ANTIRETROVIRAL THERAPY ADHERENCE AND ITS DETERMINANTS AMONG ADOLESCENTS IN KAJIADO COUNTY, KENYA

BY:

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DECLARATION

Declaration by the Candidate

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I dedicate this work to my family for their encouragement and perseverance during the period of the study. My husband David Macharia and children Sonia Wambui and Ryan Ngeru.

ABSTRACT

Background: Anti-Retroviral Therapy (ART) use has increased globally. It is estimated that 15M (41%) People Living with Human Immunodeficiency Virus (PLHIV) are receiving ART, out of which 823,000 are children. Adherence to ART influences viral load reduction, improved immunity and treatment success. Studies show an almost 100% adherence is needed to sufficiently suppress viral replication. However, several factors hinder adherence success including; poverty, substance abuse, stigma and lack of disclosure. While HIV prevalence has continued to decrease worldwide, it remains a major cause of morbidity and mortality among adolescents. Poor ART adherence increases the risk of viral drug-resistance, reduces future therapeutic options and increases the risk of transmission. Adherence has been studied extensively with adult patients, but adolescent adherence has been largely neglected in the literature.

Objective: The aim of this study was to estimate prevalence of ART adherence and to identify characteristics of adolescents and their guardians that influence ART adherence

Methods: A cross sectional, facility-based study was carried out in four select facilities in Kajiado County. Qualitative and quantitative data was collected among HIV positive adolescents and their guardians. Simple Random Sampling without replacement was used to identify participants. A sample size of 174 was arrived at using the Cochrane formula. All eligible adolescent had an equal opportunity to participate. Data was managed using Statistical Package for the Social Sciences. Proportions and frequencies were calculated for categorical data and means and medians for continuous variables. Bivariate analysis was conducted to estimate strength and direction of associations between factors using a 95% confidence intervals and P-value (<0.05). To determine and control for multiple independent risk factors, logistic regression was performed for factors with a p-value of < 0.05. Ethical clearance was sought from Moi Institutional Research and Ethics Committee.

Results: A total of 167 adolescents aged 10-19 were interviewed. Males constituted 49% and Females 51%. Estimated level of adherence was 92.8% (95% CI 87.8% - 95.8%). At bivariate analysis, significant factors at P-value *(<0.05)* were occupation ($P= 0.021$), side effects ($P= 0.009$), lack of food($P= 0.013$), having friends($P= 0.011$), confidentiality($P= 0.003$), trust($P= 0.009$) and quality of care rating($P= 0.05$), swallowing drugs at the right time($P= 0.000$) and keeping clinic appointments ($P= 0.004$). On multiple regression, two factors contributed significantly to the model, experiencing side effects and having friends who knew the adolescent status and cared for them F $(4,157)$ $=22.302$ $p<0.05$. The most common reason for missing a dose was forgetting, fear of stigma and lack of food

Conclusions: This study found a prevalence rate slightly lower than the optimum and higher

than most studies. Medication related factors were the most significant predictors of adherence

Recommendations: Adopt mechanisms to remind adolescents to take ART, improved regimen with reduced side effects, psychosocial support and stigma reduction strategies

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ALHIV	Adolescent Living with HIV
ART	Anti -Retroviral Therapy
ARV	Antiretroviral drug
AVERT	HIV and AIDS Information and Resources
CCC	Comprehensive Care Clinic
CD4	Cluster of Differentiation 4
DNA	Deoxyribonucleic Acid
HEI	HIV exposed infant
HIV	Human Immunodeficiency Virus
IREC	Institutional Research Ethics Committee
KAIS	Kenya HIV/AIDS Indicator Survey
KDHS	Kenya Demographic and Health Survey
KNBS	Kenya National Bureau of Statistics
LMIC	Low and Middle Income Countries
MCH	Maternal and Child Health
MDG	Millennium Development Goals
MOH	Ministry of Health
MTCT	Mother to Child Transmission
PEPFAR	President's Emergency Plan for AIDS Relief
PI	Protease Inhibitor
PMTCT	Prevention of Mother to Child Transmission
PRECEDE	Predisposing, Reinforcing, Enabling Constructs in Education/Environmental Diagnosis and Evaluation
PROCEED	Policy, Regulations, Organizational Constructs in Educational/Environmental Development
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations Children Fund
WHO	World Health Organization

DEFINITION OF TERMINOLOGIES

Adherence: Extent to which patients follow instructions of their health care providers regarding taking their medications

Adolescents: Include individuals 10-19 years age group according to WHO (2010). This study complied with this definition

AIDS Is the disease that develops after progressive immune deficiency caused by infection of CD_4+ T cells with the Human Immunodeficiency Virus (HIV).

CD$_4$ Antigen marker of helper/inducer T cell that recognizes antigens bound in class II MHC protein.

Caregiver Any person giving care to a child in the home environment. This can be family members, such as parents, foster parents, legal guardians, siblings, uncles, aunts and grandparents or close family friends or a community volunteer

HIV Disclosure Act of adolescents knowing their HIV status

HIV non-disclosure Act of making secret the HIV status of one or another person. Can be health workers to adolescents, adolescents to their peers or intimate relationships or parents/care givers to adolescents

Incidence The number of new cases that occur during a specified period in a population at risk for developing the disease.

Non adherence (suboptimal adherence) taking less than 95% of the prescribed pills in a given time

Optimal adherence to ART Taking medicine consistently and as prescribed pills by a health care provider at least 95% of the time

Prevalence   This refers to the number of affected persons present in the population at a specific time divided by the number of people in the population at that time.

Undetectable viral load   When the virus is not detected in the blood by a laboratory test. This is achieved when the copies of virus are less than 50 per milliliter of blood

Viral load   Levels of virus found in the blood per 10 milliliters (mls)

Viral Suppression   Is when the number of virus copies is less than 400 in a mililitre of blood

Virologic failure   Viral load above 400 copies/ml after 24 weeks of treatment, above 50 copies/ml after 48 weeks of treatment or repeated viral loads above 400 copies/ml after prior viral suppression

ACKNOWLEDGEMENT

CHAPTER ONE:

INTRODUCTION

1.1 Background Information

Human Immunodeficiency Virus (HIV) persists as a key public health issue. Globally, there are 36.9M people living with HIV out of which 2.6M are children; Seventy percent of these live in sub-Saharan Africa (Avert, 2015). It is estimated that 41% of People Living with HIV (PLHIV) are receiving Anti-Retroviral Therapy (ART) translating to 15M people out of which 823,000 are children ("Global HIV and AIDS statistics | AVERT," 2015).

Over 3 million children under 15 years of age were living with HIV in sub-Saharan Africa in 2010, representing more than 90% of all children with HIV in the world. Eastern and Southern Africa bear a larger burden with 2.2 million children with HIV, relative to the 990,000 in West and Central Africa. (Sohn & Hazra, 2013).

In Kenya, there are an estimated 1.6M People Living with HIV (PLHIV) out which 191,840 are children aged 0-14 years (Ministry of Health, 2014). Seventy-eight percent of adults who need Anti-Retroviral Therapy (ART) are accessing them compared to 42% of children (Ministry of Health, 2014). This shows that ART access is still below the recommended 90% and is worse off in children than adults. This coupled with less than optimal adherence means the battle against HIV/AIDS is far from over as witnessed by survey done by the National AIDS Control Council (NACC) which found out that one in six adults and adolescents reported missing an ARV dose at least once within the 30 days preceding the survey (National AIDS Control Council, 2014).

It is well documented that Adherence to ART influences viral load reduction, improved immunity and success of treatment among PLHIV evidenced by a longer productive life. (Kim, Gerver, Fidler, & Ward, 2014; Olisah, Baiyewu, & Sheikh, 2010; Simoni et al., 2007; Rachel C Vreeman, Wiehe, Ayaya, Musick, & Nyandiko, 2008). Studies have also continued to show an almost 100% adherence is needed to sufficiently suppress viral replication (Olisah et al., 2010).

Adherence has been studied extensively with adult patients. However, issues in adolescents adherence and possible reasons for their poor adherence have been largely neglected in the literature. (R. C. Vreeman et al., 2009). No specific literature was found for Kajiado County on this subject. However, according to NACC, 2015, the prevalence of HIV in Kajiado County is 4.7% which is an increase from 4.4% reported in 2014. Kajiado is rated 22nd out of the 47 counties in Kenya (KASF, 2014) and contributes 3.4% of all the HIV infections in Kenya (NACC, 2012).

Several factors hinder adherence success including chronic poverty, limited resources, substance abuse stigma and lack of disclosure (Simoni et al., 2007). Other factors cited include patients' age, regimen complexity, drug side-effects, advanced HIV disease and patients' mental health (Olisah et al., 2010).

Advancement in HIV treatment and care has resulted to children born with HIV living longer (National AIDS Control Council, 2014). This means that they need a life time supply of ARV. Adherence to these medications is key as there are limited treatment options. Adherence in adolescents is therefore critical for their survival as they will need the medication all their life. According to UNAIDS, AIDS is the leading cause of death among adolescents in Africa (UNAIDS, 2015). There is therefore a need to

address issues around ART adherence to improve survival and development of the adolescents.

Adolescence is the age between 10-19 yrs. (UNICEF, 2011). It is the age of transition from childhood to adulthood and is marked with physical and emotional changes. The age is also marked with sexual experimentation and is characterized by high-risk sexual behavior (Kim, Gerver, Fidler, & Ward, 2014). This further exposes the HIV free adolescents to the risk of sexual transmission. Proper Adherence to ARV has been shown to reduce viral loads to undetectable levels thus reducing the chances of sexual transmission.

Adolescents are mostly school going age with several in boarding schools. This coupled with lack of disclosure and fear of stigma makes them less likely to adhere to ART (Simoni et al., 2007).

Adolescents have been described as the 'fulcrum' and the 'center of the epidemic', with 42% of new HIV infections occurring in this age group (Kim, Gerver, Fidler, & Ward, 2014). This means the possibility of an AIDS free generation depends highly on how we respond to the needs of adolescents. World Health Organization (WHO) considers adolescence as the period between 10 and 19 years of age, during which healthy adolescents pass through well-described stages of physical, psychological and sexual maturation. These have implications for the provision of appropriate treatment and care for HIV-infected adolescents.

Adolescents are unique and usually a neglected group. While HIV prevalence has continued to decrease worldwide, it remains a major cause of morbidity and mortality among adolescents(Adejumo, Malee, Ryscavage, Hunter, & Taiwo, 2015).

1.2 Problem Statement

Poor ART adherence increases the risk of viral drug-resistance. (Olisah, Baiyewu, & Sheikh, 2010). This   decreases the treatment efficacy leading to disease progression whereby the HIV infection can develop to full brown AIDS. It also reduces future therapeutic options. In Kenya, there are three treatment options with the third line being very expensive and requiring approval by National Technical Working Group for one to be enrolled. A young person defaulting on first line and being switched to a second line at an early age will adversely affect his/her life. Poor adherence also increases the risk of transmission due to unsuppressed viral Replication (Olisah, Baiyewu, & Sheikh, 2010).

Human Immunodeficiency Virus is ranked among top causes of morbidity and Mortality in Kajiado County. (County Government of Kajiado, 2014)

According to Kenya HIV prevention roadmap, Kajiado County is ranked in the medium incidence cluster with HIV prevalence of 4.4%. (Ministry of Health, 2014). Kajiado is ranked 23rd in terms of HIV burden and contributes 1.6% to the national incidence rate. There are an estimated 20,100 adults and 2956 children living with HIV in Kajiado County. (Ministry of Health, 2014).

Kajiado County is near Nairobi County, which has a HIV prevalence of 6.8% (ranked 8th nationally) and falls in the high incidence counties. This has a spill-over effects on Kajiado County because Kajiado offers access to affordable housing to Nairobi workforce (MOH, 2015).

Kajiado County HIV/AIDS strategic plan also prioritizes defaulter tracing as a key activity.

There was no literature specifically tackling the issue of adherence among the different populations within Kajiado County. However, the three key county specific document reviewed cited HIV/AIDS as a key cross-cutting issue.

1.3 Justification of the Study

Use of ART among HIV positive adolescents is key to preventing new infections as optimal ART use decreases both vertical and horizontal transmission of HIV(Young, Wheeler, McCoy, & Weiser, 2014)

This study provides baseline information on the level of success of ART adherence among adolescents in Kajiado county and determinants thereof. This information will be useful in policy formulation to improve retention in care for adolescents as well as provide more adolescent friendly services at the Comprehensive Care Clinics (CCC) in Kajiado County.

The study results will be helpful in policy formulation to improve access to care and treatment by adolescents. They will also help in project design as key barriers to adherence will be identified and projects can be designed to address these barriers

The was carried out in Kajiado North sub-county which is one of the five sub-counties in Kajiado. Kajiado North sub-county was selected because it has both urban and rural populations making it more representative of the county. It is also the most populous of the five sub-counties

1.5 Research Questions

1.   What is the prevalence of ART adherence among adolescents attending CCC clinics in Kajiado North Sub-county?

2.   What are the determinants ART adherence among adolescents attending CCC clinics in Kajiado North Sub-county?

1.6. Objectives of the study

1.6.1 Broad Objective

To determine the prevalence ART use and its determinants among adolescents in Kajiado North sub-county

1.6.2 Specific Objectives

1. To estimate the prevalence of ART adherence among adolescents attending CCC in Kajiado North Sub-county

2. To identify client factors affecting ART adherence among adolescents CCC in Kajiado North Sub-county

3. To identify socio-environmental factors affecting ART adherence among adolescents attending CCC in Kajiado North Sub-county

4. To identify health care related factors affecting ART adherence among adolescents attending CCC in Kajiado North Sub-county

CHAPTER TWO:

LITERATURE REVIEW

2.1 Global

Human Immunodeficiency Virus continues to affect individuals all over the world with the recent trends indicating an increase in new infections among adolescents. The gains in medical technology have significantly reduced the rates of new HIV/AIDS infections. According to research by UNAIDS; the number of AIDS related deaths dropped by 48% between 2004 and 2014 (UNAIDS 2014). However, according to (World Health Organization, World Health Organization, & Department of HIV/AIDS, 2015), the rate of new infections indicates a worrying trend among adolescents.

