosed their HIV status when evaluated against those who had not done so (18% against 40% respectively, p=0.040). Fewer adolescents among those who rated the support provided by the main caregiver as 'good', reported missing the medications compared to those who rated the support provided by the main caregiver on the contrary (22% and 57% respectively). Nonetheless this association failed to reach statistical significance (p=0.060). Reporting that the support from the caregiver affects how the respondent took their medicines was associated with 70% decrementin odds of being non-adherents (OR 0.322 (95% CI 0.116-0.895), p=0.026). Ever being treated differently by family members and/or friends because of taking the prescribed medications was found to increase the probability of being non-adherents by about 5 times (OR 4.68 8 (95% CI 1.127-19.505)p = 0.037. In addition, reporting ever missing taking medicines as a result of using alcohol or abusing other substances was significant predictor of adherence to HAART (OR 10.500 (95% CI 1.157-95.254), p = 0.024). Other social attributes failed to showsignificant association with adherence to HAART as shown in Table 4.6

Table 4.7: Evaluation of the relationship between social factors and adherence to HAART

Attributes	Ever missed		OR (95% CI)	χ2, df, P-
	Yes	**No**		
Knows HIV status				
Yes	19(23.2)	63(76.8)	0.151(0.013-1.756)	2.943,1,0.086
No	2(66.7)	1(33.3)	Ref	
Disclosed HIV status				
Yes	11(17.7)	51(82.3)	0.324(0.107-0.978)	4.208,1,0.040
No	8(40.0)	12(60.0)	Ref	
Rating of the support provided by caregiver				
Good	17(21.8)	61(78.2)	0.209(0.043-1.026)	4.315,1,0.060
Fair/Poor	4(57.1)	3(42.9)	Ref	
Support from caregiver affects how you take your medicines				
Yes	8(16.0)	42(84.0)	0.322(0.116-0.895)	4.947,1,0.026
No	13(37.1)	22(62.9)	Ref	
Ever been treated differently by family members/friends because of the medications				
Yes	5(55.6)	4(44.4)	4.688(1.127-19.505)	5.150,1,0.037
No	16(21.1)	60(78.9)	Ref	
Drinks alcohol or abuses other substances				
Yes	10(27.8)	26(72.2)	1.329(0.493-3.580)	0.317,1,0.574
No	11(22.4)	38(77.6)	Ref	
Ever missed taking your medicine as a result of using alcohol or any other substance				
Yes	9(42.9)	12(57.1)	10.500(1.157-95.254)	5.713,1,0.024
No	1(6.7)	14(93.3)	Ref	

4.6 Health system factors associated with adherence to HAART

4.6.1 Health system factors on HAART regimen provided association with adherence

The daily pill burden was a significant factor associated with adherence to HAART. Lower pill burden (1 or 2 pills daily) was associated with 87% lower odds of being

non-adherent to HAART (OR 0.127 (95% CI 0.027-0.591), p = 0.003). The line of the HAART prescribed to the adolescent, daily frequency of drugs and timing of taking the drugs were not significant factors for adherence to HAART among the adolescents(Table 4.6).

Table 4.8: Association between health system factors on HAART regimen provided with adherence

Characteristic	Ever missed medications		OR (95% CI)	χ^2, df, P-value
	Yes	No		
Therapy				
Second line	4(30.8)	9(69.2)	1.215(0.325-4.538)	0.084,1,0.772
Not sure	2(12.5)	14(87.5)	0.390(0.079-1.925)	1.408,1,0.235
First line	15(26.8)	41(73.2)	Ref	
Daily frequency of drugs				
Once	2(25.0)	6(75.0)	1.018(0.189-5.471)	0.001,1,0.984
Twice	19(24.7)	58(75.3)	REF	
Time of taking medicines				
Evening	2(33.3)	4(66.7)	1.528(0.258-9.049)	0.221,1,0.638
Morning and evening	1(16.7)	5(83.3)	0.611(0.067-5.582)	0.194,1,0.660
At specific time e.g. 8.00 a.m. and 8.00 p.m.	18(24.7)	55(75.3)	REF	
Pills taken in a daily (24hrs)				
1 or 2	2(6.5)	29(93.5)	0.127(0.027-0.591)	8.741,1,0.003
3 +	19(35.2)	35(64.8)	REF	
Ever experienced a bad side effect				
Yes	6(50.0)	6(50.0)	3.867(1.090-13.714)	4.806,1,0.028
No	15(20.5)	58(79.5)	REF	

4.6.2 Health Sytem factors on facility home distance, health providers and clinic operation association with HAART adherence

Those who reported that the healthcare workers in the CCC were good in terms of being caring, friendly and listening were found to have about 80% lower odds of having ever missed their medications (odds ratio (OR) 0.212 (95% CI 0.057-0.789), p=0.023). Respondents who said that the psychosocial support groups were very helpful had significantly lower odds of being non-adherent to HAART compared to

those who had a different opinion about the helpfulness of the groups (OR 0.067 (95% CI 0.007-0.644), p = 0.012). Study participants who responded on the affirmative on being asked if they found the CCC working hours' convenient were significantly less likely to be non-adherent (OR 0.169 (95% CI 0.047 - 0.614), p = 0.008). Other health system attributes assessed in the current survey were not significantly related to the adherence to HAART in adolescents (Table 4.7).

