# PREDICTORS OF NON-ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV-INFECTED CHILDREN BELOW 10 YEARS ATTENDING LEVEL 4 AND 5 HEALTH FACILITIES IN TURKANA COUNTY, KENYA

# $\mathbf{BY}$

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SCHOOL OF PUBLIC HEALTH AND COMMUNITY DEVELOPMENT

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# **DECLARATION**

I declare that this thesis is my original work and has not been submitted for the award of a degree in any institution of higher learning.

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# **DEDICATION**

I would like to dedicate this thesis to myself. For it to always be a reminder that no matter how far, unsure, challenging or rough the journey is, with focus, perseverance, and ambition the destination is reached.

#### **ABSTRACT**

The use of more effective antiretroviral therapy (ART) has significantly improved survival of children infected with Human Immunodeficiency Virus (HIV). However, the benefits of these treatments are limited by non-adherence to the antiretrovirals among pediatrics, particularly in resource-limited settings. In Kenya viral suppression among HIV positive children on ART remains low at 67.1% compared to 90.6% in adults (KENPHIA Report, 2019). In Turkana County, 20% of the 1887 children on ART are virally suppressed (Kenya County Profiles Report, 2016). This study sought to determine the predictors of nonadherence to antiretroviral therapy among children below 10 years receiving HIV care and treatment at level 4 and 5 health facilities in Turkana County, Kenya. The study determined: the prevalence of ART non-adherence among HIV-infected children on care; formulation and regimen specific factors associated with ART non-adherence; social-family factors associated with ART non-adherence and health system factors associated with ART nonadherence among HIV infected children. Data was collected through a cross-sectional mixed study design from 173 out of 253 eligible participants attending selected Ministry of Health level 4 and 5 facilities. Data on non-adherence was collected based on Morisky medical scale(rated as 0 being good adherence, 1-2 being inadequate adherence, and 3-8 being poor adherence) and hospital medical records whereas data on predictors of non-adherence were collected using semi-structured questionnaires. Key informant interviews and focused group discussions were conducted. Data was analyzed descriptively and summarized using frequencies, means and standard deviations and associations were tested using Pearson's Chisquare test. Multiple logistic regression analysis was conducted to establish the relationship between the variables (ART formulation and regimen factors; socio-family factors; health care factors) and results summarized using 95% confidence interval and odds ratio. Results revealed a cumulative 45.1% (n=78) ART non-adherence prevalence. Whereas the formulation and regimen factors are clinically important, only ART negative side effects variable was statistically significant ( $\chi 2 = 5.53$ ; p=0.02). However, on regression it did not reach statistical significance. Among socio-family factors, disclosure to other family members ( $\chi 2 = 6.67$ ; p=0.04; OR=0.185), missed ART days ( $\chi 2 = 110.90$ ; p=0.01; OR=128.44) and missed ART administration (p=0.02; OR=2.042) by caregivers were shown to have a major effect on ART non-adherence among the children. Through Chi-square test of association all the health care variables assessed were strongly positively related and significant. However, after logistic regression, ART accessibility was statistically significant as the main health care predictor to ART non-adherence among children ( $\chi 2 = 99.33$ ; p = 0.01; OR=1.875). The present study recommends further sensitization of the community to support caregivers in ART administration to children upon caregiver disclosure of the child's HIV status; sensitization of caregivers on ensuring the child adheres to the ART regimen and not miss intake on any day; county government should take innovative initiatives of ensuring ART accessibility to the caregivers regardless of the distance.

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# LIST OF ACCRONYMS AND ABBREVIATIONS

**3TC** : Lamivudine

**AIDS** : Acquired Immuno-Deficiency Syndrome

**ART** : Anti-Retroviral Therapy

**ARVs** : Anti-Retroviral Drugs

**AZT** : Zidovudine

CASE : Centre for Adherence Support EvaluationCALHIV : Children and Adolescents living with HIV

**EFV** : Efavirence

**HIV** : Human Immuno Deficiency Disease

**HMIS** : Health Management Information System

**KENPHIA**: Kenya Population-based HIV Impact Assessment

**LDL** : Low detectable Levels

**LPV/r** : Lopinavir/Ritonavir

**LTFU** : Lost to Follow-Up

**MEMS** : Medication Event Monitoring System

MMAS : Morisky Medication Adherence Scale

MTCT : Mother to Child Transmission

**MUERC**: Maseno University Ethics and Review Committee

NACOSTI: National Commission for Science, Technology and Innovation

**NASCOP** : National AIDS and STI's Control Programme

**NVP** : Nevirapine

**SEAC** : Standardized enhanced adherence counseling

**SMART** : Standardized Monitoring and Assessment of Relief and Transitions

**TB** : Tuberculosis

**UNAIDS** : United Nations Program on HIV/AIDS

**USAID** : United States Agency for International Development

VL : Viral Load.

#### **DEFINITION OF OPERATIONAL TERMS**

**Active on Care**: The child has not missed any clinic appointment in the health facility he/she is enrolled in

**Adherence**: The extent to which a person's behavior- for instance taking medication following a diet and/or changing lifestyle corresponds with agreed recommendation from a health care provider. It also refers to the intake of more than 95% of ARV doses taken as prescribed by the clinician.

Antiretroviral (ARV) drugs: Medicines used to treat HIV

**Antiretroviral Therapy (ART):** Use of a combination of three or more ARV drugs for the treatment of HIV

**Caregiver:** Any person, male or female, to whom the responsibility of taking ART medication by HIV positive child is placed and is responsible for approximately 90% administration of ARVS to the child.

Children/Pediatric: Any human being below the age of 10 years

**Formulation and Regimen Specific Factors:** Refers to the physical characteristics of the ART, that is, solid or liquid form of the drug, drug size, palatability, dosage, and number of pills taken daily

**HIV Viral Suppression**: A measure of success for ART medication resulting in a blood viral load of less than 1000 RNA copies per every milliliter of blood in an HIV-infected child.

**Low Level Viremia**: One or more viral loads results that are detectable (more than 50 copies/ml) but equal to or less than 1000 copies/ml

Non-adherence: Intake of less than 95% of ARV doses taken as prescribed by the clinician

**Predictors**: Variables or factors that contribute to ART non-adherence

**Prevalence**: Refers to a proportion of the population categorized as having specific characteristics in each period of time.

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# **CHAPTER ONE**

# INTRODUCTION

# 1.1 Background of the Study

The introduction of antiretroviral therapy (ART) has altered HIV infection from a rapidly terminal disease into a chronic disease (Vreeman et al., 2018). ART suppresses HIV replication, reduces HIV morbidity and mortality and improves the lives of HIV infected children (Safira et al., 2018). However, for the ART to be successful, adherence to the ART regimens must be observed. Additionally, adherence to ART and success of treatment have other public health benefits such as reducing community viral load as well as reducing injection, sexual and perinatal-related transmission (Mukui et al., 2016).

Children who are not adherent to the ART regimen predispose themselves to greater risks of viral resistance to the available antiretroviral drugs, immunologic decline resulting in opportunistic infections like tuberculosis, HIV disease progression, and transmitting resistant HIV at sexual debut (Vreeman et al., 2018). Therefore, children's HIV-related morbidity and mortality decrease when there is good ART adherence, that is, intake of 95% or greater of doses as prescribed. Globally and in Sub-Saharan Africa ART accessibility has expanded rapidly, especially with the World Health Organization (WHO) guidelines of test and treat. Nonetheless, ART implementation among children below 14 years faces major challenges of ART non-adherence (Wadunde et al., 2018)

The Kenya 2018ART guidelines recommends immediate ART initiation for HIV-infected infants/children to reduce mortality among young children. However, ART adherence remains to be one of the greatest obstacles in pediatric HIV care (Nichols et al., 2019).

Various techniques have been developed for quantifying adherence and they include patient self-reports, observing clinic appointments, pill counts, biological markers (viral load values), and electronic monitoring systems such as the Medication Event Monitoring System (MEMS) (Alemu et al., 2014). However, all these techniques have their limitations. However, as much as self-reports tend to overestimate adherence levels, it has been found that it correlates fairly well with the actual medication intake (Naomi et al., 2018)

The resource-limited settings of Sub-Saharan Africa contribute to over 90% of the 3.4 million HIV-infected children (UNAIDS Global AIDS Update, 2018) with approximately 24.6% to 100% of HIV-positive children having perfect adherence (Vreeman et al., 2014). According to Enana et al., (2018), a case-control study done in Botswana among children

below 5 years depicted that missed ART drugs, greater immune suppression, and advanced HIV disease were the major factors associated with ART non-adherence.