A 2015 study by UNAIDS indicates that there were 250,000 cases of new infections among persons between the ages of 10-19 years with adolescent girls making up the majority. Some of the contributing factors include lack of sex education, early marriage, child abuse and domestic violence against the youth. Fortunately, the rate of mother to child infection has decreased significantly over the years through maternal testing and PMTC (Prevention of Mother to Child Transmission programs (Agwu & Fairlie, 2013). The UNAIDS study found that over 130,000 adolescents died of HIV/AIDS related complications in 2013 making this the highest cause of adolescent mortality in Africa (UNAIDS 2013). These statistics indicate the necessity of further research into adolescents contracting HIV/AIDS despite the gains made in fighting the disease.

The adherence to medication/ ART is critical for the survival of HIV/AIDS infected people particularly for the young (McGrady, Brown, & Pai, 2016). However

according to (World Health Organization, World Health Organization, & Department of HIV/AIDS, 2010), studies indicate that despite knowing the importance of the treatment, some infected persons are unable to adhere to the stringent conditions. According to research studies, when adherence rates are under 80%, there is a high probability of the development of drug resistant strains of the virus (Amaco, Alfonso & Fisher, 2006). Lack of adherence is a serious issue that has long-term effects on the person living with HIV/AIDS due to the risk of reinfection by drug resistant strains. A recent study in Zambia exposes some of the causes of lack of adherence to ART treatment. Many people fear discrimination and social exclusion making them unable to accept or disclose their status (Musheke, Bond & Merten, 2013). This is especially important for adolescents who may lack privacy especially in a school setting as taking ARVs may lead to accidental disclosure of their HIV seropositive status. Economic constraints, long delays in receiving treatment and a negative perception of ART also contributed to the decreased adherence to treatment (Musheke, Bond & Merten, 2013).

There are numerous studies that discuss the issue of adherence to ART for both adults and children. As such, different ways of measuring adherence have been explored by researchers. One of the most effective modes of determining the extent of adherence in a population is through the analysis of prescription claims that provide a reliable source of information (Fairman & Motheral, 2000). Other methods include measuring the CD4 lymphocyte count as well as evidence of drug resistance can be used to determine non-adherence to ART (Simoni, Montgomery, Martin, New, Demas & Rana, 2006).

In 2013, nearly half of all adolescents living with HIV globally were in six countries

- 15% South Africa
- 8% Nigeria
- 7% United Republic of Tanzania
- 7% Kenya
- 7% Ethiopia
- 6% India
- 5% Uganda
- 5% Zimbabwe
- 5% Mozambique
- 4% Malawi
- 4% Zambia
- 2% Indonesia
- 2% Cameroon
- 2% Côte d'Ivoire
- 1% Democratic Republic of the Congo
- 20% Remaining
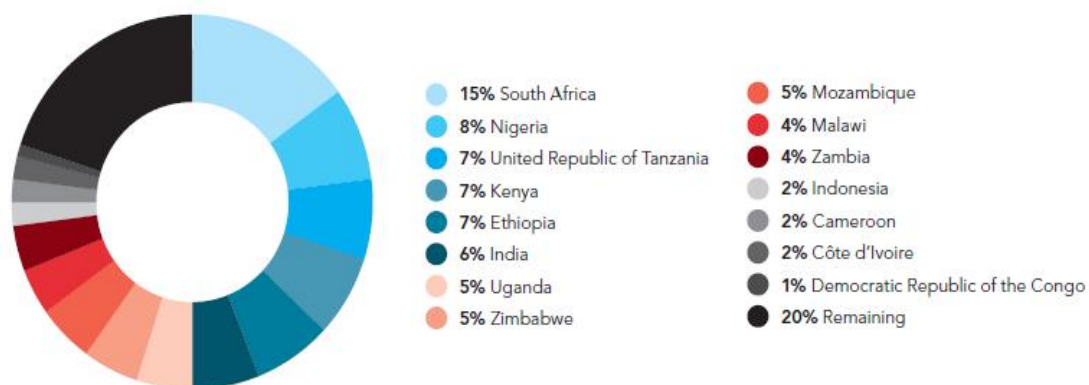
Source: UNAIDS 2013 estimates.

Figure 1: HIV Prevalence among Adolescents

2.2 Regional

Adolescents are some of the most high-risk persons with regards to the spread of HIV/AIDS. The reason for this is that adolescence is a pivotal part of any child's development. At this stage, children rapidly evolve emotionally, mentally and physically. Furthermore, they can make their own decisions and have less supervision from their guardians (Agwu & Fairlie, 2013). Evidence suggests that the rates of unprotected sex among adolescents are very high between 27-90% (Cluver, Hodes, Toska et al., 2015). These rates are of concern especially due to the extremely low rates of disclosure among adolescents. For example, in Uganda the 84% of sexually active adolescents have never discussed the issue of HIV/AIDS. Furthermore, over 90% of these people are unaware of their partners HIV status (Kerrissey, 2008). Factors contributing to lack of disclosure include fear of rejection, lack of confidentiality and fears from the family (Kerrissey, 2008). A cohort study conducted in South Africa found that HIV-positive children in low-income settings face many challenges to adherence to antiretroviral treatment (ART) and have increased

mortality on treatment compared to children in developed countries. (Grimwood et al., 2012).

On the other hand, many adolescents contract the disease from their parents rather than external contributions. As such, parents have the responsibility of disclosing their status to the children as well as support them in their treatment. According to recent study, the disclosure rate between parents and children ranges between 45%-70% (Tiendrebeogo, Hejoaka, Belem, et al., 2013). In Kenya, studies indicate that parents and caregivers of these adolescents fear the stigmatization of their children such that some of them fail to disclose to the child their HIV/AIDS status. This further discourages the adherence to ART as the children cannot fully participate without knowing and accepting their HIV/AIDS status. A 2010 study of children and their guardians in Western Kenya found that 118 out of 120 caregivers had not informed the adolescents of their HIV status (Vreeman, Nyandiko, Ayaya, et al. 2010). This occurs regardless of whether the caregiver is a biological or non-biological guardian (Safreed-Harmon, Siripong, Kerr, et al., 2007).

However, broaching the issue with children is not a simple task as the approach can have lasting effects on the child's perception of illness. According to a study conducted by Abadia-Barrero and LaRusso, children of different ages view HIV/AIDS differently therefore there must be an appropriate method of disclosure to these children at all ages. The common theme of social exclusion has been observed in numerous studies concerning disclosure and the adherence to HIV/AIDS treatment. Therefore, promoting disclosure in a sensitive manner that aims to educate the child is an important aspect of their reaction to treatment.

Despite the negative connotations linked to disclosure, there are some positive aspects of the practice. First, there is much better adherence to ART for the child. Secondly, it leads to more responsible sexual activity among adolescents. When adolescents can understand their health status and the consequences of their actions, they take a greater responsibility over their health (Gyamfi, Okyere, Appiah-Brempong, Adjei & Mensah, 2015).

Research from past studies and medical sites indicate that adherence to ART among the youth is over 70% for Africa and Asia while this number drops to 50-60% in North America and Europe (Kim, Gerver, Fidler &Ward, 2014). Globally, the rate of adherence to ART is at 62% (Kim, Gerver, Fidler & Ward, 2014). Unfortunately, many of these young people are unable to adhere to their treatment due to fear of disclosure and reprisal from the society. According to a study conducted in Zambia, adolescents living with the disease are forced to cope on their own without social support other than that received from the primary caregivers (Denison, Denis, Banda, Packer, et al., 2014). When one or both parents are deceased, there is a significant risk of non-adherence to treatment. In Kenya, over 66% of adolescents living with HIV/AIDS have either lost one or both parents (Vreeman, Wiehe, Musick, et al., 2008).

While there are fears of subsequent disclosures of HIV status and resulting negative social responses have been reported in other studies, we could not find any literature stating whether disclosure to children does indeed increase the amount of stigma and discrimination that families experience or not. This in turn suggests that stigma, isolation, and discrimination should be monitored very closely when evaluating programs to increase pediatric disclosures. Understanding exactly how caregivers in

this setting perceive the benefits and risks of disclosure of a child's HIV status enables clinicians and care systems to address these fears and to open.

Adherence to antiretroviral therapy (ART) is important when it comes to suppression of HIV, overall health improvement and cutting back on the transmission rate of the virus. Unlike other chronic diseases whereby drugs remain effective even after the dosage is interrupted for a while, non-adherence to ART leads to loss of virologic control which may result in drug resistance and eventually lack of any medical solutions.

A patient's social situation and clinical condition are some of the major factors that affect adherence to ART. Therefore, it is very important that patients obtain and comprehend as much as they can about the HIV disease especially the importance of therapy, the prescribed regimen and the possible outcome of drug resistance as a result of lack of adherence to ART.

For patients who want to start taking or retaking the ART it is important for them to first get an assessment from a clinician to determine a patient's adherence readiness. Coming up with a plan that the patient can follow is a major starting point to effective treatment and some of the factors to consider include the patient's daily schedule, patient's tolerance of pill number, size and frequency plus any issues affecting absorption. After taking all this into consideration, a medical choice and administration schedule should be developed in accordance to the patient's routine daily schedule.

Developing a good patient-provider relationship is a key factor when it comes to the Improvement of adherence plus positive reinforcement can really aid a patient in

maintaining high adherence levels. Patients who have a had a history with non-adherence are at risk of poor adherence if they restart the medication with the same drugs therefore reasons for previous poor adherence should first be identified.

According to studies conducted by Bikaako-Kajura and colleagues (2006), John-Stewart and colleagues (2013), and Vreeman and colleagues (2010), it was ascertained that disclosing to an infected child his/her HIV status is highly beneficial in different ways some of which include responsible adolescent sexual behavior, adherence to medication and it also results in the child better understanding his/her condition and how to manage it.

In a study conducted in Uganda, it was observed that adherence to ART was better in children who knew their HIV status (Bikaako-Kajura et al.2006). It was noted however in another study that some children were still reluctant to go to hospital even after disclosure (Hammami et al., 2004). Therefore, disclosure should be done in such a way that it will lead to positive effects for the children in their early years.

Healthy and responsible sexual behavior in teenagers is another benefit associated with disclosure to children. Findings reported by Santamaria and colleagues (2011), stated that the longer a child longer children were informed of their HIV status, the more likely they were to reveal their status to their sexual partners, and by so doing restricting the spread of the virus and avoid re-infection with different strains of the virus. This was supported by a report by American Academy of Pediatrics (1999), which suggested that, once fully informed of their status, children could, among other things, consider the consequences of their sexual behaviors.

Providing biomedical information and offering psychological and emotional support to both the child and the caregiver are some of the ways in which health care workers provide help during the disclosure process. This was supported by a study done in South Africa Myer and colleagues (2006) on health care provider views about disclosing HIV status to infected children, in which almost all participants agreed on the need to help caregivers disclose HIV status to infected children. The findings also supported a comprehensive literature review (Pinzon-Iregui, Beck-Sague, & Malow, 2013), which affirmed the need for disclosure guidelines based on cultural factors, national realities, and individual family circumstances.

Based on research in Zimbabwe, Campbell et al. (2012) have described an 'adherence competent community' as 'a social landscape where local community members, nurses, NGOs, guardians, and children themselves are able to optimize opportunities... to promote optimal child health'. Programs are increasingly acknowledging and seeking to address a range of determinants of adults living with HIV (ALHIV) wellbeing (Skovdal & Belton, 2014). These include broad-based interventions to support caregivers of HIV-positive children with the purpose of increasing children's retention in care (Busza, Dauya, Bandason, Mujuru, & Ferrand, 2014).

2.3 Kenyan Situation

According to Kenya National Bureau of Statistics, 2009, the estimated population of adolescents in Kajiado County is 212,322 and 29,281 in Kajiado North Sub-County. Out of this, an estimated 2989 are adolescents living with HIV. Other literature specific to Kajiado County was not available for review hence literature on studies done in Kenya was reviewed. The other challenge encountered with Ministry of health data is their classification of pediatric (0-14) and Adult (15-64) ART clients thus missing out on adolescents. A study by National AIDS Control Council found

that among persons who were receiving ART, 16.3% had missed taking a pill in the past 30 days. Among persons on ART who had not missed taking a pill in the past 30 days, 78.5% were virologically suppressed. In comparison, only 57.9% of persons who had missed taking a pill in the past 30 days were virologically suppressed. Although the study did not indicate how significant these findings were, it is a clear pointer to the importance of total adherence to ART if viral suppression is to be achieved.

HIV prevention and care services in resource-limited settings has had an improved scale up in the last five years which has resulted in countless lives being saved and more than three million people gaining access to ART. There's still a lot that needs to be done to ensure the current trend continues but the much that has been done needs to be greatly appreciated. More effective drugs, which are less toxic, are easier to take, and have greater genetic barriers to the emergence of resistance, as well as improved models on how to best deliver HIV services, are needed.

A major area of need in resource-limited settings is improved access to appropriate laboratory tests for commencing and monitoring ART. To ensure the benefits of ART, maximal suppression of HIV is required. This is true both for the long-term prognosis of the individual and for potential community-level benefits, such as reduced risk of transmission.

One major objective of ART is making sure that there is maximum durability of current drug regimens. This is done through improved adherence support, continued upkeep and maintenance of health care systems to make sure that there is uninterrupted access to ART services and through the identification of the early warning signs of potential virologic failure before the development of multiple HIV

drug resistance, which will limit the response to future ARTs. Adherence to ARTs is high in Africa and this has been supported by studies which show that patients in Africa take up to 90% of their prescribed antiretroviral drugs and this has aided greatly in the scale-up of ART, and continued success of first-line regimens in resource-limited settings.