Table 4.9: Association between health system factors and adherence to HAART

Factor	Ever missed medications		OR (95% CI)	χ2, df, P-value
	Yes	**No**		
Distance from home to the hospital				
Very far	5(50.0)	5(50.0)	5.167(1.134-23.548)	5.012,1,0.039
Far	10(26.3)	28(73.7)	1.845(0.594-5.734)	1.139,1,0.286
Near	6(16.2)	31(83.8)	Ref	
Rate the health care workers in the CCC in terms of being caring, friendly and listening				
Good	15(20.3)	59(79.7)	0.212(0.057-0.789)	6.048,1,0.023
Average/Poor	8(61.5)	5(38.5)	Ref	
CCC working hours being convenient				
Yes	14(19.2)	59(80.8)	0.169(0.047-0.614)	8.494,1,0.008
No	7(58.3)	5(41.7)	Ref	
Rate the waiting time during your clinic appointment				
Appropriate	10(17.2)	48(82.8)	0.284(0.101-0.799)	6.016,1,0.016
Long	11(42.3)	15(57.7)	Ref	
Pharmacy: Drugs counted before refill				
Yes	21(25.3)	62(74.7)	0.747(0.659-0.847)	0.672,1,0.565
No	0(0.0)	2(100.0)	Ref	
Psychosocial support groups				
Very helpful	17(21.3)	63(78.8)	0.067(0.007-0.644)	8.732,1,0.012
Not helpful/Not sure	4(80.0)	1(20.0)	Ref	

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATION

5.1 Discussion

The study aimed at determining adherence to HAART among adolescents and deciphering the factors associated with it. Adolescents represents a unique and sometimes neglected group in the planning of healthcare services. The situation is even worse in sub-Saharan Africa (SSA), where more than eight out of ten of the world's HIV-infected adolescents live (UNICEF, 2016). This study findings highlight crucial considerations for optimizing treatment adherence in the study area and similar settings in SSA. This study found high self-reported non-adherence to antiretroviral therapy where 24.7% amongst adolescents living with HIV translating to about one in four adolescents being non-adherent to HAART. The poor adherence among adolescents documented in this study is a significant concern, given the limited HAART options available and the risk of drug resistance. A study done in Malawi reported much higher levels of self-reported non-adherence with nearly half (45%) of all ALHIV in this setting reporting missing HAART in the past month (Kim *et al.,* 2017). A recent study done in Zambia showed that 28.3% were non-adherent to HAART (Okawa.T *et al.,* 2018). In a survey done in Southwest Ethiopia and reported that 36% of the study participants had poor adherence to HAART. Non-adherence rates in Uganda were 18% (Mutumba *et al*., 2016) while a survey done in Rwanda (Fawzi *et al.,* 2016) reported a non-adherence rate of 37%. The observed variations in statistics on non-adherence could be attributed to differences in demographic characteristics, socioeconomic and cultural contexts under which the studies were conducted. For example, the research by (Okawa *et al*., 2018) focused on adherence to HAART among late adolescents (15 to 19 years) while our study population comprised all adolescents (10 to 19 years). Further, the Ethiopian study was done at the Clinic of Jimma University Teaching Hospital and recruited People Living With HIV/AIDS rather than adolescents alone.

5.1.1 Adolescent individual factors

5.1.1.1 Social demographic factors

A declining trend of the proportions of adolescents who were non-adherent was observed with the increasing age of the adolescents. The transfer of responsibility for treatment from caregivers to adolescents themselves is likely implicated. Compared with early adolescents, late adolescents are more likely to know their HIV status, be independent from their caregivers, take responsibility for on their medications and have wider social interactions (Okawa *et al*., 2018).

Being in a day school was associated with lower odds of being non-adherent compared to being in a boarding school. The most likely explanation to this finding is that adolescents who are in day schools have more access to psychosocial support and also have some support from the family members and caregivers. This is in agreement with a study by (Kikuchi. K *et al.,*2014) which found that the caregiver's and/or parents'presence is vital for adolescents' well-being, particularly in terms of economic and emotional stability in their daily life.

(Nabukeera-Barungi *et al.,* 2015) noted that adolescents reported stigma and discrimination at school by fellow students and teachers as well. Those in boarding schools lacked privacy to take their medication, which lead to missing doses. Additionally,those who did not disclose their HIV status to the school authorities found it very difficult to get permission to leave school so as to keep the clinic appointments.