According to KENPHIA report (2019), Kenya has the fourth highest HIV epidemic with an overall HIV prevalence of 4.9% (1.3 million adults living with HIV) with approximately 139,000 (0.7%) children under the age of 14 years being HIV positive of which 109,671 children are on ART contributing to ART coverage of 78.9%. The reports also indicate children below 14 years treatment outcome across the UNAIDS 90-90-90 as 78.9%, 93.2%, and 67.1% respectively while that of adults above 14 years was indicated as 79.5%, 96.0% and 90.6% respectively. While efforts have been made in adult HIV management, achieving the UNAIDS and Kenyan goal of 90%, virologic suppression among children living with HIV has remained a national challenge at 67.1% as compared to that of the adult at 90.6% as reported (KENPHIA Report, 2019)

The KENPHIA report (2019) lists Turkana as the 6<sup>th</sup> highest county with a high HIV prevalence of 6.8% while Homabay county has been listed to have the highest HIV prevalence of 19.6%. Garissa was recorded as the county with the least HIV prevalence of less than 0.1%. In comparison, Turkana still records the highest HIV prevalence of 6.8% when compared to the neighboring ASAL counties, that is, Baringo at 1.8%, West Pokot at 1.3%, Samburu at 1.9% and Marsabit at 1.2% as well as the county with the lowest ART adherence of 39.7%(KENPHIA, 2019 report)

Turkana County has an overall of 1887 HIV positive children below the age of 14 years, with 713 (38%) currently on ART. The MTCT rate still remains high within County at 18.3%. According to the Kenya HIV County Estimates report (2018), there were 81 reported HIV related deaths within the county among HIV positive children below 14 years. Additionally, according to the Kenya County Profiles Report (2016), viral suppression among children in Turkana County was 20% giving a picture of poor adherence to ART among children compared to that of adults at 40%. In the KENPHIA report (2019), Turkana recorded the 6<sup>th</sup> highest county with a HIV prevalence of 6.8% with the lowest viral suppression among adults at 39.7% in Kenya. However, the KENPHIA Report, 2019 does not show various suppression percentages among children in different counties. Adherence is a complex behavior normally influenced by factors that are divided into four major categories; (1) medication factors such as food requirement, palatability, pill counts or dosing complexity (2) patient related factors such as age, sex, alcohol use or drug use (3) patient-health care provider relationship (4) the health care system (Wadunde et al., 2018). Adherence in

children has mostly been seen as multi-faceted (Alemu et al.,2014). The limited availability of a single-tablet or once daily regimen and palatable formulations for the children contributes greatly to pediatric non-adherence (Clay et al., 2015). Moreover, the children are dependent on their caregivers for drug administration and clinic attendance hence some barriers encountered by the caregivers contribute to pediatric non-adherence to ART. These barriers are not limited to the care giver being busy, forgetting dose administration, child refusal to take the medication and changes in routine (Shubber et al., 2016).

Health Care facilities are divided into six different levels in Kenya. Level 1 to 5 are managed at the county level whereas the sixth level is managed by the national government. In Turkana County, 78% of HIV infected persons attend level 4 and 5 health facilities for HIV care and treatment (Kenya HMIS Statistics Report, 2019) indicating that a lot of people bypass the low-level health facilities and go to high level facilities.

Sustaining adherence represents a significant challenge for children receiving ART. In order to facilitate adherence as well as improve viral suppression among the children, it is vital to identify potentially relevant issues in pediatric patients that influence adherence and to determine interventions to improve adherence among these populations. Understanding the various challenges that clients, caregivers and health workers face is critical to close children living with HIV virologic gap.

# 1.2 Statement of the Problem

In Kenya, ART adherence among children as seen through viral load suppression is at 67.1% as compared to adult suppression which is at 90.6% depicting non-adherence among children (KENPHIA report, 2019).

The 20% suppression rate among children compared to that of adults at 39.7% in Turkana county is a cause for alarm despite the robust heath care system implemented by the ministry of health and supported by various HIV implementing partners within the county (KENPHIA report, 2019). With the global UNAIDS 2030 goal of 90% viral suppression, there is need to understand the where the disconnect is as children under 10 years are dependent on the caregivers for ART administration and attending of clinic appointments as they have also not been done full disclosure. Hence it is expected that the adherence level of children below 10 years be the same as the adults' both at National level and county level. Additionally, looking at the counties neighboring Turkana and have been categorized as ASAL, Turkana still has the highest ART prevalence and lowest viral suppression among adults, adolescents, and children (KENPHIA report, 2019).

Whereas the adherence level among children below 10 years in Turkana County is known, there is limited research done that showcases predictors of non-adherence among children in Turkana County especially among the level 5 and level 4 heath facilities where approximately 78% of the HIV patients receive care and treatment. This study sought to identify predictors that may contribute to non-adherence among HIV positive children below 10 years in Turkana County, Kenya.

# 1.3 Study Objectives

# 1.3.1 Main Objective

To determine the predictors of non-adherence to antiretroviral therapy among HIV infected children below 10 years attending level 4 and level 5 health facilities in Turkana County.

# 1.3.2 Specific Objectives

- To assess the prevalence of ART non-adherence among HIV infected children below
   years attending level 4 and 5 health facilities in Turkana County.
- ii. To assess the formulation and regimen specific factors independently associated to ART non-adherence among HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana County
- iii. To assess the social-family factors independently associated to ART non-adherence among the HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana County.
- iv. To assess health system factor independently associated to ART non-adherence among HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana

# **1.4 Research Questions**

- i. What is the prevalence of ART non-adherence among HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana County?
- ii. What are the formulation and regimen specific factors associated with ART non-adherence among HIV infected children below10 years attending level 4 and 5 health facilities in Turkana County?
- iii. What are the social/-family factors associated with ART non-adherence among HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana County?

iv. What are the health systems specific factors associated with ART non-adherence among HIV infected children under 10 years attending level 4 and 5 health facilities in Turkana County?

# 1.5 Study Justification

ART non-adherence among children has major consequences which include, but not limited to drug resistance, opportunistic infections and likelihood of HIV-related mortality (Neupane et al., 2019). Pediatrics grow up and become adolescents and hence may increase chances of secondary HIV transmission or transmission of resistant HIV strain at sexual debut (Vreeman et al., 2018). It is due to these consequences and accessibility of ART in Turkana that it is prudent to investigate what are the predicators that cause ART non-adherence and determine various interventions that will ensure ART adherence among children below 10 years within the county.

Despite improving availability of ART, adherence to ART and ART regimens may be complicated among children residing in resource-limited settings (Fetzer, 2011). Turkana being an arid and semi-arid region with limited resources and other competing factors (79% level of illiteracy (SMART Survey Report, 2019), long travel to the health facilities to receive care and treatment, poor infrastructure, limited health care workers, pastoralism among others (Masaba et al., 2022) there is limited data on the predictors of non-adherence among children below 10 years. The only known data is the prevalence which again is cumulative based on routine data. There is paucity of reports on ART non-adherence among children below 10 years living in resource limited settings (Fetzer et al., 2011). Therefore, evaluating and understanding these predictors to ART non-adherence among children will help in planning improvement interventions and designing care and treatment programs to address these concerns as well as accelerate achievement of the UNAIDS goal of 95% suppression.

The study will also aid in academia in the understanding of predictors to non-adherence among children in Turkana County and similar counties within Kenya; generation of policies for purpose of funding to HIV programs and related programs targeting children and generation of data to inform programming. According to the Kenya HMIS statistics report (2019), Turkana has 18 health facilities providing HIV care and treatment;1 level-5 health facility, 9 level-4 health facilities, 6 level-3 health facilities and 2 level-2 health facilities. Nonetheless, in Turkana County, 78% of HIV infected persons attend level 4 and 5 health

facilities for HIV care and treatment (Kenya HMIS Statistics report,2019) indicating that a lot of people bypass the low-level health facilities and go to high volume facilities. The study will therefore focus on the level 4 and 5 health facilities.

# 1.6 Significance of the Study

The study will help in assessing level of non-adherence and provide evidence-based evaluations of factors affecting ART non-adherence among the children below 10 years in receiving ART in Turkana County, Kenya.

Identifying various predictors to non-adherence among children will enable designing of improvement interventions aimed at reducing non-adherence among children and hence lead to ART adherence and consequently viral suppression among children. Findings on formulation and regimen specific factors will be used to give insights on various interventions that can be done while administering the ART to the child.

The findings obtained from the study will be used by health planers such as the Ministry of Health, and other stakeholders implementing HIV programs. It will enable the stakeholders design programs aimed at alleviating non-adherence among children as well as serve as resource for new research on the identified gaps.

The study will also be used as important literature for future researchers who would want to undertake similar study.

# 1.7 Study Limitations

- i. Non-adherence assessment was based on the caregivers' self-report which might have affected the result. This was addressed through various questions that were asked regarding predictors of ART non-adherence.
- ii. Over/under-estimation of non-adherence as the study considered any child who has ever missed their doses as non-adherent regardless of number of times missed or doses missed. This was addressed through use of MMAS-8 score which is the standard tool used to assess non-adherence among HIV positive people.