It has been proven that HIV-related stigma greatly compromises ART adherence by undermining social support and adaptive coping. This analysis is in line with prior work that demonstrated the importance of social ties in promoting adherence, particularly in resource limited settings and reflects the importance of social integration to the experience of HIV-positive persons engaged in treatment. This mostly occurs in settings of extreme poverty where factors that hinder treatment are numerous and where social ties may be very vital for survival.

Western Kenya parents and caregivers of HIV-infected children who are on ART described disclosing or not disclosing information about a child's HIV status as critical to the experience of having a child on ART. The caregivers' views about disclosing children's HIV status included perceived risks and benefits for pediatric ART adherence, child well-being, and social relationships. To them, informing children of their own HIV status or disclosing the child's diagnosis to other people could ensure continued pediatric ART adherence through addressing the children's developmental needs so that they can understand why they are taking medicines.

According to (Ministry of Health, 2014), majority infected persons were concerned about the risks involved with disclosing HIV status, especially the risks involved if others respond negatively by either stigmatizing, isolating, or discouraging the family or if the child might be negatively affected by disclosure. Very few caregivers had

disclosed to their infected children their HIV status while most of them had disclosed the child's status to other people. Some of the caregivers were looking out for children who were either likely too young or developmentally unready for disclosure but another reason for the low rates of disclosure may be as a result of some of the caregivers' being concerned about the potential negative impact on the child or on the family's social relationships.

Analyzing caregivers' disclosure practices and views of the effects of disclosure is very important to the ongoing care of children who are undergoing ART by (Arrivé et al., 2012). This is particularly for comprehending how the caregivers might interact with their children and with their peers and how this may affect the child's HIV care over time.

Analysis done from various other settings in sub-Saharan Africa point to the fact that understanding the existing framework whereby children and caregivers communicating about health issues is essential when it comes to shaping the process of disclosure that will follow. These findings from western Kenya suggest that exploring caregivers' perceptions of how disclosure will impact the child's care and adherence, the child's psychological well-being, and the child and family's social relationships are key to health care systems caring effectively for children.

Certain findings from western Kenya according to (National AIDS Control Council, 2015), point to the fact that analyzing caregivers' perceptions of exactly how disclosure will impact the child's care and adherence, the child's psychological well-being, as well as child and family's social relationships are key to health care systems caring effectively for children. These findings are identical to those that were found in research done in Kenya's urban capital, whereby potential societal discrimination,

lowered self-esteem, and concerns about confidentiality featured prominently among the reasons why adolescents are reluctant to telling others about their HIV status. Similar views and beliefs among pediatric caregivers can subsequently be explored in other resource-limited settings, including sub-Saharan Africa. Studies also suggested that adherence to ART might be enhanced by a disclosure process that informs children about their HIV status in a developmentally appropriate manner. The fact that pediatric adherence might be enhanced by disclosure is in accordance with many studies from both resource-rich and resource-limited settings.

Revealing a child's HIV diagnosis to even one or two adults who are supportive may create an environment in which the priority can change from concealing the condition and the medications to taking the medications routinely. Plus having at least one other adult who is aware about the medications may enable the caregiver to get the help and support that they need to help them provide better and consistent care to the child.

According to (Mandalazi, Bandawe, & Umar, 2015), parents' and caregivers' fears resulting from the negative impact of disclosure on the child's psychological state is something that was commonly encountered in this study. They have also been commonly reported in various other studies that have been conducted based on the same issue. Rates of depression, anxiety, and emotional and peer problems however are no higher among children who have been informed of their HIV status. These facts are based on evidence from both resource rich and resource limited settings. This existing evidence may be useful in curbing caregivers' fears and doubts about the impact of disclosure on the child's mental health.

2.4 Conceptual Framework

Figure 2 Conceptual Framework

Adapted from: http://www.peertechz.com/HIV-Clinical-Scientific-Research/JHCSR-2-107.php
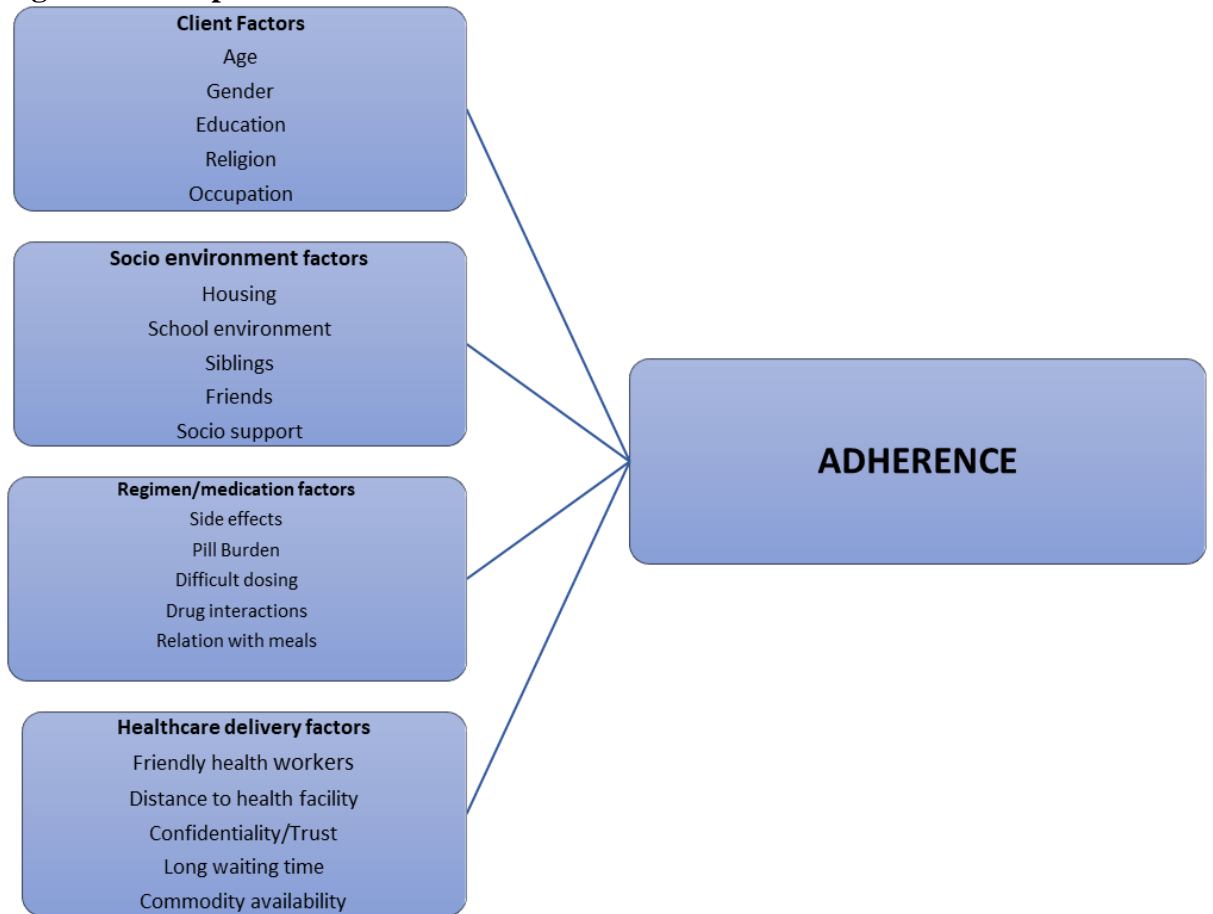
CHAPTER THREE:

RESEARCH DESIGN AND METHODOLOGY

3.1 Study Area

The study was conducted in Kajiado County which is one of the 47 counties of the Republic of Kenya. It stretches from Nairobi in the North to the Tanzanian border in the south. There are five constituencies namely: Kajiado South, Kajiado Central, Kajiado West, Kajiado East and Kajiado North and this also forms the Sub-Counties.

The county has a population growth rate of 5.5 percent; total population was estimated at 807,070 with 401,785 being females and 405,245 males as at the Kenya Bureau of statistics of 2012. The population is projected to grow to 1 million by the year 2017.

According to Kajiado Health Strategic Plan, 2015, the county has 1 County referral hospital, 3 sub-county hospitals, 15 Health centers and 66 Dispensaries giving a total of 85 Government owned health facilities. The total number of hospital beds in public health facilities is 395.   Most government facilities have inadequate infrastructure, equipment and staffing posing challenges to provision of quality services. There are 20 Faith based Organizations, 201 Private and NGO-owned health facilities (SARAM, 2012). Most of these are concentrated in the urban areas which have a high population density. Over 60% of the population lives more than 5km from the nearest health facility (Kajiado CDP, 2011).

Source: (Source: Kajiado County Integrated Development Plan 2014- 2017, 2014)
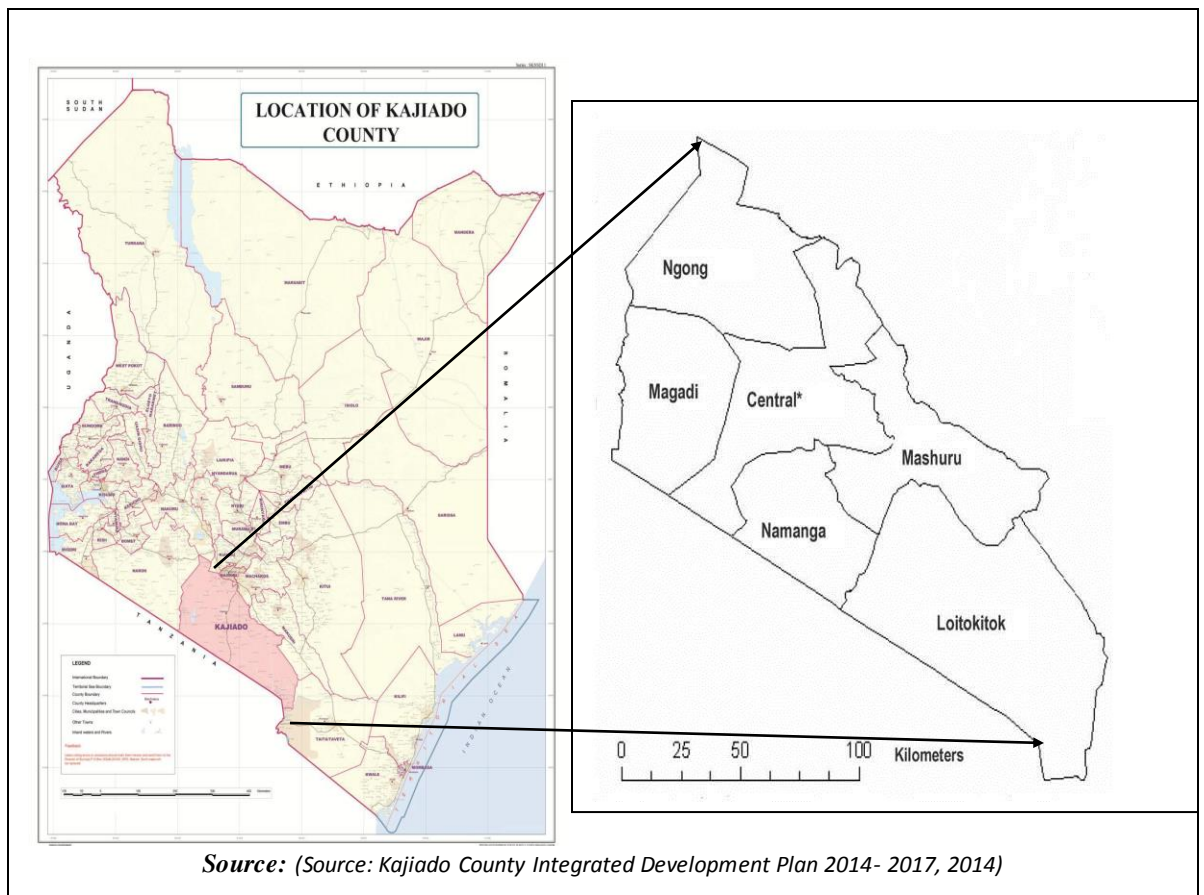
Figure 3: Map of Kajiado County

The study was carried out in four select facilities in Kajiado North of Kajiado County namely Kajiado North namely Ngong Sub-County hospital, Ongata Rongai Health Centre, Beacon of Hope clinic and DREAM center. The inclusion criteria for DREAM center was based on Adolescents who live in Kajiado and are accessing ART services in Dreams. Ngong and Ongata Rongai are government managed health facilities in Kajiado North while Beacon of Hope Clinic is a private health facility based in Ongata Rongai.

The clinics run daily from 8am to 5pm with adolescent support groups being run during school holidays. The study was designed to cover august holidays to enable access adolescents in boarding school easily.

Ngong Sub-County hospital

Ngong has a population of 237,805 with 68,120 households. The number of children under 5 years is 6000. Ngong hospital is a level 4 hospital with a working staff of 67. It has one maternity ward, one pediatric/women ward. It has an average be occupancy of 3 days and an actual physical count of the cots are 3. The workload for Ngong sub-county hospital as of August 2016 was 4570.

Ongata Rongai Health Centre

This facility is in the fast growing Ongata Rongai town. It is a level 3 government owned and managed facility. According to 2009 projections, the facility catchment is estimated at 120,000 persons. It has a workforce of 35 personnel comprising of one medical officer, 5 Clinical officers, 14 Nursing officers, 7 Public Health Officers, one nutritionist and the rest comprise of non-medical staff.

Beacon of Hope clinic

Beacon of Hope is a private health facility based in Ongata Rongai. It has been rated as the best performing ART site within Kajiado County. The clinic gets support from BOH the NGO and has also benefited from donor funding from Elizabeth Glassier Pediatric AIDS Foundation (EGPAF).

Dream Centre

The DREAM Center of Nairobi was opened on April 25th, 2008. It is in an area of Nairobi on Langata Road. This area neighbors Ongata Rongai which is in Kajiado County. The center therefore attracts a lot of clientele from this neighborhood due to the incentives offered and the high quality of care provided.