The results from the present study indicated that there was no significant association between religion and adherence to HAART. Similarly, a study done in Nigeria documented no association between the two variables (Ashraf. *et al*., 2017).

5.1.1.2 Influence of disclosure and social support on adherence to HAART

In this survey, disclosure of HIV status was associated with decreased risk of non-adherence to ART among the study participants. This is not surprising as one can speculate that when a patient does not understand the reasons for taking the prescribed medication, the cooperation needed could be compromised. In line with this, disclosure might help the patient/client understand why he or she is taking daily medications and the benefits thereof (Kabogo. J *et al.,* 2018). Based on such evidence, the American Academy of Pediatrics has recommended age-appropriate disclosure of HIV status to children, with full HIV disclosure occurring by adolescence in order to achieve better disease outcomes and assist the child's psychological adjustment to knowing his or her status (American Academy of Pediatrics Committee on Pediatric AIDS, 2012). The WHO published a similar set of guidelines in 2011 which recommended beginning the disclosure process at 6 years old, with full disclosure being accomplished by the age of 12 (WHO, 2011).

Research undertaken, with patients aged between 10 and 19 years, in Eastern Cape, South Africa, showed a significant association between adherence to HAART and disclosure of HIV status (OR = 2.65, 95% CI[1.34–5.22]) (Cluver *et al*., 2015). A recent study done in Tanzania, associated HIV status disclosure with an eight-fold increment in the odds of being adherent to treatment (AOR=8.173, p<0.05) among children aged 6 to 17 years (Bulali *et al*., 2018).

In Thailand, (Sirikum *et al.,* 2015) measured adherence pre and post disclosure in a prospective manner. Contrary to what was found in the current survey, the study showed no statistical significant change in adherence at 6 and 12 months post disclosure. However, the study team noted that this lack of association may have resulted from unusually high levels of adherence reported at baseline.

Caregiver's support was associated positively with adherence to therapy in the current study. Previous research studies have shown similar findings. For example

(Chirambo. L *et al*.,2019) documented that the families of ALHIV supported them in uptake of therapy. The support rendered ranged from occasional reminders to direct observation of swallowing the pills.

5.1.1.3 Substance abuse and adherence to HAART

In line with the findings in this study which showed association between alcohol use and non-adherence to HAART, a Malawian study showed that alcohol use in the past 30 days was associated with non-adherence (OR 4.96, 95%CI [1.41–17.4]) (Kim.S *et al.,* 2014). (Gross.R *et al.,* 2016) identified frequency of cannabis use during the past 3 months as the strongest independent predictor of non adherence to HAART among African American Adolescents and Young Adult Males Living with HIV.

Participants incriminated substance abuse including alcohol as a reason for suboptimal HAART adherence including missing doses. The deleterious effects of alcohol and other substances of abuse in relation to poor disease outcomes and HAART non adherence among both adolescents are well documented (Gross.R *et al.,* 2016). Some studies have associated lower levels of alcohol use with an increase in HIV medical care appointment adherence (Outlaw *et al*., 2010). Usually it is the heavy drinking that is associated with non-compliance with HAART. All this possibly points to the need for the development of efficacious substance use reduction programs for this population.

5.1.2 Health sytem factors influence on HAART adherence among adolescent

5.1.2.1 Regimen related factors

This study showed that those on a single regimen had better adherence and lowered chances of being non adherent to HAART since this lowered the daily pill load. This is in concordance with findings a meta-analysis done on studies between 2005 and 2014 that showed a significantly higher adherence in patients with a once-daily fixed-dose compared to any other treatment regimen. Once-daily fixed dose regimens have been proved to be a crucial step to simplify HAART treatment and are currently

the easiest method to increase adherence. Experiencing adverse effects while being on HAART as a significant barrier to adherence this is in agreement with research by (Denison *et al.,* 2015) which reported HAART side effects among the reasons for incomplete adherence to among ALWIH.

5.1.2.2 Health system factors on facility home distance, health providers and clinic operation association with HAART adherence

The participants who rated the health care workers in the CCC as being caring, friendly and listening were less likely to be non-adherent to HAART. This is in concordance with the findings by (Asire. B *et al.,* 2017) who observed that adolescents are attracted to adolescent friendly services. Other health system attributes that were found to facilitate adherence to HAART among the adolescents included CCC working hours being convenient, waiting time during the clinic's appointment being appropriate and having psychosocial support groups. A study carried out in Uganda showed that peer support groups promote adherence to therapy.The study also revealed that the presence of counselors and caring health workers helped ALWHIV to adhere to their medication. Other health system's facilitators of adherence noted in the Ugandan study included scheduling clinic visits during school holidays, providing food support, transport to clinics, short waiting time, telephone calls from the facilities and text messages (Nabukeera-Barungi *et al.,* 2015). Overall, the findings on health system factors emphasize the need to create and sustainan adolescent friendly treatment spaces (both physical and social environments) in order to increase self-efficacy for medical care engagement (Gross. R *et al.,* 2016). Primary care providers working with ALWHIV need to be trained in the cultural and developmental needs of this group.