# 1.8 Delimitations

The boundary of the research will be within Turkana County focusing on Level 4
and Level 5 health facilities providing HIV care and treatment to children below
10 years.

#### **CHAPTER TWO**

# LITERATURE REVIEW

# 2.1 Prevalence of ART adherence among the HIV positive Children on care

The information on the prevalence of ART adherence among the children is critical as it provides a guide to clinical decision makings, evaluating adherence interventions as well as prompt interventions that will reduce the risk of drug resistance (Vreeman et al., 2018). For ART to be successful in the treatment of HIV, maintaining a high level of adherence is expected from the patients (Safira et al., 2018). The estimates of ART adherence among children are hampered untested and heterogeneous measures.

Currently, there are various methods being implemented to assess ART adherence among the HIV patients and they include; observing clinic appointments, provider estimation, pill counts, client self-report, electronic monitoring device such as the Medication Event Monitoring System (MEMS), Morisky Medication Adherence Scale (MMAS) and blood stream/biological markers (viral load levels) (Naomi et al., 2018). Research studies have showed that, self-reported adherence ranges from 0% to 100% (Alemu et al., 2014). An effective method of self-report that has been highlighted is the utilization of the Center for Adherence Support Evaluation (CASE) tool which according to researchers is a tool that predicts adherence level to ART (Vreeman et al., 2018).

The non-adherence levels in the sub-Saharan African countries have been reported to be high with Ghana at 14%, Rwanda at 23%, Zambia at 40% and a pooled analysis of African adherence studies where 23% non-adherence prevalence was reported (Mukui et al., 2016). A pooled analysis of non-adherence prevalence from developed countries indicated 45% non-adherence level in North America, 43% in Spain, 37% in Sweden and 34% in Brazil (Mills et al., 2006). In a systematic review of ART adherence studies among the children in middle and low income countries, the estimates of pediatric ART ranged from 49% to 100% with 76% of articles reporting greater that the 75% (Wadunde et al., 2018). However, different authors contrasted these values through a systematic review that showcased wide ranges in pediatric ART adherence (Vreeman et al, 2018). According to Ssanyu et al., (2020) children and adolescents living with HIV have low viral suppression compared to the adults. The study also depicts that 79% of CALHIV are virally suppressed in sub-Saharan Africa as compared to 90% of adults (Ssanyu et al., 2020). In resource limited settings, caregiver report is the most commonly used adherence assessment method for the HIV infected children though it tends to overestimate adherence to ART as compared to other more objective measures like electronic

dose monitoring, pharmacy refill and pill counts (Vreeman et al., 2018). According to a study done by Vreeman et al., (2014), caregiver-reported adherence was found to be generally higher than adherence informed by MEMS. The study also found out that, there was generally poor agreement between MEMS and caregiver-reported missed doses. The study concludes that, despite the high rates of adherence among the children as reported by the caregiver report, late doses, missed doses, sub-therapeutic drug level and treatment interruption of more than 48 hours contributed greatly to high non-adherence prevalence among the children on ART. A study done in Tanzania showcased that, only 24.6% of children aged between 2 to 17 years had good ART adherence when subjected to the three adherence measures which included pill count, two-day self-report and visual analogue scale (Nyogea et al., 2015)

Disclosure to the children about their HIV status has also been seen to have an impact on prevalence of ART adherence among the children. According to the Kenya ART guidelines (2018), disclosure should be initiated when the pediatric attains 6 years with full disclosure expected to be done by the time the child attains 10 years. Studies have shown that there is sub-optimal ART adherence of 38% poor adherence among children unaware of their HIV positive status (Nichols et al., 2019).

A study done by Masaba et al., (2022) ascertained that SEAC implementation also has an impact on enhanced ART adherence among children in Turkana County. The study concluded that, children in Homabay County had better ART adherence after SEAC when compared to children receiving care and treatment in Turkana County mainly because of the pastoral lifestyle of the Turkana's, poor road networks, long distances from the facilities as well as poor health seeking behaviors.

# 2.2 ART non-adherence among HIV positive children

The shift to the utilization of ART for HIV disease treatment has resulted to increasingly complex drug regimen which pose a significant challenge to both the health care provider and the patient with respect to adherence (Alemu et al.,2014). That notwithstanding, the success of ART for treatment of HIV is highly dependent on maintaining a high level of 90% to 95% adherence to the ARVs (Safira et al., 2018). Adherence in children has mostly been seen as multi-faceted (Alemu et al.,2014). Moreover, the children are dependent on their caregivers for drug administration, hence some barriers encountered by the caregivers contribute to children non-adherence to ART. These barriers are and not limited to the care giver being busy, forgetting dose administration, child refusal to take the medication and changes in routine (Shubber et al., 2016). In order to facilitate adherence as well as improve viral

suppression among the children, it is vital to identify potentially relevant issues in pediatric patients that influence adherence and to determine interventions to improve adherence among these population (Vreeman et al, 2018). To aid in conceptualizing pediatric adherence, it is prudent to consider four main influences to non-adherence amongst the HIV infected children which include; (1) pediatric characteristics (2) medication regimen such as food requirement, pill counts or dosing complexity (3) caregiver and family characteristics (4) the health care system (Endalamaw et al., 2018). According to Vreeman et al., (2014), pediatric adherence among Kenyan children is best understood as behaviors that are shaped by the context in which adherence takes place hence shift beyond just the caregiver and individual related factors.

# 2.2.1 Formulation and Regimen Specific Characteristics that contribute to ART non-adherence among the children

According to the Kenya ARV guidelines (2018), the preferred 1<sup>st</sup> line regimen for children is as follows:

- i. Birth to 4 weeks- AZT+3TC+NVP which is administered twice daily
- ii. 4 weeks to less than 3 years- ABC+3TC+LPV/r administered twice daily
- iii. 3 years to 14 years (<35kg body weight)- ABC+3TC+EFV administered twice daily Studies have shown emerging data highlighting reduced efficacy of ART regimens among CALHIV. A study conducted in South Africa by Techau (2014) showcased ART non-adherence among children when abacavir was used as part of first line regimen compared to older regimens like stavudine. Palatability of medication greatly affects its adherence. Children struggle with unpalatable ARV syrups such as the Kaletra (LPV/r) (Coetzee & Bland, 2015). A study done in South Africa revealed that the palatability of the LPV/r led to vomiting which disrupted dosing. The study also showed that, the bitter taste of the LPV/r contributed greatly to pediatric refusing the drug and developing a negative attitude towards the drug. Caregivers were thus tasked to mask the bitter taste of LPV/r with sweet alternative which again posed a major challenge in resource limited settings (Coetzee & Bland, 2015).

A study done in Tanzania on ART adherence among HIV infected children showed that, children who were prescribed a fixed-dose combination of ARV drugs had better adherence as compared to those children who were prescribed unfixed dose combination (Nsheha et al., 2014). This was mainly contributed to the increased pill burden for those on unfixed dose combination (Nyongea et al., 2015). The limited availability of a single-tablet or once daily regimen and palatable formulations for the children contributes greatly to pediatric non-

adherence (Clay et al., 2015). The study by Nsheha et al. (2014) also showed that, those children who developed ARV side effects were significantly less likely to adhere to the ARVs as compared to those children who did not develop any drug side effects. These findings however contrast with finding from Uganda (Nebot et al., 2019) and a study from USA (Kim et al., 2014) which depicted that, children on complex ART regimen had better adherence as compared to those on simple regimens.

In a study done in Ethiopia (Gebre Eyesus et al., 2021), most healthcare workers and caregivers reported high pill burden, pediatric dislike of the medication majorly due to the bitter taste, daily intake of the medication, and spitting out of medication as the major causes of non-adherence to ART among the children. The caregivers also reported that the prescribed time of drug administration was conflicting with their normal working hours hence missed dose administration in several days. Intake of other medications also affected ART adherence among children according to a study by Humphery et al. (2019). The study showed that, HIV-infected children who had TB and were on TB treatment were three times more likely not to be virally suppressed. This contributed to the pharmacologic interactions between rifampicin and ritonavir higher drug toxicities and increased pill burden.

# 2.2.2 Socio-Family characteristics that contribute to ART non-adherence among the children

In resource-limited settings, caregiver report is one of the most commonly used methods of assessing adherence for the HIV-infected children (Vreeman et al., 2014). A study done in Western Kenya, showed that HIV stigma and HIV disclosure to the children pose significant challenge to ART adherence (Humphrey et al., 2019). The study supported that, the association between community-level factors such as stigma and treatment interruptions had huge impact on pediatric adherence to ART. A study done in South Africa showed that, caregiver failure to disclose the children' HIV status to household members disrupted their ability to administer ARVs (Coetzee & Bland, 2015). The non-disclosure was attributed to stigma and denial of the HIV status among the caregivers.