The center is run by the Community of Sant 'Egidio in partnership with the Congregation of the Daughters of Charity. It has a fully equipped and functioning molecular biology laboratory which enables them to undertake Viral load testing onsite.

3.2 Study Population

The study population was HIV positive adolescents aged (10-19) years and attending the four selected ART sites. All active adolescents that were currently accessing ART treatment in the four ART sites were line listed. A list was developed for each site.

3.3 Study Design

The study was descriptive cross-sectional study. Both qualitative and quantitative data were collected. The study was facility based.

3.4 Sample size determination

The sample size was determined using the Cochrane, 1977 formula. According to a recent study done in Kisumu (Marima, 2011), the average adherence rate among adolescents was found to be 86%. This is the prevalence that was used to determine the sample size

$$n = \frac{Z^2 p q}{e^2}$$

Where;

Z= standard variate (1.96) which correspond to 95% confidence interval

p= 0.86 (proportion of HIV positive adolescents patients on ART treatment who adhere to treatment regimen

q=1-p =0.14

e = 0.05 (acceptable error margin or precision of measurement)

Thus $n = \dfrac{1.96^2 \times 0.86 \times 0.14}{(0.05)^2}$

= **185 respondents**

Adjustments based on adolescent population in Kajiado County

N=Target population = 2989

Expected adjustment in sample size,

n=(nN/n+N)

= (185) (2989)/2989+185

=174

Figure 4: Sample size Determination

3.5. Sampling

3.5.1 Sampling techniques and Procedures

There are five sub counties in Kajiado County; Kajiado North subcounty was purposively selected. All the four facilities offering ART in Kajiado North subcounty were included in the study. The sample size was distributed proportionately among the four health facilities.

A list of all adolescents on care were generated from the electronic medical records system or a manual line list developed where electronic records were not available or incomplete. Simple Random Sampling without replacement was then used to select study participants. Random numbers were generated using excel and corresponding adolescent scheduled for interview. According to health facility-based data, 2017, there are an estimated 144 HIV positive adolescents at Beacon of Hope, 76 at Dream Centre, 88 at Ngong and 24 at Ongata Rongai. The sample size of 174 respondents were distributed proportionately between the four health facilities.

Facility	Number of adolescents	Proportion of total	Number of respondents
Beacon of Hope	144	43%	75
Ngong Sub-county	88	27%	46
Ongata Rongai	24	7%	13
Dream Centre	76	23%	40
Total	332		174

3.6 Study variables

- Dependent variables – ART adherence

Adherence was measured by administering the Case Adherence Index questionnaire. Those who scored more than ten was considered adherent and those with a score less than ten was considered non-adherent

- Independent variables

  Viral load suppression - viral load test results of less than 400 copies of the virus per milliliter of blood

  Disclosure status-Disclosed/Not disclosed

  Socio demographic factors - Age, Sex, School level

Support factors-Participation in support group

Regimen factors – side effects, pill burden

3.7 Eligibility Criteria

3.7.1. Inclusion Criteria

Adolescents living with HIV and aged between 10 to 19 years who were accompanied by their parents/guardians to the clinic and had been taking ARVs for at least 90 days.

3.7.2. Exclusion Criteria

Adolescents with severe disability and are unable to communicate effectively

Very sick adolescents who needed prompt care

3.8 Data Management and Analysis

3.8.1 Data Collection Tools/Instruments

Quantitative data was collected using an interviewer-administered questionnaire, CASE adherence tool and Patient Data Extract Tool. Qualitative data was obtained from focus group discussions with disclosed adolescents and caregivers.

Qualitative data was collected using Focus Group Discussions (FGD). Two types of FGD were held, one with adolescents to understand their issues and another with their caregivers to understand their perspectives.

During clinic days, adolescents were requested to volunteer for the FGD. Only adolescents who have been disclosed to were invited to participate in the FGD. The FGD started when 12 adolescents were ready to participate.

Below is a further description of the tools; which are also attached as appendices

(i)) Case Adherence Index tool: The CASE tool has been used to measure adherence successfully in similar studies. The tool was chosen since there is no gold standard for

measuring adherence and its ease of use. The CASE adherence tool consists of three adherence questions. The answers provided for each question are scored and a cumulative value calculated. A higher composite score signified better adherence. The highest score attainable was 16.

(ii)) Questionnaire: An interviewer administered questionnaire was designed for this study. The questionnaire was available in two languages, English and Kiswahili. The questions covered included demographic characteristics of respondents, ART access factors, socio-economic factors. The tool was only administered to adolescents who were fully disclosed to.

(iii) Patient Medical Record Data Tool: This tool was used to indicate latest data on Viral loads levels, CD_4 count levels and duration for which the ART had been taken. It was also used to assess whether full disclosure had been done.

(iv) Focused Group Discussion tool: To obtain a more in-depth information on adherence, one FGD was conducted with disclosed adolescent patients and one with their caregivers.

3.8.2 Study Execution

The study was conducted by the principal investigator together with three research assistants. The research assistants were trained by the principal investigator on how to address confidentiality and fill the questionnaires. The research assistants already have a medical background as they were already working in these facilities.

The study participants were interviewed during their regular hospital visits and the questionnaire were filled shortly before or after their clinic visit.

The FGDs were conducted by the principal investigator with the help of the research assistants.

3.8.3 Pilot Study

A pilot study was carried out in Kitengela Sub-County hospital. The main purpose of the pilot study was to test the data collection tools, assess the feasibility of the study, familiarize with the challenges expected and adjust where necessary.

Kitengela was selected because it has a similar set up to the selected study sites i.e. it is an urban set up in Kajiado County but within a different sub county. A total of 15 respondents meeting the criteria were interviewed and feedback used to improve data collection tools.

3.8.4 Main Study

Pre study visits were done in November 2016 to help develop a sampling frame. Data collection was done from June-August 2017.

3.9. Data Analysis and Presentation

3.9.1 Data Entry and Cleaning

It was anticipated that data would be collected directly into CS PRO software. However, during the pilot study, it was realized that this would not work well due to lack of appropriate gadgets. Paper questionnaires were printed and coded based on CCC numbers. These identifiers were then removed after data entry.

3.9.2. Data Analysis

SPSS version 22 software was used for quantitative data analysis factors that influence ART adherence. Bivariate analysis was carried out to determine individual

factors related to adherence and Chi square test was used to evaluate crude odds ratios at 5% level.

A multiple logistic model was used to model adherence and a 95% confidence interval was constructed to evaluate significance of adjusted odds ratios.

3.10. Ethical Approvals and Considerations

Protocol approval was sought and obtained from Moi University Institutional Ethical Review Committee (IREC).

Permission was also sought from the Kajiado County Health Management team and from participating health facilities

Other aspects that governed the research include the following;

Informed consent/assent: the study involved minors and therefore guardians/caregivers were requested to give written consent prior to the study. The purpose of the study was explained fully to the participants. Caregivers participating in the FGD also gave written consent.

Confidentiality: Names of participants were not recorded. Unique identifiers were used instead

Laws on research: The Kenyan laws and Moi University regulations pertaining research were fully observed during the entire period of the study.

3.11. Limitations and delimitations

The study relied on self-reporting from adolescents and their caregivers to assess adherence. This may lead to an over estimation of the prevalence of adherence. To overcome this, other proxy indictors were used to assess adherence namely viral load results and observing clinic appointments.

The survey was carried out in four CCC facilities in Kajiado North Sub-county. Further, sampling was done meticulously to ensure a representative sample as much as possible to increase the level of generalizability of the research findings in similar settings

3.12. Dissemination of research findings

The findings will be presented to the Moi University in a thesis form. Once approved the final report will be shared with Kajiado County Health Management Team and the participating health facilities.

CHAPTER FOUR:

RESULTS

This chapter describes the results from the study that was done between April 2017 to August 2017. It includes both quantitative and qualitative data.

4.1. Demographic Characteristics of Respondents

The table below shows demographics of respondents.

Table 1: Demographics of respondents

Variable	Category	Frequency n= 167	Percentage (%)
Health Facility	Beacon of Hope	73	44
	Ongata Rongai	12	7
	Ngong SCH	44	26
	Dream Centre	38	23
Sex of respondent	Male	82	49
	Female	85	51
Level of Education	No formal education	1	1
	Primary	109	65
	Secondary	47	28
	Vocational	9	5
Marital status	Single	159	95
	Married	3	2
	Divorced	2	1
	Separated	3	2
Occupation	Self-employed	3	2
	Other employment	1	1
	Unemployed	7	4
	Student	154	92
Religion	Christian	160	96
	Muslim	7	4
Age	Early Adolescence (10-14)	94	56
	Late Adolescence (15-19)	73	44
Residence	Urban	87	52
	Rural	80	48
Primary Caregiver	One Parent	66	40
	Both parents	52	31
	Relatives	32	19
	Siblings	1	1
	Pastor	3	2
	Others	12	7

The respondents consisted an almost 50% for both sexes. Early adolescents (10-14) were slightly more than half (56%). The mean age of the respondents was 14.23yrs with a standard deviation of ±2.576 meaning that 95% of the respondents aged between 9-19 years.

On the level of education, 65% were in primary school followed by secondary school at 28 percent. This corresponds to the finding on occupation that 92% were students. Most of the respondents were single at 95% and 96% were Christians.

There was an almost 50% spread for both urban and rural residents.

On provision of care, 71% of the adolescents lived with at least one biological parent, 19% lived with other relatives. The remaining 10% were cared for by siblings or other community structures such as pastors and community health workers.

4.2 Prevalence of Adherence

4.2.1-Overall crude prevalence

The study found a crude prevalence rate of 92.8% (95% CI 87.8% - 95.8%).
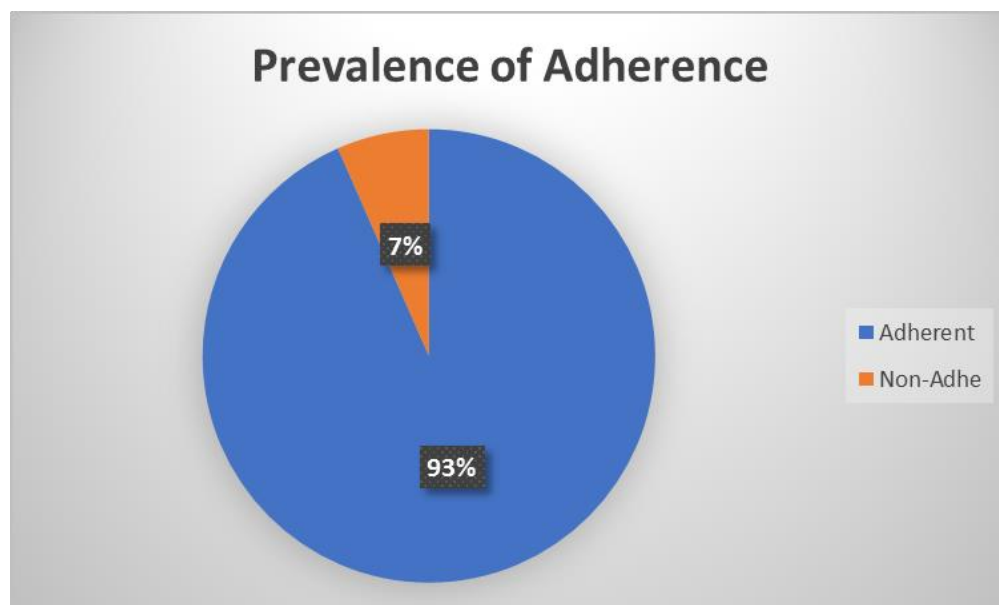
Figure 5: Prevalence of Adherence among adolescents

4.2.2 Prevalence by age category
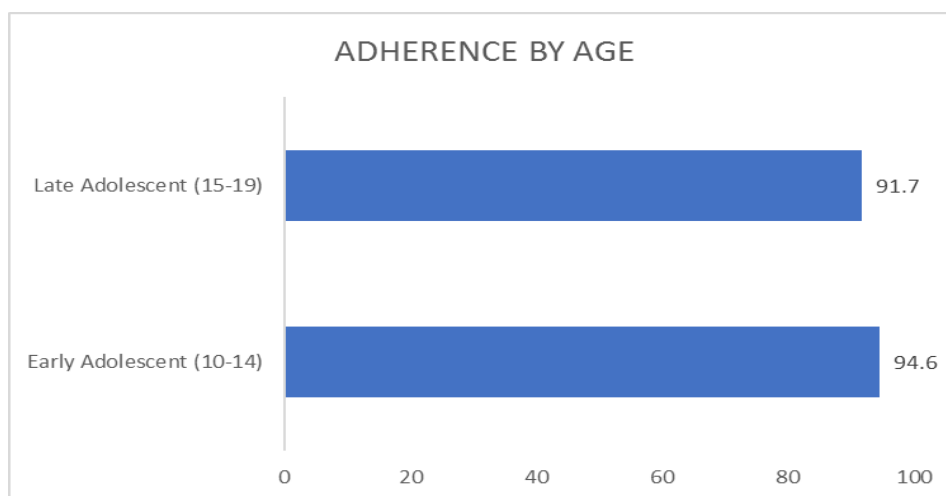
Figure 6: Prevalence by age category

Prevalence of adherence among early adolescents was 94.6% compared to late adolescents whose rate was 91.7%. This means the younger adolescents were more likely to be adherent.

4.2.3 Prevalence by gender

There was no difference between prevalence among males and females both reporting a prevalence rate of 95%.

4.2.4 Comparison of Adherence levels and Viral Load results

Table 2: Viral Load results

Viral Load Results	Frequency (n=122)	Percent (%)
Not Suppressed >1000copies/ml	33	27
Suppressed<1000copies/ml	89	73
Total	122	100

A total of 122 adolescents had their viral load results documented. Seventy three percent had achieved viral suppression which a result less than 1000 copies/ml. Of

those who had attained viral suppression, 97.6% were adherent compared with 91.7% adherence rate for those who were unsuppressed.