5.2 Conclusions

Although the prevalence of HIV/AIDS is reducing, adherence remains one of the challenges to the control of HIV/AIDS as evidenced in the current study where one in every four respondents reported poor adherence to HAART. The HAART adherence among the adolescents in this study was low with only 75% of the subjects adhering to HAART and 24.7% being non-adherent (95% confidence interval).

This study identified several individual factors that have a positive effect on HAART adherence among study participants which include;supportive parents or care givers, disclosure of HIV status at an early stage, being on a day school and age above 18 years. However, individual factors such as non disclosure, early and mid adolescent,being in a boarding school, use of alcohol and abuse of other substance are associated with suboptimal HAART adherence among adolescent.

The study also identified health system factors such as the HAART regimen provided where by single dose regimen was associated with better adherence as compared to regimen with twelve hourly dosage,this increases the number of daily pill burden which was mentioned as among the reasons of missing the daily dose.caring and listening healthcare providers, convenient clinic hours and age specific psychosocial support groups as other factors contributing to HAART adherence among adolescent. Very far distances from the facility contributed to suboptimal adherence due to the possibility of missing their clinic appointment.

The findings highlights the pressing need for better interventions targeting ALWHIV to facilitate optimal adherence to HAART, retention in care and improved treatment outcomes in order to optimize adherence to HAART in ALHIV.

5.3 Recommendation

Based on the findings of this study, there is a need to design strategies to address the barriers to HAART adherence in the studied population. Programme specifically tailored to address the challenges which are pertinent to ALHIV may help improve adherence to HAART.

In order to meet the needs of ALHIV and provide effective adherence support, flexible, responsive and adaptive service-delivery models are required. Differentiated care such as youth club model, weekend and after-hours clinics, mechanisms to fast-track HAART refill pick-up, clinic and community based support groups need to be implemented.

Adherence support can be reinforced further through the use of social media and youth focused material.The clinical encounter forms in use need to be revised to include tools for monitoring regimen adherence such as Morisky medical adherence scale,this will help in monitoring specific client adherence and take action early by supporting the adolescent address the issues of non adherence. Addittional tools to screen use of drugs and substance abuse such as CRAFFT screening test which will help identify adolescent with use of drugs or other substances which have been associated with poor HAART adherence. This tools will assist the health providers have a better monitoring of the adolescent on care and continuously assess their risk to poor HAART adherence thus taking early measures to support them have good adherence.

Given the difficulties experienced with adherence in most adolescents, regimen simplification can assist in improving adherence. To reduce pill load which this study identified as one of factors that may affect adherence we recommend transition to the once daily fixed dose combinations once adolescents achieve the appropriate weight and age without delay as per the current National guidelines on use of HAART.

Parents and caregivers of ALHIV need to be equipped with the skills and knowledge to disclose their own and the adolescent's HIV status, incrementally in accordance with the adolescent's age, cognitive skills and emotional maturity. Adolescents who have been informed of their HIV status need be provided with continuous support to prevent disclosure negatively affect their psychological and social wellbeing. Furthermore, efforts should be made to explore the potential role of trusted family members in contributing to the disclosure process

Psychosocial support in the form of support group participation need to be strengthened at the facility and can be aligned or provided separately at schools and community level. This has proven to be an effective group-management approach to providing integrated clinical, HAART refill and psychosocial care that supports adherence.

Peer psychosocial support outside of routine clinic hours specifically for ALHIV such as Saturday morning Teen clinics, provide age-segmented group adherence,

psychosocial support and youth activities while ALHIV individually collect pre-packed HAART refills and are seen clinically.

Youth-orientated service provision to the extent that the context allows, ALHIV oriented health providers, hours or allocated space within the facility.

Prioritise a reduced frequency of HIV care related visits, with longer periods between HAART refills, quick pick-up and psychosocial support services as close to home as possible.This will support access to HAART for adolescents in boarding school thus ensuring they never run out of medicine.

This study also recommends that future studies to longitudinally follow a cohort of adolescents living with HIV to investigate long-term antiretroviral therapy adherence and factors associated with adherence.

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APPENDICES

Appendix I: Informed consent/assent form for the adolescent

STUDY TITLE: ADHERENCE TO HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AND ASSOCIATED FACTORS AMONG HIV POSITIVE ADOLESCENT 10-19 YRS) IN MURANGA COUNTY HOSPITAL

Lead Investigator

Mburu Muiyuro

Mobile phone number: 0720034295

Supervisors

Dr. Kenneth Ngure,

Jomo Kenyatta University of Agriculture and Technology

Dr. Joseph Mutai

Institute of Infectious Diseases and Tropical Medicine - KEMRI

Introduction: The human immunodeficiency virus infection continues to increase especially in adolescents. HIV infection causes progressive destruction of the CD4+ cells and increase in viral load leading to the onset of AIDS when immune system failure occurs. With antiretroviral drugs, HIV has become a chronic manageable illness. Good adherence is important in the success of HAART. Several factors have been shown to affect adherence to HAART. This study seeks to determine the level and factors affecting adherence to HAART in adolescents.