The HIV status of the caregiver has been seen to induce a certain protection from non-adherence in the pediatric (Wachholz & Ferreira., 2007). Children have more than twice the odds of not being virally suppressed if their caregivers were not virally suppressed, compared to children with suppressed caregivers (Humphery et al., 2019). A study done in Western Kenya showed that children are dependent on caregivers for drug administration and it is plausible that the caregiver's adherence practices is duplicated to the children (Humphery et

al., 2019). The study by Wickersham et al. (2018) showed that where the caregiver was positive and not on ART, the children' risk of non-adherence increased. In the study, the HIV positive caregivers who were not on ART either did not believe on the necessity or efficacy of the medication on their own disease hence were unable to adhere to their own treatment.

This posture of not believing in the drug efficacy or necessity has a negative reflection in the adherence to the treatment of the pediatric under their care. Studies have shown that, instances where the caregiver is virally suppressed, the children also tend to adhere to medication and achieves viral suppression (Masaba et al., 2022). A study done in Western Kenya showed that 25% of caregivers in the study reported a late dose administration and treatment interruption to the children contributing to non-adherence of ART among the children (Mukui et al., 2016). Children who had their biological parents as the primary caregivers have been seen to have better adherence as compared to those children taken care by adoptive parents or foster caregivers (Humphery et al., 2019). Caregivers of HIV positive children involved in a study carried out in Ethiopia highlighted potential barriers to pediatric adherence as household food insecurity, fear of stigma and discrimination, lack of a private place to administer the drug once visitors are around, non-disclosure of HIV and lack of social support (Geber Eyesus et al., 2021). In the sub-Saharan region, most children who were orphans or have biological mother migrate for work had their grandmothers as their primary caregivers. However, most household members also administered medication to the children which becomes a challenge when doses are changed more so in settings where communication among family members was poor (Coetzee & Bland, 2015).

This study by Coetzee & Bland (2015) also showed that grandmothers were frequently unable to fulfill their responsibilities since they had limited understanding of the ART regimen hence high level of non-adherence among the children whose primary caregivers were the grandparents. Health care providers involved in a study carried out in Ethiopia described the caregivers of non-adherent children as grandparents, having lack of understanding of the importance of ART or were less educated (Endalamaw et al., 2018). The caregivers also reported that the prescribed time of drug administration was conflicting with their normal working hours hence missed dose administration in several days.

# 2.2.3 Health Care system characteristics that contribute to ART non-adherence among the children

Characteristics of health care system have been seen to have influence on the adherence of ART among the children. These characteristics include; pediatric-health care worker relationship, drug availability at the hospital, proximity of the health facilities and financial cost of the drugs (Masaba et al., 2022). A study done in Western Kenya showed that, the frequent treatment interruptions of more than 48 hours among the children was a concern as the interruptions increased risk of drug resistance and viral rebound (Vreeman et al., 2014). In resource limited settings, unplanned treatment interruptions are contributed to proximity to the health facility, erratic drug supplies, HIV stigma, financial cost of drugs and food insecurity (Naomi et al., 2018). A study done in Kenya by Mukui et al. (2016) showed that waiting time at the facility influenced clinic appointments and revisits for pill refills hence contributing greatly to poor adherence. Good patient-health care provider relationship and patients; contentment with the health care services provides at the health facility have shown a strong correlation to ART adherence (Mukui et al, 2016). However, heath care provider rotation has presented a potential gap between the patient and the health care provider impacting on adherence (Geber Eyesus et al., 2021).

A study done in East Africa by Vreeman et al (2018) showed that, a facility with high workload may have limited time and resources to thoroughly assess adherence with individual families. On the other hand, high volume sites may be more experienced in detecting and managing families' struggles with adherence among the children resulting in better adherence among the children. Lack of nutritional support at the facility level is an important factor to ART adherence according to the study done by Geber Eyesus et al (2021). The study revealed that households with food insecurity contributed to the highest number of children who were non-adherent to their medication. Thus, caregivers would come to the facility with the expectation of being given nutrition supplement to support the drug intake. Unavailability of nutrition supplements/support at the facility level led to 43% of caregivers not administering medication to the children as they claimed not to take medicine on an empty stomach. Long distance to the clinics has also been highlighted as one of the health service barriers to ART adherence as the long distance creates a risk factor for lost to care (Schubber et al., 2016). Thus, shorter distances to the facilities have been associated with better ART adherence (Bermudez, et al., 2016). This contrasts with a study done in Kenya (Wakibi et al., 2011) which highlighted that, proximity to the heath facility predicted ART non-adherence. The respondents from Wakabi et al (2011) study who visited the facility within a walking distance from their homes were about two and a half times more likely not to adhere to their ARVS as compared to had to travel long distances to access the health facilities.

# 2.3 Conceptual Framework

#### **Independent Variables** Prevalence of ART nonadherence MMAS-8 Score **ART** formulation and regimen specific factors **Palatability** Pill Count **Dependent Variable Intervening Variables** ART side effects New ART regimen ART Non-Child on other Medication Initial adherence education of children levels **Social-Family Factors** among Refresher Disclosure to family members children courses Caregiver Missing to administer below 10 drugs to the child Patient support years Disclosure to the teachers Caregiver HIV Status Caregiver marital status Caregiver Literacy level Health care system factors ART Availability ART Accessibility ART Acceptability Financial cost of ART Clinical Setting and service

Figure 2.1 Conceptual Framework.

**Source: Researcher Data** 

delivery

# CHAPTER THREE METHODOLOGY

# 3.1 Study Site

This study was conducted in 10 health care facilities (9 level 4 health facilities and 1 level 5 health facilities) in Turkana County. The County is located in a semi-arid and arid area which ranges in altitude from 369 m near the shores of Lake Turkana to 900 m at the foot of escarpment near the Ugandan border to the west. The northern part towards southern Sudan and Ethiopia is more arid than the western region towards Uganda, which is semiarid. The region lies between Longitudes 34°30' and 36°40'East and between Latitudes 1°30' and 5°30' North. The main economic activities for the Turkana population are pastoralism. According to the Kenya HMIS Statistics report (2019) Turkana has a total of 18 health facilities providing ART services to people living with HIV.

# 3.2 Study Design

Cross sectional study design was used for this study to examine the relationship between ART non-adherence and other dependent variables; formulation and regimen variables (palatability, pill count, ART negative side effects, Child on other ,medication and new ART regimen); social- family variables (Disclosure to other family members, disclosure to the child, caregiver HIV status, caregiver marital status, caregiver missing ART administration and missed ART drugs) and health care system variable (ART availability, ART acceptability, ART accessibility, financial cost of accessing ART and clinical service delivery) as they exist among HIV positive children below 10 years at a single point in time.

# 3.3 Study Variables

The independent variables were; prevalence of non-adherence; formulation and regimen specific variables(ART bitter taste, High ART Pill burden, ART negative side effects, child on other medication and child on new ART regimen); socio-family variables (caregiver literacy level, caregiver marital status, caregiver HIV status, Disclosure to the child, disclosure to other family members, number of days missed ART drugs and number of missed ART drug) and health care system variables (ART availability, ART accessibility, ART acceptability, financial cost of accessing ART and clinical service delivery per department at the health care facility). The dependent variable was ART non-adherence.

# 3.4 Target Population

The study targeted a population of 258 HIV positive children less than 10 years of age who were actively receiving care and treatment across the 10 health facilities for more than 6 months.

# 3.5 Sampling Design

# 3.5.1 Sample Size Determination

The Fischer *et al.*, formula (for sample size less than 10,000) was used to calculate sample size from the stratified selected health facilities:

$$n=\frac{3.84fq}{PV^2}$$
 Where:

 $\mathbf{n} = \text{sample size}$ 

f = is the so-called design effect=1.2

 $\mathbf{q} = \text{equal to } 1 - \mathbf{p}$ 

**P**= anticipated proportion of facilities with the attribute of interest

**V**<sup>2</sup>=relative variance=1.5<sup>2</sup>

3.84= square of the normal deviate 1.96 needed to provide an estimate at the 95% CI

Thus:

$$n = \frac{3.84*1.2*(1-\frac{10}{18})}{\frac{10}{18}*1.5*1.5} = 173 \text{ as the sample size}$$

After determining the sample size, allocation by facility was done proportionate to the children enrolled for care and treatment at the facility.

Table 3.1: Sample size distribution table.