4.3 Association Between Adherence and Client Factors

Table 4.3: Bivariate analysis between Adherence and Client Factors

Client Factors	Category	Adherent		Crude odds ratio	Fischer Exact test
		Yes	No	CI 95%	P value
Age category	Early Adolescent (10-14) *	89	5	1.594 (0.467-5.445)	0.329
	Late Adolescent (15-19)	67	6		
Gender	Male *	78	4	1.750 (0.467-5.445)	0.288
	Female	78	7		
Education Level	Primary and below *	104	6	1.699 (0.492-5.833)	0.294
	Secondary and above	51	5		
Occupation	**Student**	**147**	**7**	**0.127 (0.28-0.585)**	**0.021**
	All others*	**8**	**3**		
Religion	Christian *	150	10	2.5 (0.274-22.827)	0.385
	Muslim	6	1		
Residence	Urban *	79	8	0.385 (0.098-1.504)	0.134
	Rural	77	3		
Viral Load	Suppressed*	83	2	3.662 (0.586-22.899)	0.163
	Not Suppressed	34	3		
Duration on ART	Below 5 years*	30	1	2.647 (0.261-26.823)	0.377
	Above 5 years	34	3		

*reference group

On assessing the client factors, only occupation was found to be statistically significant at 95%. Students were more likely to be adherent than non-students.

All the other factors namely religion, residence, age, gender, education level, viral load and duration on ART were not significantly associated with adherence at 95% CI From the focus group discussion; the adolescent had a clear understanding of ART and importance of adherence. The adolescents explained that '*ART are drugs taken to reduce number of virus in the body'*. They help reduce multiplication of the virus and that they help boost immunity. The group explained that if you don't take ART

medication, *'The virus will multiply', 'You can get sick' and 'you can develop resistance'.*

From the FGD, the group mentioned stress as a key factor that makes them not take drugs. That they feel sad sometimes because they have the virus and can't really understand. They ask themselves *"why me? Why did God choose me to have this virus"?* one female, 13yrs said that *"I feel tired of taking ARV all the time. I wish a day would come when I will no longer need to take the ARVs".*

The adolescents explained that addressing the stress factor will help them adhere better to ART. They mentioned that if they play games like football or engage in other hobbies, it will help them forget about their status and enjoy their life.

4.4 Medication related factors

Table 4.4: Relationship between Adherence and Medication Related Factors

Medication Factors	Category	Adherent		Crude odds ratio	Fischer Exact test
		Yes	No	(95% CI)	P value
ART medications are easily accessible	Yes	150	10	0.333 (0.035-3.132)	0.342
	No *	5	1		
I swallow drugs at the right time	**Yes**	**146**	**5**	**0.051 (0.013-0.201)**	**0.000**
	No*	**9**	**6**		
I discontinue medication if I experience side effects	**Yes**	**12**	**4**	**7.889 (1.954-31.85)**	**0.009**
	No	142	6		
I skip the medications when food is not there	**Yes**	**12**	**4**	**6.714 (1.719-26.227)**	**0.013**
	No	**141**	**7**		
I hide medications from colleagues	Yes	84	7	1.5 (6.422-5.331)	0.379
	No	72	4		
I do not mind taking alcohol and other drugs	Yes	12	3	4.5 (1.054-19.217)	0.063
	No	144	8		
Medications have difficult dosing to follow	Yes	24	0	0.929 (0.888-0.972)	0.198
	No	131	10		
I am keen not to miss clinic appointment for drug refill	Yes	140	6	**0.120 (0.032-0.444)**	**0.004**
	No	14	5		
I discontinue drugs if I feel better	**Yes**	**4**	**2**	**8.278 (1.333-51.39)**	**0.053**
	No	**149**	**9**		
I discontinue if I am taking other medications	Yes	2	1	7.50 (0.625-89.949)	0.190
	No	150	10		
I was given limited information on how to take ART	Yes	62	4	0.857 (0.241-3.052)	0.540
	No	93	7		

On assessing the medication related factors, four factors were found to be significant at *p≥0.05*. Swallowing drugs at the right time was promotive for adherence. Adolescents who reported continuing with medication despite experiencing side effects were 7.8times more likely to be adherent than those who discontinued. Having food to take with medication was also significant for adherence as well as keeping client appointments for drug refill.

FGD 1, Female 13yrs; *"I understand the importance of these drugs. I try not miss them at all. But it becomes difficult when there is no food at home."* These was echoed by several other adolescents who depicted the same scenarios at home.

4.4.1 Reason for missed dose

The most common reason for missed dose was forgetting at 50%, fear of stigma at 17% and lack of food at 8%
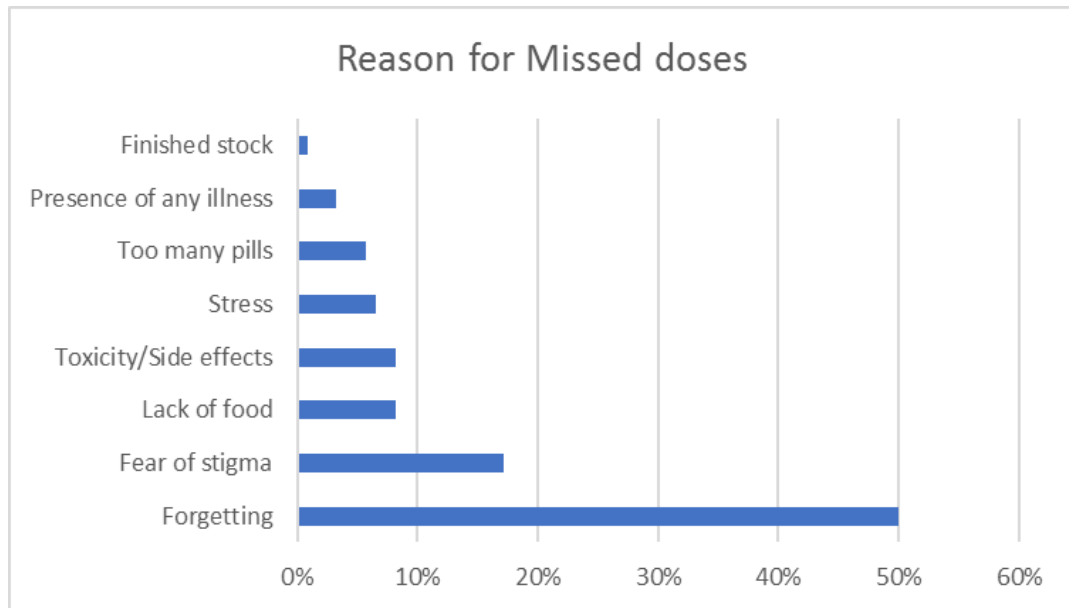
Figure 7: Reason for missed dose

4.4.2 Side effects experienced

The most common side effect experienced because of taking ARVs was nausea at 31% followed by itching 17% and rashes 13%
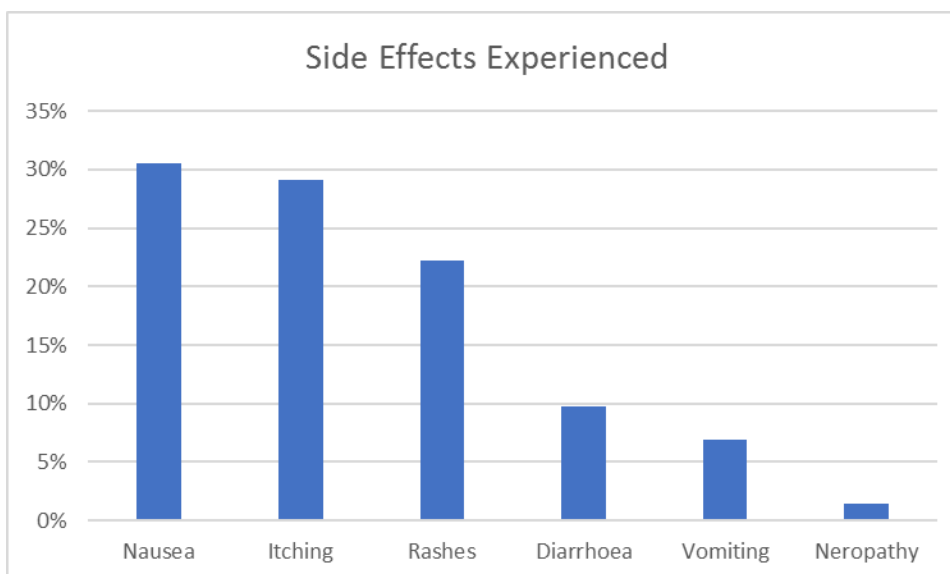
Figure 8: Side Effects Experienced

4.5. Social Environmental factors

Table 5: Relationship between Adherence and Social Environmental Factors

Social/ environmental factors	Category	Adherent		Crude odds ratio	Fischer Exact test
		Yes	**No**	**(95% CI)**	**P value**
People I live with remind me to take drugs	Yes	124	9	1.161(0.239-5.642)	0.605
	No	32	2		
I cannot take drugs with people looking	Yes	86	8	2.171(0.555-8.490)	0.207
	No	70	3		
Disclosure of HIV status is important	Yes	136	10	1.397(0.169-11.534)	0.608
	No	19	1		
The school environment has privacy with medications	Yes	48	2	0.500(0.104-2.402)	0.306
	No	108	9		
My other siblings do not know my status	Yes	69	5	1.039(0.304-3.548)	0.596
	No	86	6		
I have friends who know my status and care for me	**Yes**	**39**	**7**	**5.205(1.446-18.738)**	**0.011**
	No	116	4		
The housing arrangement has no privacy	Yes	52	6	2.331(0.679-7.999)	0.147
	No	101	5		
I participate in social support groups for HIV infected	Yes	121	6	0.327(0.094-1.140)	0.078
	No	33	5		

One factor was found to be statistically significant at $p \geq 0.05$ that is having a friend who knew status of the adolescent and cared for them. Adolescents who reported having a friend who knew their status and cared for them were 5.2 times more likely to be adherent than those who did not have a peer supporter. Other factors such as participation in support group, privacy and housing arrangement were not significant at 95% CI.

From the FGD, disclosure was discussed at two levels, the caregiver disclosing the HIV+ status to the adolescent and the adolescent disclosing his status to his friends and teachers or other adults. The adolescents reported that it was not important for them to disclose their status to other people. The adolescent felt that their HIV positive status should be kept within the family.

On the issue of informing adolescents on their positive status, there was no consensus on whether it is better to disclose or not. One group agreed that disclosure is important because it is important for society to know the adolescent status. The adolescent should also know their status to avoid infecting other people. It is important for adolescent to know so that they can know how to protect themselves from re-infection One group said it is not important for society to know their status citing reasons below;

"The adolescent will fear stigma and walk away. Their HIV status knowledge should only be between family members" late adolescent male, 16 years

"For younger children, disclosure should not be done since they may not understand fully" late adolescent female, 18yrs

The group also suggested that the best person to disclose to the adolescent should be doctor because he is knowledgeable on HIV and gives guidance and counselling.

Others felt it should be done by the doctor in the presence of the parents' reason being '*parent knows how you got it and you spend most of the time with them*' FGD 1, *early adolescent female, 14 years.*

The group also felt that the public should be educated on the plight of the HIV + and how HIV- people can support those living with the virus. This will help address the issue of stigma and living with HIV will not seem like such a big deal. *"HIV should be treated like any other illness" late adolescent, female 15years*

4.5.4 Healthcare delivery system factors

Table 6: Relationship between Adherence and Health Care Delivery System Factors

Healthcare Delivery System Factors	Category	Adherent		Crude odds ratio	Fischer Exact test
		Yes	No	(95% CI)	P value
Health workers give useful information	**Yes**	**147**	**8**	**0.163 (0.037-0.723)**	**0.034**
	No	**9**	**3**		
Sometimes I find drug stock outs during visit	Yes	6	1	2.500 (0.274-22.827)	0.385
	No	150	10		
Health workers are friendly to patients	Yes	150	9	0.180 (0.032-1.021)	0.089
	No	6	2		
Confidentiality and privacy are maintained	**Yes**	**142**	**6**	**0.118 (0.032-0.0437)**	**0.003**
	No	**14**	**5**		
I trust health workers	**Yes**	**137**	**6**	**0.158 (0.044-0.570)**	**0.009**
	No	**18**	**5**		
Services are costly	Yes	4	1	4.194 (0.424-41.510)	0.271
	No	151	9		
The clinic has long waiting time	Yes	16	3	3.234 (0.778-13.439)	0.118
	No	138	8		
The clinic makes call/send SMS reminder for revisit	Yes	106	7	1.079 (0.268-4.349)	0.61
	No	49	3		
There is provision of quality care	**Yes**	**149**	**9**	**0.121 (0.019-0.750)**	**0.05**
	No	**4**	**2**		
The clinic is located too far from home	Yes	30	3	1.575 (0.394-6.294)	0.374
	No	126	8		

On assessing the healthcare delivery factors, several factors were found to be significant at $p \geq 0.05$. These included rating of information given by healthcare workers, confidentiality, trusting healthcare workers and rating of the quality of care provided. Other factors were not significant at $p \geq 0.05$; including cost of services, location of clinic and length of time clients had to wait during clinic visits.