Purpose of study: The Researcher is conducting a study in adolescents (10- 19 years) on care at the Murang'a County Hospital. The study seeks to know HAART adherence and associated factors among adolescent on care and treatment at the facility.

Adolescents will be interviewed individually and by taking part in this study you will help your health caregivers to provide the best care to you and also institute policies that will help take care of you and other adolescents on HAART.

Benefits: No direct benefits or payments, however, the adolescent will have a chance to ask questions they may have regarding their management and these will be answered. In addition, the data collected will help the health care workers at Murang'a County Hospital institute measures aimed at improving adherence at the same time improving quality of care

Risks: There are no known risks of you taking part in this study. Refusal to participate will in no way jeopardize your treatment.

Voluntariness: Participation in this study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point.

Procedure: The study will be conducted using a questionnaire, focus group discussion and data will also be abstracted from the pharmacy database and clinic appointment records.

Privacy and Confidentiality: The interviewer will keep all the information about you confidential, your name will not be used during the study, questionnaires will be numbered instead. Only study personnel will have access to the data collected, and data will be kept in a secure place.

Problems or Questions: If you ever have any questions about the study or about the use of the results you can contact the lead investigator **Mburu Muiyuro** by calling, 0720034295.

If you have any questions on your rights as a research participant you can contact the Kenyatta National Hospital Ethics and Research Committee (KNH-ECR) via email: uonknh_erc@uonbi.ac.ke

Respondent's agreement

I…………………………………………………………………………………….. ....hereby consent to participate in the study entitled Adherence to HAART and Associated Factors among HIV adolescent at Murang'a County Hospital. The nature of the study has been explained to me and I understand that my participation or refusal to participate will not in any way affect the course of my treatment at Murang'a County Hospital. I have been assured that no detriment to my health or care will ensue during the course of my participation in the studyI confirm that I have fully explained to the participant the nature and scope of the study and the contents of this consent form in detail. I confirm that no coercion or remuneration, monetary or otherwise has been offered to the participant.

Signed………………Date……………

Interviewer…………… signature…………Date ………………….

SWAHILI VERSION OF CONSENT FORM

STUDY TITLE: Uzingatiaji wa tiba za kurefusha maisha na mambo yanayo changia miongoni mwa vijanwalio na virusi vya ukimwi katika hospitali ya kaunti ya Murang'a

Kuanzishwa: Kiwango cha maambukizi ya virusi vya ukimwi kinaendelea kuongezeka kwa vijana. Maambukizi ya virusi vya ukimwi husababisha uharibifu wa seli za CD4+ na kuongezeka kwa mzigo wa virusi mwilini na kusababisha kinga za

mwili kushindwa kuzuia magonjwa. Madawa ya virusi vya ukimwi yameweza kuthibiti ukimwi, uzingatiaji mzuri wa madawa ni muhimu katika matibabu. Mambo kadhaa yameonyeshwa kuathiri uzingatiaji huu. Utafiti huu una madhumuni ya kuamua kiwango cha, na mambo yanayoathiri uzingatiaji wa madawa kwa vijana wanaopata matibabu katika hospitali ya kaunti ya Murang'a.

Madhumuni ya Utafiti: mtafiti afanya utafiti kwa vijana (miaka 10 hadi 19) wanaofuatiliwa kwa kliniki ya CCC katika Hospitali ya kaunti ya Murang'a. Utafiti huu una madhumuni ya kuamua kiwango na mambo yanayohusiana na uzingatiji wa dawa za kutibu ukimwi. Wewe mwenyewe ama mkiwa na mlezi wako mtahojiwa. Kushiriki kwako katika utafiti huu utasaidia madaktari wako kutoa huduma bora kwako na pia kuanzisha sera ambazo zitasaidia kutunza vijana wengine wanaotumia madawa haya.

Faida za Utafiti: Hakuna faida kwa mtu binafsi, hata hivyo, vijana watapata fursa ya kuuliza na kujibiwa maswali kuhusu malezi wanayopata kutoka kwa kliniki. Aidha, takwimu zitakazokusanywa zitasaidia madaktari kuweka mikakati ya kukomeza madhara ya kutozingatia matibabu.

Madhara: Hakuna hatari inayojulikana wewe kushiriki katika utafiti huu. Kutoshiriki katika utafiti huu hakutaathiri malezi unayopokea katika kliniki hii.

Hiari ya kushiriki: Kushiri kwa utafiti huu itakuwa ni kwa hiari yako. Hakutakuwa na zawadi au fedha kwa ajili ya kushiriki na kila mtu yuko huru kushiriki au kuondoka kutoka kwa utafiti huu wakati wowote.