Facility Level	Name of facility	Target population (<10 years)	Proportion sample size per facility
Level 5	Lodwar County and Referral Hospital	113	76
	Kakuma Mission Hospital	37	24
	AIC Lokichoggio Health Centre	20	14
	Lokichar Sub-County Hospital	20	14
Level 4	Lorgum sub-County Hospital	14	9
	Lokitaung Sub-County Hospital	14	9
	Lopiding Sub-County Hospital	13	8
	Kakuma Sub-County hospital	10	7
	Kaikor Sub-County Hospital	10	7
	Lowarenga'k health centre	7	5
Total Sam	ple size	•	173

# 3.5.2 Sampling Procedure

The health facilities were sampled using a dual frame sample framework that has been adapted from the USAID 2001 sampling manual for facility survey (USAID, 2001). Stratification was done based on the MOH levels (MOH, 2012). Level 4 and 5 (private and public) health facilities were selected for the study. Thereafter, patients were recruited sequentially as they came in for their clinic appointments at the health care facilities. Sequential selection was due to the erratic attendance to the clinic by the children and the limited sample size for the study.

Recruitment of the participants at the level 5 health facility occurred weekly (since the facility has weekly children's clinic) while that of level 4 health facilities took place daily when they had the children clinic days so as to capture as many as possible. During recruitment, the health care worker informed the caregiver (child being present) of the study, what it entails as well as their willingness to participate. Once the caregivers sign the accent and consent form, and once the health worker ascertains the child is also willing to participate, the health care worker will then refer them to a private room where the research assistant was waiting to administer the questionnaire.

# 3.6 Inclusion and Exclusion Criteria

# 3.6.1 Inclusion Criteria

- i. Parents or caregivers of HIV positive children who were enrolled and actively receiving care across the targeted health facilities
- ii. HIV positive children whose parents had given consent to participate in the study.
- iii. HIV positive children under 10 years who were accompanied by the caregiver to the clinic
- iv. Parents of children on first line or second line regimen for at least 6 months

### 3.6.2 Exclusion Criteria

- i. Caregivers of children who are critically sick
- ii. Parents/caregivers of HIV positive children not enrolled in the selected health facilities.

# 3.7 Data Collection Tools

Data collection tools for the study included:

Patient hospital records where data on vial load (which will be used to measure prevalence of adherence) was extracted as well as the socio-demographic characteristics of both the

caregiver and the child. Pharmacy data abstraction form were used to give percentage of pills taken by the child

For objective 1, Morisky Mediation Adherence Scale 8 (MMAS-8) was used to measure the prevalence of non-adherence whereby each caregiver was asked 8 questions as per the MMAS-8 and response to each question scored. Upon completion of all questions, the points were summed up for the total score which interpreted whether the patient has good adherence rating= 0, Inadequate adherence rating= 1-2 or Poor adherence rating= 3-8.

# For objective 2, 3 and 4:

- i. Semi-structured Questionnaires were administered through personal interviews with the caregivers/parents of the 173 children to collect data on the family/social factors, ART factors and health care factors that lead to ART non-adherence. (During the interviews COVID-19 protocols were strictly observed in that; the interviews took place in a well-ventilated environment; social distancing was observed; both the interviewer and interviewee had their face masks correctly-worn during the interview and sanitizer provided for sanitization before and after the interview).
- ii. A minimum of 3 focused group discussion (FGDs) were conducted where each group had a maximum of 8 persons. The first group consisted of adherence counselors from the targeted health facility, the second group consisted of nurses and clinical officers working at the Lodwar County and Referral Hospital while the third group consisted of clinicians and nurses drawn randomly from the targeted level 4 health facilities. 3 FGDs were done with each having a representation of an adherence counselor, clinician and nurses from the 10 health facilities.
- iii. 11Key Informant Interviews were conducted with key informants; 3 sub-county AIDs and STI coordinators from the ministry of health, 3 technical advisors and 5 program officers from partners implementing HIV program within the county who provided the managerial and programmatic perspectives on main causes of ART non-adherence and possible interventions (Following the Corona virus 2019 protocols, the interviews were done through mobile phones and recorded to minimize on contact).

# 3.8 Pre-testing Study Tools

Pre-testing of the data tools was done to determine the tool's feasibility, validity as well as to determine the ability of the research assistants in data collection. The pre-testing was done at St. Elizabeth hospital in which 10 caregivers of children below 10 years enrolled and receiving HIV care and treatment at the health care facility. To be checked during pre-testing

was whether the tools were clear, accurate and relevant, whether questions were flowing and also how much time was approximately be required to administer the tools. Tools to be used were 6% of the questionnaires (10 respondents) and 2 Key informant interviews. Pre-test was done at a level 3 health facility because the pretest was aimed to access response and not the facility. Additionally, delivery of HIV care and treatment is standardized across the 6 level of health care facilities.

# 3.9 Validity and Reliability of Data collection tools

To assess validity, the study tools were pretested to caregivers of children under 10 years receiving HIV Care and treatment at the St. Elizabeth Lorgum Health center during the pediatric clinic days. Only relevant questions were asked to the respondents and the Key Informants. Research assistants were also trained on data collection and expert review of the tools done by an external researcher.

To determine reliability, the study employed the split half technique which assured consistency. The method ensured the pretested tools were grouped into halves and each of the halves analyzed and results used to determine which tools will be used for data collection.

# 3.10 Data Analysis and Presentation

Data management was done using statistical package for social scientist. Descriptive analysis was used to determine the prevalence of ART non-adherence, that is, objective 1 where MMAS-8 was used to determine the non-adherence prevalence. To determine the relationship between each dependent variable and non-adherence that is, formulation and regimen specific factors, social family factors and health care system factors, bivariate analysis was used. Chi square test of independence was used to assess the association between the variables studied and the response status with the adherence categories that is, formulation and regimen specific factors, social family factors and health care system factors. Multivariate logistic regression was performed to all factors that were significant after bivariate analysis to identify factors independently associated with ART non-adherence, that is, formulation and regimen specific factors, social family factors and health care system factors,. Odds ratios and the corresponding 95% confidence interval was used to measure the association of independent variables with the dependent variable. A p value of <0.05was significant.

# 3.11 Ethical Considerations

Ethical clearance was sought from Maseno University Ethical Review Committee (MUERC). Permission to collect data was obtained from Maseno University School of Graduate studies,

NACOSTI and Turkana County government. Confidentiality, privacy (where interviews were done in a private room and data collected stored under lock and key) and anonymity (unique identifiers were used to name the respondents) were observed. Written informed consent was obtained from participants (Parents/caregivers) before being recruited in the study. Participation was voluntary and the participants were free to leave the study without any cost.

# **CHAPTER FOUR**

#### **RESULTS**

#### 4.1 Introduction

This chapter discusses the findings obtained from the questionnaires administered to the respondents, Key informant interviews as well as focused group discussions and discusses the respondent's characteristics and their opinion on the factors affecting adherence to Antiretroviral Therapy (ART) among the children in Turkana County. Data collection was done between 10<sup>th</sup> May 2021 to 29<sup>th</sup> July 2021. The response rate was 100% (173).

# 4.2 Socio-demographic characteristics of respondents

The study sought to know the distribution of the respondents by child's gender, relationship of caregivers to the child under ART, caregiver's education level and their marital status. As indicated on table 4.1, of the 173 caregivers to children under ART interviewed, the findings indicated that 50.9% (88) of the children interviewed were male while 49.1% (85)were female; 53.2% (92) of caregivers were the biological mothers, 15% (26) were biological fathers, stepparents were 11.6% (20) while grand-parents only constituted 0.6% (1) of the caregivers. The caregivers marital was considered with 55.5% (96) caregivers being in marriage relationships, 13.3% (23) were polygamous, 12.7% (22) widowed, 12.1% (21) were separated while 6.4% (11) were not in any marriage relationship. The caregivers who had no formal education were 63% (109) while 27.2% (47) had primary education, 9.2% (16)had high school and 0.6% (1) had tertiary education.

Table 4.1: Socio-demographic characteristics of the Caregivers of children under ART

Variables	Categories	Frequency	Percent (%)
Gender	Male	88	50.9
Gender	Female	85	49.1
	No formal Education	109	63
Education level of the	Primary school	47	27.2
caregivers	High/secondary school	16	9.2
	Tertiary education	1	0.6
	Biological Mother	92	53.2
	Biological Father	26	15
	Stepparents	20	11.6
Relationship of	Foster Parent/Guardian	18	10.5
Caregivers	Sibling	10	5.8
	Uncle	5	2.8
	Aunt	1	0.6
	Grandparent	1	0.6
	Married	96	55.5
Marital status of	Polygamous	23	13.3
Marital status of	Widowed	22	12.7
Caregiver	Separated/Divorce	21	12.1
	Never Married	11	6.4

# 4.3 Prevalence of ART non-adherence among respondents

This objective sought to establish the prevalence of ART non-adherence among HIV infected children below 10 years attending level 4 and 5 health facilities in Turkana County. The variables are Morisky score per difference adherence levels. To get the Morisky score, eight different questions were asked to the caregiver each with a score and thereafter the scores summed up to give an adherence level.