From the FGD, one male adolescent explained that *"I have a watch to remind me take drugs. I also put a reminder on my mom phone when I am on holiday"*

Another recommended having a treatment supporter e.g. parents who will remind them take drugs at the right time will help in their adherence. They also felt that adolescent should be educated on importance of adherence

Marking appointment dates on calendar was also mentioned as a method of increasing adherence so as not to miss clinic appointments

4.6. Predictors of adherence
Table 7: Binary Logistic regression of Client factors

Variable	B	S.E.	Wald	df	Sig.	Exp (B)	95% C.I for EXP(B)	
							Lower	Upper
Age	-0.574	1.849	0.096	1	0.756	0.563	0.015	21.1
Education	1.935	1.999	0.937	1	0.333	6.924	0.138	348.053
Occupation (Indicate Comparison group)	**-0.976**	**0.489**	**3.982**	**1**	**0.046**	**0.377**	**0.144**	**0.983**
Viral Load	1.422	1.305	1.187	1	0.276	4.147	0.321	53.57
Duration on ART	3.151	2.527	1.554	1	0.213	23.348	0.165	3308.56
Constant	-3.037	1.897	2.564	1	0.109	0.048		

(Model summary: $\chi^2 (5, N=167) = 8.855, P<0.115$)

The table above is a linear model of logit of adherence with age, Education, Occupation, viral load and duration of ART as explanatory variables. Results of this overall fit shows that all the factors linearly joined, is not significant χ^2 (5, N=167) = 8.855, P<0.115. Controlling for other factors, Age, Education Viral Load and Duration on ART are not significantly associated with natural log of ODDs of adherence. Occupation was the only significant variable, respondents were classified as belonging to student occupation category or Other. In this study this variable was significantly associated with adherence with students being 0.33 more likely to adhere compared to non-student

Table 8: Binary Logistic regression of Healthcare delivery factors

Variable	B	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Health care workers give useful information	1.156	.969	1.424	1	.233	3.179	.476	21.247
Confidentiality is maintained	.878	.948	.858	1	.354	2.406	.375	15.431
I trust Health care workers	1.233	.849	2.107	1	.147	3.431	.649	18.127
Quality Care is provided	**2.261**	**1.061**	**4.541**	**1**	**.033**	**9.590**	**1.199**	**76.712**
Constant	-3.512	.489	51.609	1	.000	.030		

(Model summary: χ^2 **(4, N=167) = 14.911, P<0.005**)

A binary logistic regression was used to fit the odds of adherence to ARVs. Data on delivery factors and their relationship with adherence fitted well into the logistic

model χ^2 **(4, N=167) = 14.911, P<0.005.** Table 8 shows the model fit with Quality of care having significant association with adherence, controlling for all other delivery factors. The odds of adherence are 9.59 higher for those who believe quality of care is provided compared to those who disagree with this assertion. However, Healthcare worker's information, Confidentiality and Worker's Trust did not show any significant association with the odds of adherence

Table 9: Binary Logistic regression of Medication Related Factors

Variable	B	S.E.	Wald	df	Sig.	Exp (B)	95% C.I.for EXP(B)	
							Lower	Upper
Swallow Drugs at the Right Time	**-0.989**	**0.402**	**6.053**	**1**	**0.014**	**0.372**	**0.169**	**0.818**
Discontinue ART if I experience Side Effects	0.407	0.324	1.585	1	0.208	1.503	0.797	2.834
Skip Medication If I have no Food	0.075	0.389	0.038	1	0.846	1.078	0.503	2.309
Discontinue ART Drugs If I feel Better	0.077	0.481	0.026	1	0.872	1.081	0.421	2.776
Constant	0.276	2.024	0.019	1	0.892	1.318		

{Model summary: χ^2 **(4, N=167) = 12.993, P<0.05**.}

A binary logistic regression model was used to fit adherence to medication related factors χ^2 **(4, N=167) = 12.993, P<0.05**. In this study, Discontinuation of ART, Skipping Medication and Discontinuation of ART Drugs was found to be independent of adherence at 5% level of significance. The chi square result was. This study demonstrated that there was a difference in the odds of adherence among those who strongly agreed with swallowing of ARTs at right time compared to those who did not agree with this assertion, p=0.014.

Table 10: Binary Logistic regression of Socio environmental factors

Variable	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
People Remind Me to take drugs	-.780	.951	.673	1	.412	.459	.071	2.955
Cannot take Drug with Other People Looking	-.299	.919	.106	1	.745	.742	.122	4.492
Disclosure is Important for adherence	.425	1.289	.109	1	.741	1.530	.122	19.135
School provides privacy to take drugs	.614	.966	.404	1	.525	1.847	.278	12.256
Siblings Know my HIV status	.814	.803	1.027	1	.311	2.257	.467	10.900
I have Friends who know my status and Care for me	**-2.528**	**.821**	**9.487**	**1**	**.002**	**.080**	**.016**	**.399**
Housing provides Privacy	-.683	.889	.591	1	.442	.505	.088	2.884
I participate in Support Group	1.317	.829	2.520	1	.112	3.731	.734	18.960
Constant	-1.859	.991	3.518	1	.061	.156		

Model Summary: χ^2 **(8, N=167) = 16.446, P<0.05.**

A binary logistic regression was fitted to the socio environmental factors to explain adherence **and it was found to be** statistically significant χ^2 **(8, N=167) = 16.446, P<0.05** at 5%. Being reminded to take drugs, not taking drugs when people are seeing, Disclosure, schools providing privacy, Housing providing privacy and participating in support groups turned out to be independent of adherence as indicated in Table 10 above. This study established that having a friend who has been disclosed to significantly improved the odds of adherence, p=0.002

Table 11: Multivariate Analysis; Predictors of adherence

Model	β	Std. Error	Sig.	95.0% Confidence Interval for β	
(Constant)	12.706	0.594	0.0000	11.532	13.88
Swallow right time	1.366	0.543	0.0130	0.294	2.438
Side Effects	-1.524	0.513	0.0030	-2.536	-0.511
Friends Know stats and care	-1.47	0.328	0.0000	-2.117	-0.823
Confidentiality is maintained	1.406	0.51	0.0070	0.398	2.414

A multiple regression was run to predict adherence from all the significant factors at bivariate level. In the final model, only two factors contributed significantly to the model, experiencing side effects and having friends who knew the adolescent status and cared for them $F_{(4,157)} = 22.302$ $p < 0.05$. The other two factors did not add significantly to the model i.e. swallowing drugs at the right time and confidentiality at health facility.

CHAPTER FIVE:

DISCUSSION

5.1 Prevalence of Adherence among adolescents in Kajiado

This study found an adherence rate of 92.8% (95% CI 87.8% - 95.8%). This is comparable to similar study done in Uganda in 30 Health facilities that documented an adherence rate of 90.4% among adolescents (Nabukeera-Barungi et al., 2015). A study in Nigeria by (Lawan, Amole, Jahun, & Abute, 2015) documented a prevalence rate of 90.5%.

(Reda & Biadgilign, 2012) also found that antiretroviral therapy adherence in sub-Saharan Africa are comparable or higher than developed world, contrary to common believe.

It is also comparable to the KAIS 2012(National AIDS Control Council, 2014) study which found a prevalence of 91% among general population. It is higher than 86% documented by Marima, 2011 in a similar study among adolescents in Kisumu; Wakabi S, 2011 also found a lower prevalence at 82% in Nairobi based study. Several studies in Africa and other developing countries document adherence levels less than 75% (Jobanputra et al., 2015; Sethi, Celentano, Gange, Moore, & Gallant, 2003; Sullivan et al., 2007).

This improved adherence level can be attributed to the significant gains made in the care and treatment for adolescent. It can also be attributed to a change in strategy to the new directive of test and treat approach. The new directive by World Health Organization on 90:90:90 also means that clinicians are spending more time and efforts on retention in care and not just focusing on new enrollments. However, this is

still lower than the optimum level of nearly 100% and at least 95% for viral suppression to occur (Jobanputra et al., 2015; Sethi et al., 2003; Sullivan et al., 2007).

A total of 122 adolescents had their viral load results documented. Seventy three percent had achieved viral suppression which a result less than 1000copies/ml. This finding agrees with discussion above. Since viral load result can be used as a proxy indicator of adherence (Flynn et al., 2004). one study published in the AIDS research and Human retroviruses journal by (Martin et al., 2008) on the relationship between adherence and viral load, found that a decrease in adherence was related to an increase in treatment failure irrespective of the regimen the patient was taking.

5.2 Relationship between Adherence and Client Factors

On assessing the client factors, occupation was found to be significant. Other client factors such as age, gender, education level, religion, residence viral load and duration on ART were not significant at 95%. Being a student was promotive for adherence. This could be because the students are likely to be of a younger age and have caregiver influence. They are also likely to engage in factors to decrease stress such as games and other sporting activities. This aspect came out strongly during the FGD.(Denison et al., 2015).

Residence did not affect adherence contrary to a study finding in Uganda by (Inzaule, Hamers, Kityo, de Wit, & Roura, 2016; Nabukeera-Barungi et al., 2015) found that attending a rural health facility decreased adherence. This could be because the urban residents were more likely to be literate and use technology e.g. alarms and calendars to remind them to take their medication. Rural residents were also more likely to seek treatment at a facility further away from home due to fear of stigma; that someone may recognize them at the local clinic. Rural health facilities are also likely to have

personnel issues since most health practitioners prefer urban set up. (Nabukeera-Barungi et al., 2015).

The finding that age or gender does not affect adherence agree with other studies (Hughes, 2013; Machado et al., 2009) who found no association between adherence and age or gender and other epidemiological factors. However, it differs from two studies (Ankrah et al., 2016; Lall, Lim, Khairuddin, & Kamarulzaman, 2015) who found a direct relationship between age and adherence, an increase in age lead to a decrease in adherence. According to (Kgatlwane, 2010), who carried out a similar study in Botswana decrease in age led to an increase in adherence. This could be due to caregiver influence on younger adolescents which may decrease in late adolescence. Therefore, these studies do not provide conclusive evidence whether age affects adherence or not.

This study did not find an association between adherence and gender. This is similar to findings by (Kgatlwane, 2010) in a similar study in Botswana. Other studies found that being female decreased the adherence levels documented (Lemly et al., 2009)

5.3 Relationship between Adherence and Medication related factors

On assessing the medication related factors, four factors were found to be significant at $p \geq 0.05$. The most significant factors were swallowing drugs at the right time, experiencing side effects, availability of food and keeping clinic appointments.

Swallowing drugs at the right time ($P=0.000$) was highly significant and this could be because the adolescents were largely drawn from peri urban population with access to gadgets that reminded them to take ARV medication. They were also more likely to have higher literacy levels and could use calendars to help keep their clinic

appointments. The issue of social desirability can also not be ruled out since adherence was measured based on self-reports.

On availability of food, a large population of the adolescents interviewed living in informal settlements with low economic status. This affected the quality and quantity of food they had access to. This in turn affected their ability to swallow their ARVs as they reported taking ARVs on an empty stomach had undesirable effects.

The most common reason for missed dose was forgetting at 50%, fear of stigma at 17% and lack of food at 8%. This is similar to findings by (Ankrah et al., 2016; Xu, Munir, Kanabkaew, & Le Coeur, 2017) who found forgetfulness and fear of stigma to be the most common reason for adolescent missing their ART doses. (Chandwani et al., 2012) also documented similar findings in a study with a diverse cohort of adolescents living with HIV.

The most common side effect experienced because of taking ARVs was nausea at 31% followed by itching 17% and rashes 13%. This finding is similar to (Nabukeera-Barungi et al., 2015) findings that adverse side effects were significant in level of adherence by adolescents.

5.4 Relationship between Adherence and Social Environmental factors

Having a friend who knew their status and cared for the adolescents was significant for adherence. A similar study done in Nigeria found that stigma and discrimination decreased adherence (Lawan et al., 2015). The same study found that avoidance by friends, feeling anxious and depressed led to a decrease in adherence. Adolescent were more likely to experience depression since HIV has no known cure and diminish the desire to take medication.

Another study done in southern Ghana also agreed with this findings documenting stigma and discrimination as key factors affecting adherence (Ankomah et al., 2016). The fear of stigma from friends and neighbors affected their ability to take ARVs. The fear that a peer may find out their HIV status and share with other people. This could be the same reason that the adolescents during FGDs felt that their status should be kept a secret between family members. They will therefore miss ARV doses if they suspect someone may find out their status.

Other social environmental factors were not significant including housing conditions, participation in support groups, privacy in school settings and disclosure. The finding on lack of privacy in boarding school agrees with findings from Uganda by ((Reda & Biadgilign, 2012, Inzaule et al., 2016) who found that stigma in boarding schools led to a reduction in adherence. The findings also agree with several other studies that found no relationship between adherence and disclosure (Di Risio, 2009). Several studies have also indicated that   disclosure is beneficial for adherence (Abadía-Barrero & LaRusso, 2006; Arrivé et al., 2012; Bikaako-Kajura et al., 2006; Midtbø, Shirima, Skovdal, & Daniel, 2012; Turissini et al., 2013).

5.5 Relationship between Adherence and Healthcare delivery system factors

Significant factors were rating of information given by healthcare workers, confidentiality, trusting healthcare workers and rating of the quality of care provided This is in tandem with several studies (Ankrah et al., 2016; Nabukeera-Barungi et al., 2015) who found that support from healthcare workers increased adherence to ARVs. The finding also agrees with (Ankomah et al., 2016) who found a direct relationship between drug stock out and adherence.

Location of clinic and length of time clients had to wait during clinic visits were not significant factors. This agrees with findings by (Kgatlwane, 2010) who found no association between distance travelled to the clinic and adherence. The findings differ with(Ankomah et al., 2016) who found that long distance to treatment Centre, financial costs and delay at the clinic were significantly associated with adherence.

5.6 Discussion of the model

This study found that adherence among adolescents is a largely dependent on the side effects experience and having a peer supporter. This is in line with other studies that found that social support was a key driver of adherence and a fulfilling life. Having a close confidant when going through difficult situations such as terminal illness helps the adolescent to have something to hope for and therefore see ARV as their hope for tomorrow.(O'Laughlin, Wyatt, Kaaya, Bangsberg, & Ware, 2012). The treatment support also helps keep the adolescents connected with other social events keeping them connected to the community. This is critical as the HIV positive adolescents may miss some of the engagements to attend to clinic appointments and their treatment supporter will serve as their connection so that they don't feel left out.

Having a treatment supporter also helps reduce stigma which was found to be significantly associated with adherence (Weiser et al., 2003).