Utaratibu: Utafiti utafanyika kwa kutumia dodoso, vikundi vya majadilianona, data kutoka kwa chumba cha madawa and uteuzi recodi.

Siri ya Utafiti:Taarifa zote kukuhusu zitawekwa siri na watafiti. Majina yako hayatatumika wakati wa utafiti, badala yake dodoso zitakuwa na nambari. Watafiti na wasaidizi ndio tu watakuwa na idhini ya kufikia takwimu hizi.

Matatizo au maswali: Iwapo utakuwa na maswali yoyote kuhusu utafiti au matumizi ya matokeo unaweza kuwasiliana na mpelelezi mkuu, Mburu Muiyuro nambari 0720034295.

Kama una maswali yoyote juu ya haki zako kama mshiriki katika utafiti huu, unaweza kuwasiliana na Hospitali kuu ya Kenyatta na Kamati ya utafiti (KNH-ESRC) kwa kutukia barua pepe uonknh_erc@uonbi.ac.ke

Idhini ya Muhojiwa

Mimi……………………………………………………………….nimekubali kwa hiari yangu kushiriki katika utafiti huu. Nimeelezewa na nimeelewa kuhusu utafiti huu, maswali yangu yamejibiwa na nikiwa na maswali ninaweza kupiga simu kwa Mburu Muiyuro nikitumia nambari 0720034295.

Nimeelewa ya kwamba kushiriki au kutoshiriki kwangu hakutaathiri kwa njia yoyote matibabu yangu katika Kliniki hii. Nimepewa uhakika kwamba kushiri katika huu utafiti hakuna hathari kwa afya yangu au huduma ninayopokea katika Hospitali hii ya Kaunti ya Murang'a

Sahihi…………………………………………Tarehe……………………….

Kidole

Mimi nathibitisha kwamba nimeelezea kikamilifu upeo wa utafiti huu na yaliyomo katika fomu hii ya idhini.Nathibitisha kuwa sijashurutisha ama kupeana manufaa yoyote, fedha ama vingenevyo ndio muhonjiwa ashiriki kwa huu utafiti.

Mtafiti………………………sahSTUDY TITLE: adherence to highly active antiretroviral therapy and associated factors among hiv positive adolescent 10-19 yrs) in muranga county hospital

Lead Investigator

63

Mburu Muiyuro

Mobile phone number: 0720034295

Supervisors

Dr. Kenneth Ngure,

Jomo Kenyatta University of Agriculture and Technology

Dr. Joseph Mutai

Institute of Infectious Diseases and Tropical Medicine - KEMRI

Introduction: The human immunodeficiency virus infection continues to increase especially in adolescents. HIV infection causes progressive destruction of the CD4+ cells and increase in viral load leading to the onset of AIDS when immune system failure occurs. With antiretroviral drugs, HIV has become a chronic manageable illness. Good adherence is important in the success of HAART. Several factors have been shown to affect adherence to HAART. This study seeks to determine the level and factors affecting adherence to HAART in adolescents.

Purpose of study: The Researcher is conducting a study in adolescents (10- 19 years) on care at the Murang'a County Hospital. The study seeks to know HAART adherence and associated factors among adolescent on care and treatment at the facility.

Adolescents will be interviewed individually and by taking part in this study you will help your health caregivers to provide the best care to you and also institute policies that will help take care of you and other adolescents on HAART.

Benefits: No direct benefits or payments, however, the adolescent will have a chance to ask questions they may have regarding their management and these will be answered. In addition, the data collected will help the health care workers at Murang'a County Hospital institute measures aimed at improving adherence at the same time improving quality of care

64

Risks: There are no known risks of you taking part in this study. Refusal to participate will in no way jeopardize your treatment.

Voluntariness: Participation in this study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point.

Procedure: The study will be conducted using a questionnaire, focus group discussion and data will also be abstracted from the pharmacy database and clinic appointment records.

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If you have any questions on your rights as a research participant you can contact the Kenyatta National Hospital Ethics and Research Committee (KNH-ERC) via email: uonknh_erc@uonbi.ac.ke

PARENTS/GUARDIAN agreement

I……………………………………………………………………………………..
...........................hereby   consent   to   allow
………………………………………………………………….to participate in the study entitled   Adherence to HAART and Associated Factors among HIV adolescent at Murang'a County Hospital. The nature of the study has been explained to me and I understand that his/her participation or refusal to participate will not in any way affect the course of his/her treatment at Murang'a County Hospital. I have been assured that no detriment to his/her health or care will ensue during the course of his/her participation in the study

I confirm that I have fully explained to the participant the nature and scope of the study and the contents of this consent form in detail.