# **4.3.1 Morisky Medication Adherence Scale (MMAS 8)**

Table 4.2 outlines the responses to all the eight questions in the Morisky medication adherence scale (MMAS 8) between the different adherence levels among the children under ART within level 4 and 5 health facilities in Turkana County.

Responses to all questions in the 8-item MMAS were statistically significant to ART non-adherence level among the children under ART drug monitoring based (p=0.01).

Table 4.2: Response to the Morisky Medication Adherence Scale (MMAS-8) questionnaire observed Adherence levels of children under ART

Morisky Medication Adherence Scale	Patient Response	(Yes/No)		χ2- Value	P Value
(MMAS-8)	High Adherence54.9 % (n=95)	Medium Adherence12.8 % (n=22)	Low Adherence32.5 % (n=56)	_	
1. Do you ever forget to give the child his/her medicine?	No/Yes=94/1	No/Yes=14/8	No/Yes=25/31	60.94	0.01
2. Are there times you are engaged and delay/forget administering ART to the child?	No/Yes=93/2	No/Yes=10/12	No/Yes=0/56	142.23	0.01
3. Sometimes, if the child feels worse when he/she had taken medication, do you stop administering the drug to the child?	No/Yes=95/0	No/Yes=19/3	No/Yes=18/38	91.13	0.01
4. When the child feels better, do you sometimes stop giving him/her medication?	No/Yes=94/1	No/Yes=20/22	No/Yes=47/9	15.45	0.01
5. Did you give the child his/her full dose medication for yesterday?	No/Yes=0/95	No/Yes=22/0	No/Yes=47/9	19.84	0.01
6. When you see the child's negative symptoms under control, do you sometimes stop giving him/her the drug?	No/Yes=95/0	No/Yes=21/1	No/Yes=35/21	46.15	0.01
7. Taking medication every day is a real inconvenience for some people. Do you feel under pressure about sticking to the child's treatment plan?	No/Yes=94/1	No/Yes=14/8	No/Yes=12/44	100.02	0.01
8. How often do you have difficulty in remembering to give the child all his/her medication?	No/Yes=95/0	No/Yes=21/1	No/Yes=44/12	23.60	.01

# 4.3.2 Morisky score per level of adherence

Figure 4.1 showcases the Morisky mean score per level of adherence to ART by the children under ART as per caregivers' responses. From the MMAS-8 score, 54.9% (95) of children under ART had high adherence (score=0); 12.7% (22) had medium adherence (score 1-2), and 32.5% (56) low adherence (3-8). High adherence level had a mean score of 0.02±0.01 (SD=0.21), medium score mean was 1.59± 0.13 (SD=0.59) while low adherence had a mean score of 3.93±0.14 (SD=1.04).

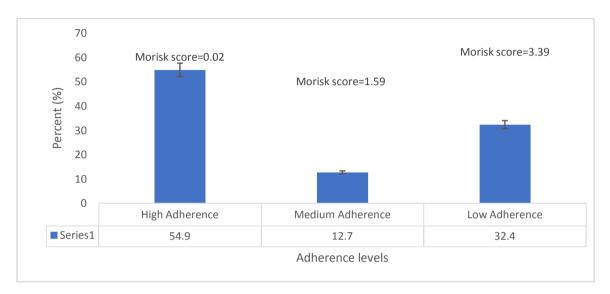


Figure 4.1: Morisky Score per level of adherence

Source: Survey Data

# 4.3.3 Formulation and regimen specific factors that contribute to ART non-adherence

This objective sought to establish the formulation and regimen specific factors that influence adherence to ART among the children in Turkana County attending level 4 and 5 health facilities. The variables assessed were palatability, ART pill burden, dosing complexity, side effects and intake of other medications. Table 4 outlines the mean score on adherence to ART drugs among children affected by formulation and regimen factors and variable association to ART non-adherence. According to table 4.3, 32.0% (40) of children attributed ART non-adherence to bitter taste of the ART drugs, 15.2% (19) attributed non-adherence to high ART pill burden, 32.8% (41) to ART negative side effects, 13.6% (17) to the child being on other medication while 8% (10) attributed ART non-adherence to the child being on new regimen.

Table 4.3: Regimen specific and refusal to take drugs Reasons for non-adherence to drugs among children

Reasons	Factors for Non- adherence	Categories	No of respondent	Percent (%)	Morisky score	SD	χ2	p value
	Bitter taste of	Yes	85	68	3.05±0.32	2.02	1.23	0.54
	ART Drugs (palatability)	No	40	32	2.02±0.21	1.92		
	High ART pill	Yes	106	84.8	4.58±0.47	2.06	2.99	0.22
ъ .	burden	No	19	15.2	2.11±0.19	1.93		
Regimen	ART negative	Yes	84	67.2	5.66±0.27	2.02	4.97	0.08
specific	side effects	No	41	32.8	2.21±0.22	1.71		
	Child on other	Yes	108	86.4	4.18±0.46	1.91	5.53	0.02
	medication	No	17	13.6	1.99±0.18	1.88		
	Child on new	No	115	92.0	4.48±0.34	2.21	1.03	0.60
	ART regimen	Yes	10	8.0	2.31±0.26	1.78		

# 4.3.4 Bitter taste of ART drugs

The study sought to determine if the bitter taste of ART influenced non-adherence among the children under ART. The results as shown on Table 4 indicate a mean score of  $3.05\pm0.32$  (SD=2.02) among those who indicated that ART bitter taste was the major reason for ART non-adherence and a lowmorisky Score of  $2.02\pm0.21$  (SD=1.92) for those who indicated that the bitter taste was not a reason for non-adherence. The bitter test of ART drugs and adherence among the HIV positive children under ART were weakly positively correlated but not statistically significant, r (2) = .01, p< .99. A chi-square test of independence was performed to examine the relation between bitter test of ART and adherence among children under ART drugs. The relation between these variables were not statistically significant,  $\chi^2$  (1, N = 173) = 1.23, p = .54.

# 4.3.5 High ART Pill Burden

The results from Table 4indicate a mean morisky score of  $4.58\pm0.47$  (SD=2.06) among those who indicated that the high pill burden was reason for non-adherence and a mean morisky score of  $2.11\pm0.19$  (SD=1.93) for those who indicated that high pill burden was not a reason for ART non- adherence. The high ART pill burden and non-adherence among the HIV positive children under ART were weakly positively correlated but statistically not significant, r(2) = .143, p < .11. A chi-square test of independence was performed to examine the relation between ART drugs burden and non-adherence among children under ART drugs. The relation between these variables were statistically not significant,  $\chi^2(1, N = 173) = 2.99$ , p = .22.

# 4.3.6 ART Negative side effects

The results from Table 4 indicate a mean score of  $5.66\pm0.27$  (SD=2.02) among those who indicated that ART negative side effects were the main reason for ART non-adherence. and a low mean morisky score of  $2.21\pm0.22$  (SD=1.71) for those who indicated that the bitter taste was not a reason for non- adherence. The ART drugs negative side effects and adherence among the HIV positive children under ART were weakly positively correlated but not statistically significant, r(2) = .092, p < .03. A chi-square test of independence was performed to examine the relation between ART drugs negative side effects and adherence among children under ART drugs. The relation between these variables was not statistically significant,  $\chi^2(1, N=173) = 4.97$ , p = 0.08.

# 4.3.7 Child on other medication

Table 4indicates a mean morisky score of  $4.18\pm0.46$  (SD=1.91) among those who indicated that the drugs were bitter and a low mean morisky score of  $1.99\pm0.18$  (SD=1.88) for those who indicated that the bitter taste was not a reason for non- adherence. The child on other medication and adherence among the HIV positive children under ART were weakly positively correlated and statistically significant, r(2) = .208, p < .02. A chi-square test of independence was performed to examine the relation between child on other medication and adherence among children under ART drugs. The relation between these variables was statistically significant,  $\chi 2$  (1, N = 173) = 5.53, p = .02.

# 4.3.8 Child's New ART Regimen

The children under different ART regimen had different adherence rates as indicated in Table 4.4. Children under ABC+3TC+EFV 58.3% (56) had high-adherence, 15.6% (15) had medium adherence while 26% (25) had low adherence. For those on ABC+3TC+LPV/r regimes52.2% (36) had high adherence to ART, 10.1% (7) were medium and 37.7% (26) had low adherence to ART. For those children under AZT+3TC+LPV/r 37.5% (3) had high adherence while and 62.5% (n=5) had low adherence.