The rating of quality of care provided at the clinic was significant at binary logistic regression of healthcare delivery factors. this is in line with findings by (Beach, Keruly, & Moore, 2006) who found the level of adherence to increase based on an improvement in the perceived quality of care provided

CHAPTER SIX:

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusions

1. This study found an adherence rate of 92.5% that is slightly lower than the optimum and higher than most studies.

2. Occupation, quality of care rating, swallowing drugs at the right time and socio support were significant predictors of adherence

3. Forgetting, fear of stigma and lack of food were the most common reason for missing a dose

4. Nausea, itching and rashes were the most common side effects experienced

6.2 Recommendations

The value of ARVs in improving the quality of life for ALHIV cannot be underrated. Since ARVs are offered free in the Government facilities, there is need to support adolescents to overcome barriers associated with ART uptake. The researcher proposes the following recommendations to curb non-adherence and reduce the risk of treatment failure.

1. **To caregivers and adolescents**: Adopt strategies to remind adolescent to take drugs and keep clinic appointments

2. **To Ministry of Health**: Improved ARV regimen with reduced side effects since side effects was key contributor to non-adherence

3. **To Ministry of Health**: Psychosocial support for adolescents to address stress which was mentioned as key factor affecting ART adherence

4. **To Ministry of Education**: Stigma reduction strategies in schools to help adolescents in boarding schools take their ARVs without worrying their peers

will discover their HIV positive serostatus. Secondly to act as treatment supports for the HIV positive adolescents

5. **To Ministry of Health**: Policy review on HIV care services to ensure all Adolescent living with HIV (ALHIV) have access to nutritious food to take with their medication. This is especially important for adolescents living with poor or inadequate caregivers. Existing strategies such as Cash transfer can easily be used to achieve this.

6. **Further research**: Why adolescents have a high viral despite being adherent

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APPENDICES

Appendix 1: CONSENT & ASSENT TO PARTICIPATE IN STUDY

Study No…........

PART 1: CONSENT

Study Title: Prevalence and determinants of antiretroviral therapy adherence among adolescents in Kajiado county, Kenya

To Study Participants

Foreword

Investigator: KIMEMIA CATHERINE *(Master of Public Health Student),* MOI UNIVERSITY
Contact Telephone Number(s): 0722 586 865 **Email**: katekimemia@gmail.com

Purpose of study: This study will seek to determine the prevalence of ART adherence, prevalence of disclosure, determine association between adherence and viral suppression and identify other factors which affect adherence to ART among HIV infected adolescents who are on ART treatment. Your participation in this study will help identify which factors influence adherence to ART among HIV infected adolescents in order to improve treatment outcomes by addressing the identified gaps

How to Participate: You will be asked a few questions while waiting for your appointment or immediately following your appointment. Filling of this questionnaire will take approximately 20 minutes.

Right to refusal or withdrawal: Taking part in this study is your choice; you can decide to participate or not to participate in the study. Your participation is entirely voluntary and you are free to agree or disagree to participate in this study. You may withdraw from study at any time even after signing this form. Your care will not change in any way if you choose not to take part in this study.

Confidentiality and the privacy of your records: We will keep your involvement in this research study confidential by identifying you in the study records by a code/unique number. Paper and computer records will be kept under lock and key and

security code respectively. Study results that will be used in final the publication (thesis) will not use your name.

Risks and benefits: There are no risks or discomforts associated with this study and neither are there any direct benefits to you for taking part in.

For further clarifications or questions on this study please contact:

The Chairman IREC, Moi University Teaching and Referral Hospital

P.O. Box 3-30100, Eldoret,

Tel +254 2033471/2/3

TO THE CAREGIVER OF THE ADOLESCENT PARTICIPANT

Your signature indicates that this research study has been explained to you, that you've been given the opportunity to ask questions, and that you agree to allow your child to take part in this study

Signature of parent/guardian/caregiver …...

Thumb print………………………… **Date……………………………**

PART 2: ASSENT

FOR THE STUDY PARTICIPANT

Your signature indicates that this research study has been explained to you, that you've been given the opportunity to ask questions, and that you agree to take part in this study.

ADOLESCENT Agree ☐ Disagree ☐

If you agree to participate into the study, indicate your signature as below

Signature of subject/participant …...

Thumb **print………………………………**

Date……………………………

FOR RESEARCH PERSONNEL

I have discussed this research study with the participant using language that is understandable to him/her. I believe I have fully informed the subject of the possible risks and benefits, and I believe the subject understands this explanation.

Name

…………………………………………………………………………………

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

(Of authorized research personnel who conducted the informed consent discussion)

KIBALI CHA KUSHIRIKI KWA UTAFITI KWA LUGHA YA KISWAHILI

Nambari ya usajili ya utafiti:

……….

Kichwa cha habari ya utafiti: Kiwango cha maambukizi na vitambulishi vya madawa ya kurefusha maisha uzingatiaji miongoni mwa vijana katika Kajiado county, Kenya

Kwako mshiriki,

Utanguluzi

Mtafiti mkuu: KIMEMIA CATHERINE *(Master of Public Health Student),* MOI UNIVERSITY

Nambari ya simu: 0722 586 865   **Barua pepe**; katekimemia@gmail.com

Kusudi na lengo la utafiti huu: Utafiti huu utajaribu kuamua kiwango cha uzingatiaji wa ART, kiwango cha kutoa taarifa, kuamua muungano kati ya uzingatiaji na kukandamiza virusi na kubaini mambo mengine ambayo kuathiri uzingatiaji wa ART miongoni mwa vijana walioambukizwa virusi vya ukimwi ambao wanapatiwa tiba ART. ushiriki wako katika utafiti huu utasaidia kutambua mambo yanayoathiri uzingatiaji wa ART miongoni mwa vijana walioambukizwa virusi vya ukimwi ili kuboresha matokeo ya matibabu kwa kushughulikia mapengo yatakayotambuliwa

Jinsi Utakavyo shiriki: Utahusishwa kushiriki kwa kujibu maswali utakayoulizwa na mtafiti msaidizi muda mdogo kabla au baada ya kumaliziwa kliniki yako. Maswali haya yatachukua muda mfupi kama dakika ishirini.

Haki yako kukataa ama kujiondoa kwa utafiti: Kushiriki kwa utafiti huu ni hiari yako mwenyewe kujitolea, na hivyo basi waweza kuamua kutoshiriki. Iwapo umeweka sahihi kushiriki kwa utafiti, unakubaliwa kubadili mawazo na kutoka wakati wowote hata baada ya kuweka sahihi. Na iwapo utabadili mawazo na kuamua kutoshiriki, hali yako ya kupata matibabu haibadiliki hata kamwe. Utaonekana na kutibiwa kama kawaida bila kufikilia ulitoka kwa utafiti.

Hakikisho la kuweka siri kwa mhusika: Kuhusika kwako na maneno yote yatawekwa siri wakati wote. Makaratasi yatakayo andikiwa maneno yako yatakuwa na nambari fiche ili mtu yeyote asijue nani ni nani. Makaratasi yote ya majibu na komputa zitafungiwa kwa kabati za siri. Ripoti itakayochapishwa katika kumalizia utafiti huu haitatumia jina la mtu yeyote.

Madhara na faida ya utafiti: Hakuna madhara wala faida inayohusishwa na utafiti huu.

Ukiwa una maswali au ungependa kupata maelezo zaidi kuhusu utafiti, wasiliana na:

The Chairman IREC, Moi University Teaching and Referral Hospital

P.O. Box 3-30100, Eldoret, Tel +254 2033471/2/3

CHETI CHA RIDHAA

I) Kwako mzazi wa mtoto mshiriki

Kuweka sahihi yako ina maana kuwa umeelezwa maneno yote kuhusu utafiti huu na ukapatiwa nafasi ya kuuliza maswali na hivyo basi umekubali kwa wazi kumruhusu motto wako kushiriki kwa utafiti huu bila kusukumwa na kushurutishwa na yeyote.

Sahihi   ya   mhusika ....

Alama ya kidole gumba ………………..   Tarehe …………………………

2) Kwa mhusika Kijana/msichana atakayeshiriki

Kuweka sahiili yako ina maana kuwa umeelezwa maneno yote kuhusu utafiti huu na ukapatiwa nafasi ya kuuliza maswali na hivyo basi umekubali wazi wazi kushiriki bila kusukumwa na kushurutishwa na yeyote.

Mhusika   ☐ Ninakubali   ☐ Ninakataa

Ikiwa unakubali kushiriki, onyesha kwa kuweka sahihi kama ifuatavyo.

Sahihi ya mhusika   ....

Alama ya kidole gumba ………………..   Tarehe …………………………

3) Kwa mtafiti msaidizi aliyehusisha mhusika

Nimezungumza na mhusika kwa lugha anayoelewa kuhusu utafiti huu. Ninaamini kwamba nimemweleza maelezo yote kuhusu madhara na faida hadi akaelewa.

Jina …………………………………………………………………………………..

Sahihi …………………………………   Tarehe ………………………

(Ya mtafiti msaidizi aliyeelezea kusudi la utafiti na kutazamia mhusika akishiriki kwa utafiti)

Appendix 2: Patient Data Extract Tool

Questionnaire No: ………………..

Research Assistant………………..

Date Collected: …………………...

1.   Indicate date last seen at Health facility ………………………………….

2. From the individual medical records indicate the current status of HIV status disclosure.

☐   DISCLOSED

☐   NOT DISCLOSED

3. Indicate the most recent levels of the following biologic markers from records;

Latest CD4 Count Levels:

………………...
......

Latest Viral Load levels:

…………………………………………………………………………………..

For how long has ARVs been taken?

....
.....

Appendix 3:Case Adherence Index Tool

Please ask each question and circle the corresponding number next to the answer, then add up the numbers circled to calculate Index score.

1. How often do you feel that you have difficulty taking your HIV medications on time? By "on time" we mean no more than two hours before or two hours after the time your doctor told you to take it.

      4   Never

      3   Rarely

      2   Most of the time

      1   All of the time

2. On average, how many days PER WEEK would you say that you missed at least one dose of your HIV medications?

      1   Everyday

      2   4-6 days/week

      3   2-3 days/week

      4   Once a week

      5   Less than once a week

      6   Never

3. When was the last time you missed at least one dose of your HIV medications?

      1   Within the past week

      2   1-2 weeks ago

      3   3-4 weeks ago

      4   Between 1 and 3 months ago

      5   More than 3 months ago

      6   Never

INDEX SCORE: **/16** _____

> 10 = good adherence   ≤ 10 = poor adherence

Source: Mannheimer, et al. AIDS Care 2006; 18:853-861.

Appendix 4:Interview Schedule for Adolescents

Questionnaire No:…………

Date administered: …………..

Interviewer: ………………….

INSTRUCTIONS

The information given will be treated with utmost confidentiality. Do not indicate the name of study participant. Please indicate by putting a tick (√) in the space(s) provided or filling in the blank space(s) your responses as appropriate

PART 1: RESPONDENTS SOCIAL DEMOGRAPHIC INFORMATION				
			CODE	
Q1	**Gender of respondent**	Male	1	
		Female	2	
Q2	**Level of education**	Vocational Institution	4	
		Secondary	3	
		Primary	2	
		No formal education	1	
Q3	**Marital status**	Single	1	
		Married	2	
		Divorced	3	
		Separated	4	
		Widowed	5	
Q4	**Occupation**	Self-employed	1	
		Other employment	2	
		Unemployed	3	
		Student	4	
Q5	**What is your Religion?**	Christian	1	
		Muslim	2	
		Hindu	3	
		None	4	
		Any other........................	5	
Q6	**How old are you?**	Indicate age in years at last birthday		
Q7	**Where do you live?**	Urban	1	
		Rural	2	
Q8	**With whom do you live in the same house?**	One parent	1	
		Both parents	2	
		Relatives	3	
		Friends	4	
		Siblings	5	
		Pastor	6	
		Other specify...................	7	

PART 2: QUESTIONS ON ADHERENCE TO ANTI-RETROVIRAL DRUGS

			CODE	
Q9	**What reasons make you miss medication doses at any one time?**	Presence of any illness Stress Lack of food to take with Toxicity /side effects Feeling better Drinking alcohol Finished stock Fear of stigma Too many pills Forgetting Any other………………..	1 2 3 4 5 6 7 8 9 10 11	
Q10	**How do you rate the kind of social support received regarding taking ART medication?**	Never Rarely Sometimes Often Always	1 2 3 4 5	
Q11	**What side effects bother you upon taking ART medications?**	None Rashes Neuropathy Nausea Vomiting Diarrhea Itching Others…………………… .	1 2 3 4 5 6 7	

PART 3: FACTORS THAT AFFECT ADHERANCE TO ANTI-RETROVIRAL THERAPY

Indicate your opinion for the responses shown under each subheading

1= Strongly disagree 2= Disagree 3= Neutral 4= Agree and 5= Strongly agree

Caregiver Factors

Caregiver Factors		**CODE**				
Q12	I have a caregiver who loves and cares for me	1	2	3	4	5
Q13	I trust my caregiver	1	2	3	4	5
Q14	I feel my caregiver supports me adequately	1	2	3	4	5
Q15	My caregiver is knowledgeable on HIV care	1	2	3	4	5
Q16	My caregiver participates in support group	1	2	3	4	5
Health care delivery system factors		**CODE**				
Q17	Health workers give useful information	1	2	3	4	5
Q18	Sometimes I find drug stock outs during visit	1	2	3	4	5

Q19	Health workers are friendly to patients	1	2	3	4	5
Q20	Confidentiality and privacy is maintained	1	2	3	4	5
Q21	I trust health workers	1	2	3	4	5
Q22	Services are costly	1	2	3	4	5
Q23	The clinic has long waiting time	1	2	3	4	5
Q24	The clinic makes call/send SMS reminder for revisit	1	2	3	4	5
Q25	There is provision of quality care	1	2	3	4	5
Q26	The clinic is located too far from home	1	2	3	4	5
Medication related factors						
Q27	ART medications are easily accessible	1	2	3	4	5
Q29	I swallow drugs at the right time	1	2	3	4	5
Q30	I discontinue medication if I experience side effects	1	2	3	4	5
Q31	I skip the medications when food is not there	1	2	3	4	5
Q32	I hide medications from colleagues	1	2	3	4	5
Q33	I do not mind taking alcohol and other drugs	1	2	3	4	5
Q34	Medications have difficult dosing to follow	1	2	3	4	5
Q35	I am keen not to miss clinic appointment for drug refill	1	2	3	4	5
Q36	I discontinue drugs if I feel better	1	2	3	4	5
Q37	I discontinue if I am taking other medications	1	2	3	4	5
Q38	I was given limited information on how to take ART	1	2	3	4	5
Social/ environmental factors						
Q39	People I live with remind me to take drugs	1	2	3	4	5
Q40	I cannot take drugs with people looking	1	2	3	4	5
Q41	Disclosure of HIV status is important	1	2	3	4	5
Q42	The school environment has privacy with medications	1	2	3	4	5
Q43	My other siblings do not know my status	1	2	3	4	5
Q44	I have friends who know my status and care for me	1	2	3	4	5
Q45	The housing arrangement has no privacy	1	2	3	4	5
Q46	I participate in social support groups for HIV infected	1	2	3	4	5

Thank you for your co-operation.