Signed……………Date………………

Interviewer…………………signature……………………..Date
……………………………

SWAHILI VERSION OF CONSENT FORM

STUDY TITLE: UZINGATIAJI WA TIBA ZA KUREFUSHA MAISHA NA MAMBO YANAYO CHANGIA MIONGONI MWA VIJANA WALIO NA VIRUSI VYA UKIMWI KATIKA HOSPITALI YA KAUNTI YA MURANG'A

Kuanzishwa: Kiwango cha maambukizi ya virusi vya ukimwi kinaendelea kuongezeka kwa vijana. Maambukizi ya virusi vya ukimwi husababisha uharibifu wa seli za CD4+ na kuongezeka kwa mzigo wa virusi mwilini na kusababisha kinga za mwili kushindwa kuzuia magonjwa. Madawa ya virusi vya ukimwi yameweza kuthibiti ukimwi, uzingatiaji mzuri wa madawa ni muhimu katika matibabu. Mambo kadhaa yameonyeshwa kuathiri uzingatiaji huu. Utafiti huu una madhumuni ya kuamua kiwango cha, na mambo yanayoathiri uzingatiaji wa madawa kwa vijana wanaopata matibabu katika hospitali ya kaunti ya Murang'a.

Madhumuni ya Utafiti: mtafiti afanya utafiti kwa vijana (miaka 10 hadi 19) wanaofuatiliwa kwa kliniki ya CCC katika Hospitali ya kaunti ya Murang'a. Utafiti huu una madhumuni ya kuamua kiwango na mambo yanayohusiana na uzingatiji wa dawa za kutibu ukimwi. Wewe mwenyewe ama mkiwa na mlezi wako mtahojiwa. Kushiriki kwako katika utafiti huu utasaidia madaktari wako kutoa huduma bora kwako na pia kuanzisha sera ambazo zitasaidia kutunza vijana wengine wanaotumia madawa haya.

66

Faida za Utafiti: Hakuna faida kwa mtu binafsi, hata hivyo, vijana watapata fursa ya kuuliza na kujibiwa maswali kuhusu malezi wanayopata kutoka kwa kliniki. Aidha, takwimu zitakazokusanywa zitasaidia madaktari kuweka mikakati ya kukomeza madhara ya kutozingatia matibabu.

Madhara: Hakuna hatari inayojulikana wewe kushiriki katika utafiti huu. Kutoshiriki katika utafiti huu hakutaathiri malezi unayopokea katika kliniki hii.

Hiari ya kushiriki: Kushiri kwa utafiti huu itakuwa ni kwa hiari yako. Hakutakuwa na zawadi au fedha kwa ajili ya kushiriki na kila mtu yuko huru kushiriki au kuondoka kutoka kwa utafiti huu wakati wowote.

Utaratibu: Utafiti utafanyika kwa kutumia dodoso, vikundi vya majadilianona, data kutoka kwa chumba cha madawa and uteuzi recodi.

Siri ya Utafiti:Taarifa zote kukuhusu zitawekwa siri na watafiti. Majina yako hayatatumika wakati wa utafiti, badala yake dodoso zitakuwa na nambari. Watafiti na wasaidizi ndio tu watakuwa na idhini ya kufikia takwimu hizi.

Matatizo au maswali: Iwapo utakuwa na maswali yoyote kuhusu utafiti au matumizi ya matokeo unaweza kuwasiliana na mpelelezi mkuu, Mburu Muiyuro nambari 0720034295.

Kama una maswali yoyote juu ya haki zako kama mshiriki katika utafiti huu, unaweza kuwasiliana na Hospitali kuu ya Kenyatta na Kamati ya utafiti (KNH-ESRC) kwa kutukia barua pepe uonknh_erc@uonbi.ac.ke

Idhini ya Muhojiwa

Mimi………………………………………………………………….nimekubali kwa hiari yangu kushiriki katika utafiti huu. Nimeelezewa na nimeelewa kuhusu utafiti huu, maswali yangu yamejibiwa na nikiwa na maswali ninaweza kupiga simu kwa Mburu Muiyuro nikitumia nambari 0720034295.

Nimeelewa ya kwamba kushiriki au kutoshiriki kwangu hakutaathiri kwa njia yoyote matibabu yangu katika Kliniki hii. Nimepewa uhakika kwamba kushiri katika huu utafiti hakuna hathari kwa afya yangu au huduma ninayopokea katika Hospitali hii ya Kaunti ya Murang'a

Sahihi……………………………………Tarehe……………………….

Mimi nathibitisha kwamba nimeelezea kikamilifu upeo wa utafiti huu na yaliyomo katika fomu hii ya idhini.Nathibitisha kuwa sijashurutisha ama kupeana manufaa yoyote, fedha ama vingenevyo ndio muhonjiwa ashiriki kwa huu utafiti.

Mtafiti………………………sahihi……………………………Tarehe………………
……

Appendix II: Study questionnaire.

STUDY TITLE: ADHERENCE TO HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AND ASSOCIATED FACTORS AMONG HIV INFECTED ADOLESCENTS AT MURANG'A COUNTY HOSPITAL.