Table 4.4: Adherence under different ART regimen

Adherence on Active	Which ART regimen is the child currently on					
ART drugs by the	ABC+3TC+EFV		ABC+3TC+LPV/r		AZT+3TC+LPV/r	
children	N	Percent	N	Percent	N	Percent
High Adherence	56	58.3	36	52.2	3	37.5
Medium Adherence	15	15.6	7	10.1	0	0.0
Low Adherence	25	26.0	26	37.7	5	62.5

From analysis, the mean morisky score of  $4.48\pm0.34$  (SD=2.21) for those who indicated child on new regiment as the main reason for ART non-adherence and a low mean morisky score of  $2.31\pm0.26$  (Sd=1.78) among those for those who indicated that child on new ART regimen was not a reason for ART non-adherence. New ART regimen and ART non-adherence among the HIV positive children were weakly positively correlated but insignificant, r(2) = .081, p<.370. A chi-square test of independence was performed to examine the relation between child on new ART regimen drugs and adherence among children under ART drugs. The relation between these variables was insignificant,  $\chi^2(1, N=173) = 1.03$ , p=.59.

The formulation and regimen specification factors; Bitter taste of ART drugs, High ART pill burden, ART negative effect and child on new ART were not independently significant and hence were not used in the logistic regression analysis. Child on other medication was statistically significant hence logistic regression was used upon which it did not reach the statistical significance as indicated in appendix X.

## 4.3.9 Social-family factors that contribute to ART non-adherence among the HIV infected children

This objective was to establish the social-family specific factors that influence ART non-adherence among the children in Turkana County attending level 4 and 5 health facilities. These factors include caregiver's HIV status, disclosure to the child, other family members and teachers, days the caregiver missed administering ART. Table 4.5 outlines the mean score on adherence to ART drugs among children affected by social and family factors and the variables association to ART non-adherence.

Table 4.5: Social-family factors affecting adherence among the children under ART-Mean Score

Social-Family factors	Variables	Morisky Score			P	
	categories	N	Mean ±SE	SD	χ 2 Value	value
Caregiver marital status	No	11	2.364±0.51	1.69	17.24	0.28
	Yes	162	$1.604\pm0.36$	4.42		
Caregiver literacy level	No	109	$1.642 \pm 0.18$	1.91	6.60	0.36
	Yes	64	$1.122\pm0.24$	1.21		
Caregiver HIV positive and	No	58	$1.500\pm0.27$	2.07	1.79	0.67
active on ART	Yes	115	$1.478 \pm 0.17$	1.82		
Disclosed to the child about	No	91	1.505±0.19	1.86	0.09	0.95
positive HIV status	Yes	82	1.463±0.21	1.92		
Disclosed the child's HIV status	No	74	$1.108\pm0.20$	1.73	6.67	0.04
to other family members/anyone else	Yes	99	1.768±0.19	1.95		
Missed giving ART drugs in the past 3 months	Yes	62	1.700±0.251	1.02	110.90	0.01
	No	111	1.078±0.120	1.24		

#### 4.3.10 Caregiver literacy level

According to Table 6,the children with caregivers who had no formal education level had a mean morisky score of  $1.642\pm0.18$  (SD=1.91), whereas those with some level of education had a mean morisky score of  $1.122\pm0.24$  (SD=1.21). The literacy level of caregiver and adherence among the HIV positive children under ART were weakly negatively correlated but insignificant, r(6) = -.117, p < .13. A chi-square test of independence was performed to examine the relation between caregiver literacy level and adherence among children under ART drugs. The relation between these variables was insignificant,  $\chi^2(1, N = 173) = 6.60$ , p = .36.

The one of the K.I.I at Elizabeth Glaser Pediatric AIDS Foundation in Turkana County noted that:

"Poor drug timings by many caregivers since they rely on rising and setting of sun hence miss on the timings is due to their literacy levels".

Since caregiver literacy level was not statistically significant independently (p = .359) and hence were not used in the logistic regression analysis.

#### 4.3.11 Caregiver marital status

From table 6,children with caregivers who are in no marriage relationship had a mean morisky score of  $2.364\pm0.51$  (SD=1.690), whereas those children with caregivers in a relation had a mean morisky score of  $1.604\pm0.36$  (4.42). The marital status of the caregiver and adherence among the HIV positive children under ART were weakly positively correlated but statistically not significant, r (8) = .036, p< .65. A chi-square test of independence was performed to examine the relation between ART drugs burden and adherence among children under ART drugs. The relation between these variables was not statistically significant,  $\chi^2$  (1, N = 173) = 17.24, p = .28. These results show that those who are in relationships showed a better mean score on adherence than those without marriage relationships. Since caregiver marital status was not statistically significant independently (p = .28) and hence were not used in the logistic regression analysis.

#### 4.3.12 Caregiver HIV status

Findings as indicated on table 6indicate that children with caregivers who were HIV positive and active on ART drugs had a low mean morisky score of  $1.478\pm0.170$  (SD=1.82) while those who whose caregiver's were not HIV positive had a high mean morisky score of  $1.500\pm0.27$  (SD=2.07). The caregivers' HIV status and ART non-adherence among the children were weakly positively correlated but insignificant, r(2) = .026, p < .73. A chi-

square test of independence was performed to examine the relation between caregiver HIV status and adherence among children under ART drugs. The relation between these variables was not statistically significant,  $\chi^2$  (1, N=173) = 1.79, p=.67. The caregiver HIV status was not statistically significant (p=.673) and hence were not used in the logistic regression analysis.

#### 4.3.13 Disclosure to the child

The caregivers who indicated to have disclosed the HIV status of the children under their care had a mean morisky score of  $1.463\pm0.212$  (SD=1.92) than those who had not disclosed who had a mean morisky score of  $1.505\pm0.195$  (SD=1.86) as shown on table 6.Disclosure to the child and ART non-adherence among the HIV positive children were weakly negatively correlated but not statistically significant, r(2) = -.019, p < .80. A chi-square test of association was performed to examine the relation between disclosure to the child and adherence among children under ART drugs. The relation between these variables was not statistically significant,  $\chi^2(1, N=173)=0.09$ , p=.95.Disclosure to the child factors was not statistically significant independently and hence were not used in the logistic regression analysis.

The **K.I.I3**at Elizabeth Glaser Pediatric AIDS Foundation-Turkana County noted that:

"Lack of disclosure makes the child not understand why he/she is taking medication hence vomit or refuse to take the medication."

#### 4.3.14 Disclosure to other family members

The results as highlighted on table 6indicate a mean morisky score of  $1.768\pm0.19$  (SD=1.95) for those children whose HIV status was disclosed to other family members and a mean morisky score of  $1.108\pm0.200$  (SD=1.725) for those whose status had not been disclosed by the caregivers. The disclosure to other family members and ART non-adherence among the children were weakly positively correlated and significant, r(2) = .185, p < .02. A chi-square test of association was performed to examine the relation between disclosure to other family members and ART non-adherence among children. The relation between these variables was significant,  $\chi^2(1, N=173)=6.67$ , p=.04. Since disclosure to other family members factor was statistically significant independently (p=.036) it was used in logistic regression results as indicated in appendix X.

#### 4.4 Missed ART Drugs

From table 6, missing of drugs among children on ART and adherence were strongly positively correlated and significant, r(2) = .797, p < .01. A chi-square test of independence was performed to examine the relation between missing of drugs among children under ART drugs and adherence among children under ART drugs. The relation between these variables was significant,  $\chi^2(1, N = 173) = 110.90$ , p = .01. Since the factor was statistically significant independently it was used in logistic regression as indicated in Appendix X.

#### 4.4.1 Moderate adherence vs. low adherence

The odd of missing ART drugs is 2.042. Thus, the odds of being "Moderate adherence" rather than "low adherence" is increased by a factor of 2.042 by missing ART drugs. Which implies that a one unit increase in score of missing drugs increases by  $(e^{0.714}) = 2.042$  the score of the odds ratio of adherence by the child with a 95% Confidence Interval for odds ratio  $(e^{0.702}, e^{0.726}) = (2.018, 2.026, p=0.019)$ . Hence, we conclude a positive association between missing drugs and adherence to drugs. While the odds of not missing drugs is 0.490, given by the reciprocal of 2.042. This implies that a one unit increase in the not missing drugs increases by 0.490 the scores of odds ratios of adherence by the child. We conclude a negative association between not missing drugs and adherence among child on active ART drugs.

#### 4.4.2 High adherence vs. low adherence

The odd of missing ART drugs is 2.042. Therefore, the odds of being "Moderate adherence" rather than "low adherence" is increased by a factor of 2.042 by missing ART drugs. Which implies that a one-unit increase in score of missing drugs increases by  $(e^{0.714}) = 2.042$  the score of the odds ratio of adherence by the child with a 95% Confidence Interval for odds ratio  $(e^{0.702}, e^{0.726}) = (2.018, 2.026)$ . Hence, we conclude a positive association between missing drugs and adherence to drugs. While the odds of not missing ART drugs is 0.490, given by the reciprocal of 2.042. This implies that a one unit increase in the not missing ART drugs increases by 0.490 the scores of odds ratios of adherence by the child. Hence, we conclude a negative association between not missing ART drugs and adherence among child on active ART drugs.