Appendix 5:Focused Group Discussion Tool

Moderator: _____

Date:_____

Secretary: _____

Venue: _____

Group No: _____

No. of people: _____

Dear participant,

I would like to inform you that your participation will be tape recorded. This information obtained will be treated with absolute confidentiality. It will be used for the purpose of this study only. Your names will not be mentioned anywhere.

QUESTIONS

1) What do you understand by the term anti-retroviral therapy (ART)?

2) What benefits do adolescents obtain from using anti-retroviral therapy?

3) Adolescents sometimes miss treatment doses, what do you think makes one to miss doses?

4) in your opinion, what are the factors that hinder adolescents from following treatment as required?

5) What ways or strategies can be used to assist adolescents follow treatment properly?

6) Is HIV status disclosure important to adolescents? Give reasons for both Yes & No

Thank you for your participation.

Appendix 6: IREC Approval

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET

Reference: IREC/2016/271
Approval Number: 0001848

31st March, 2017

Ms. Catherine Kimemia,
Moi University,
School of Public Health,
P.O. Box 4606-30100,
ELDORET-KENYA.

Dear Ms. Kimemia,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:-

"Prevalence and Determinants of Antiretroviral Therapy Adherence among Adolescents in Kajiado County, Kenya".

Your proposal has been granted a Formal Approval Number: **FAN: IREC 1848** on 31st March, 2017. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 30th March, 2018. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

INSTITUTIONAL RESEARCH &
ETHICS COMMITTEE
3 1 MAR 2017
APPROVED
P.O. Box 4606-30100 ELDORET

cc	CEO	-	MTRH	Dean	-	SOP	Dean	-	SOM
	Principal	-	CHS	Dean	-	SON	Dean	-	SOD

Appendix 7: Kajiado County Government Approval

COUNTY GOVERNMENT OF KAJIADO

DEPARTMENT OF HEALTH SERVICES
OFFICE OF THE COUNTY DIRECTOR
P.O.BOX 31, KAJIADO

Ref: KCG/HEALTH SERVICES/20/VOL3/237   8th June 2017

CATHERINE KIMEMIA
MOI UNIVERSITY SCHOOL OF PUBLIC HEALTH
P. O. BOX 4606-30100
ELDORET

RE: RESEARCH AUTHORIZATION

Reference is made to communication dated 31st March 2017 from the Institutional Research and Ethics Committee Ref. NO. IREC/2016/271 on the subject formal approval.

The department has no objection to your request to conduct research on "prevalence and determinants of Antiretroviral Therapy Adherence among Adolescents in Kajiado County, Kenya."

However, you will be expected to submit a copy of your findings to this office on completion of your research.

Thank you.

DR. EZEKIEL KAPKONI
THE COUNTY DIRECTOR OF HEALTH SERVICES.

COUNTY DIRECTOR OF HEALTH
KAJIADO COUNTY
08 JUN 2017
P.O Box 31 - 01100
KAJIADO

CC: CHIEF OFFICER FOR HEALTH SERVICES
    ALL SCMOH'S – KAJIADO COUNTY
    ALL MEDICAL SUPERITENDENTS-KAJIADO
    FACILITY INCHARGES

Appendix 8: Approval from Beacon of Hope

2nd June 2017

Chairman
Institutional Research and Ethics Committee
Moi University
School of Public Health,
P. O. Box 4606 30100
ELDORET - KENYA

Dear Prof. Were,

RE: RESEARCH PROPOSAL NUMBER FAN:IREC 1848 BY MS CATHERINE KIMEMIA

In reference to the above; Beacon of Hope health Care centre gives consent for Ms Catherine Kimemia to collect data from our Health Care centre for purposes of the research titled:

"Prevalence and determinants of antiretroviral Therapy Adherence among adolescents in Kajiado County"

Beacon of Hope (BoH) is a Faith and community based organization. Our **vision** is to be a centre of excellence in comprehensive community transformation with a **mission** to bring hope to 'women' living with and affected by HIV/AIDs within poor communities by empowering and equipping them to meet their spiritual, physical, social, emotional, economic and family needs in a sustainable way.

Our Health care centre provides primary health care services address communicable and non communicable diseases. Maternal child health includes maternity services, family planning and immunization services. Dental care is provided including oral health education. We are very involved in HIV/AIDS programs ensuring quality of care across all ages. HIV counseling and testing including STI treatment is provided; Prevention of Mother to Child Transmission (PMTCT); HIV/AIDS care and management are among the services provided.

We are pleased to accord Ms. Kimemia the support she requires to complete her study. Her research findings can help the facility improve services for adolescents especially ART adherence.

Sincerely,

Jane Wathome
Executive Director - Beacon of Hope

Appendix 9:Published Journal Article

Antiretroviral Therapy Adherence and its Determinants among Adolescents in Kajiado County, Kenya

*[1]Kimemia, C.W., [1]Too, R, [1]Kiptoo, J. P
*Corresponding Author
[1]Moi University, Eldoret, Kenya

Abstract

➢ *Introduction*

Anti-Retroviral Therapy (ART) use has increased globally. It is estimated that 15 million (41%) People Living with Human Immunodeficiency Virus (PLHIV) are receiving ART, out of which 823,000 are children. Adherence to ART influences viral load reduction, improved immunity and treatment success. Studies show an almost complete adherence is needed to sufficiently suppress viral replication. However, several factors, including poverty, substance abuse, stigma and lack of disclosure hinder success of adherence. While HIV prevalence has continued to decrease worldwide, it remains a major cause of morbidity and mortality among adolescents. Poor ART adherence increases the risk of viral drug-resistance, reduces future therapeutic options and increases the risk of transmission. Adherence has been studied extensively with adult patients, but adolescent adherence has been largely neglected in the literature.

➢ *Objective*

The aim of this study was to estimate prevalence of ART adherence and to identify characteristics of adolescents and their guardians that influence ART adherence.

➢ *Methods*

A cross sectional, facility-based study was carried out in four select facilities in Kajiado County. Quantitative and qualitative data was collected among 167 HIV positive adolescents and their guardians using interviewer questionnaires and an interviewer guide in two Focused Group Discussions.

Data was managed using SPSS (version 22). Proportions and frequencies were calculated for categorical data and means and medians for continuous variables. Bivariate correlation analysis was conducted to determine strength and direction of associations between independent factors and adherence to ART. The t-test was used to conduct this evaluation at 5% level of significance. A linear regression model was fitted to control for confounders and adjust for association between factors and adherence to ART. Ethical clearance was sought and obtained from Moi Institutional Research and Ethics Committee (IREC).

➢ *Results*

A total of 167 adolescents aged 10-19 were interviewed among whom 49%(82) were males and 51%(95) females. Estimated level of adherence was 92.8% (95% CI: 87.8% - 95.8%). The most common reason for missing a dose was forgetting, fear of stigma and lack of food. Occupation, side effects, lack of food, having friends, confidentiality, trust and quality of care rating, swallowing drugs at the right time and keeping clinic appointments were significantly associated with adherence to ART (P<0.05) at the bivariate level. Adherence to ART was linearly modeled by two factors, "Experiencing side effects" and "Having friends who knew the adolescent's status and cared for them", $F_{4, 157} = 22.302$, p<0.05.

➢ *Conclusions*

This study found a prevalence rate slightly lower than the optimum and higher than most studies. Medication related factors were the most significant predictors of adherence.

➢ *Recommendations*

Adopt mechanisms to remind adolescents to take ART, improved regimen with reduced side effects, psychosocial support and stigma reduction strategies.

Keywords:- Human Immunodeficiency Virus, Anti -Retroviral Therapy, Adolescent, Viral, Suppression, ART Adherence, Kajiado, Kenya.

I. INTRODUCTION

Human Immunodeficiency Virus [HIV] persists as a key public health issue. Globally, there are 36.9 million people living with HIV out of which 2.6 million are children; Seventy percent(70%) of these live in sub-Saharan Africa [1]. It is estimated that 41% of People Living with HIV [PLHIV] are receiving Anti-Retroviral Therapy [ART] translating to 15M people out of which 823,000 are children ["Global HIV and AIDS statistics | AVERT," 2015].

Over 3 million children under 15 years of age were living with HIV in sub-Saharan Africa in 2010, representing more than 90% of all children with HIV in the world. Eastern and Southern Africa bear a larger burden with 2.2 million children with HIV, relative to the 990,000 in West and Central Africa. [2]

In Kenya, there are an estimated 1.6 million People Living with HIV [PLHIV] out which 191,840 are children aged 0-14 years[3]. Seventy-eight percent of adults who need Anti-Retroviral Therapy [ART] are accessing them compared to 42% of children[3]. This shows that ART access is still below the recommended 90% and is worse off in children than adults. This coupled with less than optimal adherence means the battle against HIV/AIDS is far from over as witnessed by survey done by the National AIDS Control Council[4] which found out that one in six adults and adolescents reported missing an ARV dose at least once within the 30 days preceding the survey

Adherence to ART influences viral load reduction, improved immunity and success of treatment among PLHIV evidenced by a longer productive life. [5]. Studies have also continued to show an almost 100% adherence is needed to sufficiently suppress viral replication[6].

Adherence has been studied extensively with adult patients. However, issues in youth adherence and possible reasons for their poor adherence have been largely neglected in the literature. [7].

Several factors hinder adherence success including chronic poverty, limited resources, substance abuse stigma and lack of disclosure[5]. Other factors cited include patients' age, regimen complexity, drug side-effects, advanced HIV disease and patients' mental health [6]

Advancement in HIV treatment and care has resulted to children born with HIV living longer [2]. This means that they need a life time supply of ARV. Adherence to these medications is key as there are limited treatment options. Adherence in adolescents is therefore critical for their survival as they will need the medication all their life. According to UNAIDS, AIDS is the leading cause of death among adolescents in Africa[8]. There is therefore a need to address issues around ART adherence to improve survival and development of the adolescents.

Adolescence is the age between 10-19 yrs. [9]. It is the age of transition from childhood to adulthood and is marked with physical and emotional changes. The age is also marked with sexual experimentation and is characterized by high-risk sexual behavior[10]. Adolescents are mostly school going age with several in boarding schools. This coupled with lack of disclosure and fear of stigma makes them less likely to adhere to ART [5]

Adolescents have been described as the 'fulcrum' and the 'centre of the epidemic', with 42% of new HIV infections occurring in this age group [10]. This means the possibility of an AIDS free generation depends highly on how we respond to the needs of adolescents. Human Immunodeficiency Virus is ranked among top causes of morbidity and Mortality in Kajiado County. [12]. According to Kenya HIV prevention

roadmap, Kajiado County is ranked in the medium incidence cluster with HIV prevalence of 4.4%.[13]. Kajiado is ranked 23rd in terms of HIV burden and contributes 1.6% to the national incidence rate. There are an estimated 20,100 adults and 2956 children living with HIV in Kajiado County. [3]

Kajiado County is near Nairobi County, which has a HIV prevalence of 6.8% [ranked 8th nationally] and falls in the high incidence counties. This has a spill-over effects on Kajiado County because Kajiado offers access to affordable housing [13]. Kajiado County HIV/AIDS strategic plan also prioritizes defaulter tracing as a key activity.

Poor ART adherence increases the risk of viral drug-resistance.[6]. This decreases the treatment efficacy leading to disease progression whereby the HIV infection can develop to full brown AIDS. It also reduces future therapeutic options. In Kenya, there are three treatment options with the third line being very expensive and requiring approval by National Technical Working Group for one to be enrolled. A young person defaulting on first line and being switched to a second line at an early age will adversely affect his/her life. Poor adherence also increases the risk of transmission due to unsuppressed viral Replication [6].

II. MATERIALS AND METHODS

➢ *Study Site*

The study was conducted in Kajiado County, Kenya. According to Kajiado Health Strategic Plan,[13] the county has one County referral hospital, 3 sub-county hospitals, 15 Health centers and 66 Dispensaries giving a total of 85 Government owned health facilities. Over 60% of the population lives more than 5km from the nearest health facility [14].

The study was conducted in four health facilities within Kajiado North namely Ngong Sub-County hospital, Ongata Rongai Health Centre, Beacon of Hope clinic and Dreams Centre.

➢ *Study Design*

A descriptive cross-sectional design was employed in this facility based study. Both qualitative and quantitative data were collected using questionnaires.

Qualitative data was collected using Focus Group Discussions [FGD]. Two types of FGD were held, one with adolescents to understand their issues and another with their caregivers to understand their perspectives. Only adolescents who have been disclosed to were involved in the FGD. The quantitative data was collected using interviewer administered questionnaires involving 167 adolescence respondents aged 10-19 years accompanied by their parents/guardians and having been on ARV regiments for at least 90 days prior to study. Adolescents either with severe disability, very seek or