Questionnaire no……………….   Date……………….

INSTRUCTIONS: This questionnaire is to be carried out in an environment which ensures privacy and confidentiality.

(I).   Socio-Demographic Data

1.   What is your age in years? ....

2.   Circle the respondent's sex

        (a) Male

        (b) Female

        (C)Transgender

3.   What is your marital status?

        (a) Married

        (b) Single

        (c)Widowed

        (d)Divorced/Separated

        (e)Others (specify) ………………………….

4.   What is your level of education? .

        (a)Tertiary

(b)Secondary

(c)Primary

(d)Never gone to school

5 If you are still in school tick whether you are in boarding or day school

   (a) Day school
   (b) Boarding school

6. What is the source of your livelihood?

   (a) Depends on parents

   (b) Depends on Relatives

   (c) Depend well wishers

   (d) Employed

7 What is your religion?

   (a) Christian
   (b) Muslim
   (c) Hindu
   (d) Tradition
   (e) Others Specify………….

(II) **Assessing the proportion of HAART adherence**

(8) How many times do you take these drugs (HAART) in a day?

   (a)Once per day

   (b) Twice per day

(c)Three times per day

(d)Others (Specify…………………

(9) At what time do you take these medicines?

(a) At specific time e.g. 8.00 a.m. and 8.00 p.m.

(b) Morning and evening without following specific time

(c) Morning

(d) Evening

(e) The time when I remembers to take medicines

(10) How many pills do you take in a day? (24hrs)…………………

(11) Many people find it hard to always take their medications as prescribed. Have you ever missed any of your prescribed medications?

(a)Yes   (b) No

(12) If yes to above question, please fill in the table below.

Duration	How many doses did you miss?	No of doses prescribed
In the last 7days		
In the last 14days		
In the last 30 days		

(13) If you have ever missed taking your medication, what were the reasons for missing? Put a tick where applicable.

(a) Forgot ………………………………………………………

(b) Bad side effects…………………………………………………………………

(c) Did not understand instructions………………………………….

(d) Felt better……………………………………………………………………

(e) The dosage schedule is too complex ………………………….

(f)   Drugs   got finished…………………………………………………………

(g) Fear that someone will find out am taking the drugs …

(h) Didn't improve

(i) Others Specify ………………………

(III) **Social Factors**

(14) Do you know your HIV status?

(a) Yes

(b) No

(15) Have you disclosed your HIV status to any one?

(a) Yes

(b) No

(16) If yes to the above question, whom have you disclosed to?

(a) Parents

(b) Cousins

(c) Friends

(d) Others state……………………………………….

(17) What is the relationship between you and your main caregiver?

(a) Mother

(b) Father

(c) Grandparent

(d) Relative

(e) Others specify…………………………….

(18) How can you describe the kind of treatment support that you get from your care giver at   home?

(a) Good

(b) Fair

(c) Poor

(19) Does the support from your care giver at home affect how you take your medicines?

(a) Yes

(b) No

(20) Have you ever been treated differently by family members/friends because of the medication you are taking?

(a)Yes

(b)No

(21) If your answer is yes to the question above, how were treated differently?

(a) Social support was withdrawn by family members

(b) Discriminated

(c) Isolated by family members/ friends at school

(d) Stigmatized

(e) Others (Specify)………………………………………..

(22) Do you drink alcohol or abuse any other substance?

(a) Yes

(b) No

(23)   If yes please indicate what you use………….. And the reason of using it……………………………………………………………………………….

 (24) If your response to question number 14 is YES. Have you ever missed taking your medicine as a result of using alcohol or any other substance?

(a) Yes

(b) No

(IV) **Drug related factors**

(25) What line of treatment are you using?

(a) First line

(b) Second line

(c) Not sure

(26) Have you ever experienced a bad side effect due to the medicines that you take?

(a) Yes

(b) No

(27) If yes to the above question, did that affect how you take the medicines?

(a) Yes

(b) No

(28) If yes to the above (question 27).How did it affect you?

(a) Stopped taking the medicines

(b) Occasionally takes the medicines

(c) Continued to take the medication after consulting the health provider

(V) **Health system factors**

(29) How far is your home from the hospital?

(a) Very far

(b) Far

(c) Near

(30) How can you rate the health care workers in the CCC in terms of being caring, friendly and listening?

(a) Good

(b) Average

(c) Poor

(d) Don't know

(31) Are the working hours convenient with you?

    (a) Yes

    (b) No

(32) How would you rate the waiting time during your clinic appointment?

    (a) Appropriate

    (b) Long

    (c) Don't know

(33) Do the pharmacist/pharmacy technologist count the number of drugs you remaining with before issuing you with others?

    (a) Yes

    (b) No

(34) How can you describe the psychosocial support groups in terms of how you gain through health education and how they help you to continue taking the medicine?

    (a) Very helpful

    (b) Not helpful

    (c) Not sure