## 4.5 Health system factors that contribute to ART non-adherence among HIV infected children

This objective was to establish the health system factors that influence adherence to ART among the children in Turkana County attending level 4 and 5 health facilities. These factors

include ART availability, accessibility, acceptability, financial cost of ART, clinical setting and service delivery and distance from health care facility.

## 4.5.1 Clients view on ART availability at the health facilities

This was a measure of the views of clients seeking services on the availability of ART at the health care facility as highlighted in table 4.6.

**Table 4.6: Services at Health facilities** 

Heath facilities	Statements	Categories	High	Medium	Low
factors	XXII	XX7 11 ·	Adherence	Adherence	Adherence
	What is your usual mode of	Walking	57.1(32)	5.4(3)	37.5(21)
	transport to the health facility	Public transport	68.0(17)	8.0(2)	24.0(6)
		Cycling	20.0(1)	20.0(1)	60.0(3)
	Ham land de monteles to	Motorbike	51.7(45)	18.4(16)	29.9(26)
	How long do you take to travel from your residence to	Less than 2 hours	59.6(84)	9.2(13)	31.2(44)
	the health facility	Up to half a day	34.4(11)	28.1(9) 0.0(0)	37.5(12)
A "1 "1",	•	Whole day Less than 2 hours	0.0(0)	` '	0.0(0) 55.6(5)
Accessibility of health	How much time do you miss from work/home on average	Up to half a day	44.4(4)	0.0(0) 13.7(21)	
facility	to attend the clinic	Whole day	55.6(85) 54.5(6)	` '	30.7(47)
racinty	to attend the enine	Excellent	` '	9.1(1) 0.0(0)	36.4(4)
		Good	100.0(1)		0.0(0)
	Dhamma ay samyi aas		57.1 (92)	13.0(21)	29.8(48)
	Pharmacy services	Average	20.0(2)	10.0(1)	70.0(7)
		Poor	0.0(0)	0.0(0)	100.0(1)
		Don't know	0.0(0)	0.0(0)	0.0(0)
		Excellent	33.3(1)	33.3(1)	33.3(1)
	T. D. market at the state of	Good	58.9(93)	12.7(20)	28.5(45)
	Laboratory services	Average	9.1(1)	9.1(1)	81.8(9)
		Poor	0.0(0)	0.0(0)	100.0(1)
		Don't know	0.0(0)	0.0(0)	0.0(0)
	Overall, how do you feel	Excellent	0.0(0)	0.0(0)	0.0(0)
	about ART services provided at the health facility to your child?  Communication and	Good	74.4(90)	13.2(16)	12.4(15)
		Average	8.9(4)	13.3(6)	77.8(35)
		Poor	14.3(1)	0.0(0)	85.7(6)
		Don't know	0.0(0)	0.0(0)	0.0(0)
		Excellent	0.0(0)	0.0(0)	0.0(0)
		Good	80.0(92)	12.2(14)	7.8(9)
	information provided on HIV	Average	6.1(3)	16.3(8)	77.6(38)
	standard package of care	Poor	0.0(0)	0.0(0)	100.0(9)
		Don't know	0.0(0)	0.0(0)	0.0(0)
	Reliability of information given at the health facility to the actual experiences	Excellent	0.0(0)	0.0(0)	0.0(0)
		Good	77.6(90)	9.5(11)	12.9(15)
** 11 6 11		Average	8.3(4)	22.9(11)	68.8(33)
Health facility	received?	Poor	11.1(1)	0.0(0)	88.9(8)
services	XX 1.6 1	Don't know	0.0(0)	0.0(0)	0.0(0)
Financial cost	How much fare do you spend	0-100	59.2% (29)	4.1% (2)	36.7% (18)
of ART	to and from the health facility	100-200	46.0% (23)	20.0% (10)	34.0% (17)
	N	200 and above	58.1% (43)	13.5% (10)	28.4% (21)
	Nutrition services mean time	Nutrition	13.84±0.46	13.88±0.41	16.23±0.65
	Clinician mean service time	Clinician	18.00±0.84	24.29±1.50	25.68±2.49
	Adherence Counselling services mean service time	Counselling	17.79±1.02	24.37±1.71	24.73±2.48
Services delivery at the	Laboratory services mean service time	Laboratory	13.43±0.33	14.45±0.45	15.00±0.47
Health services	Pharmacy services mean time	Pharmacy	11.42±0.32	11.52±0.46	11.82±0.70

Table 4.7: Health System Factors affecting ART non-adherence

Health System Factors	$\chi^2$	P Value
ART availability	15.51	0.08
ART accessibility	99.33	0.01
ART acceptability	91.31	0.06
Financial cost of accessing ART	18.59	0.06
Clinical service delivery per department at the health	84.18	0.06
facility		

Table 4.7 indicates that ART availability and ART non-adherence among the HIV positive children were weakly positively correlated but significant, r(6) = .229, p < .0.01. A chi-square test of association was performed to examine the relation between ART availability and adherence among children under ART drugs. The relation between these variables was not significant,  $\chi^2(1, N = 173) = 15.51$ , p = .08. Since ART availability was not statistically significant independently hence it was not used in the logistic regression analysis.

The **K.I.14** at Elizabeth Glaser Pediatric AIDS Foundation project in Turkana noted that whereby health care facilities have established pediatric clinic days where children are the only patients seen during these days, the quality of services offered within these areas are wanting. The understaffing within health facilities within the county affects the service delivery. There is also need to Fast-tract the utilization of child friendly regimes that is pellets as opposed to liquid and facilities that make timely and sufficient order from KEMSA. These results further are consistent with the response from clinicians **FGD3** opinion that some of the laboratory tests require payments within the health facilities which the caregiver is not able to pay hence contribution to non-adherence among children under ART. The services required for payment are treatment of OIs except TB and Inpatient costs which are not covered by the health facilities.

#### 4.5.2 ART Accessibility

This dimension of ART service provision as evaluated by the caregivers on the location of the health facility offering HIV care clinics, the waiting time at the health facility as well as the convenience of the facility to those who seek their services. It also sought to establish the time taken by the caregivers to travel from their places of home to the health facilities to seek services for the children under ART drugs.

Table 4.6 indicates that 57.1% (32) of those walking, 68% (17) of those using public transport, 20% (1) of those cycling and 51.7% (45) of those using motorbike were highly adherent to ART respectively. From Table 8 ART accessibility and ART non-adherence

among the children were strongly positively correlated and significant, r(6) = .692, p < .01. A chi-square test of independence was performed to examine the relation between ART accessibility and adherence among children under ART drugs. The relation between these variables was significant,  $\chi^2(1, N = 173) = 99.33$ , p = 01. Since ART accessibility was statistically significant independently it was used in logistic regression and the results generated (appendix X) showcased ART accessibility was statistically significant.

The Focus group discussion (**FGD1**) on adherence by the counsellors interviewed noted that: "Distance from home to health center that may make caregivers not keep clinic appointments"

The adherence counsellor noted that distance from home to health center make caregivers not keep clinic appointments. The result further noted that the proportion of caregivers that keep clinical appointments varied from 60% according to Peer Educator, clinician about 74% and adherence counsellors was about 70%. The reasons for not keeping the appointments were that the caregivers were busy, the child was in school and that the some forget their clinic days while in some cases the caregivers' lacked food supplements in the facility.

#### 4.5.2.1 Moderate adherence vs. low adherence

The odd of accessibility of health services being is 1.875. We can therefore say that the odds of being "moderate adherence" rather than "low adherence" is increased by a factor of 1.875 by accessibility being excellence. The results indicate that a one unit increase in the accessibility being excellence increases by  $(e^{-24.700})=1.875$  the odds ratio score of adherences to drugs with a 95% Confidence Interval for odds ratio of  $(e^{-24.755}, e^{-24.645}) = (1.774, 1.981)$ . Hence, we conclude a positive association between the accessibility being excellence and adherence among child on active ART drugs.

When the accessibility of health services being good the odds ratio is 1.955, this indicates that the odds of being "moderate adherence" rather than "low adherence" is increased by a factor of 1.955 by good accessibility of health services. Which implies that a one unit increase in the accessibility being good increases by  $(e^{-0.670}) = 1.955$  the scores of odds ratios of adherence to drugs with a 95% Confidence Interval for odds ratio of  $(e^{0.655}, e^{0.685}) = (1.925, 1.984)$ . Hence, we conclude a positive association between the accessibility of health services being good and adherence among child on active ART drugs. Finally, when the odd ratio of average accessibility of health services is 0.408 we say that the odds of being "moderate adherence" rather than "low adherence" is decreased by a factor of 0.408. The

results imply that a one unit increase in the accessibility being average decreases by  $(e^{-0.896}) = 0.408$  the odds of adherence to drugs by the child with 95% Confidence Interval for odds ratio of  $(e^{-0.951}, e^{-0.841}) = (0.386, 0.431)$ . Thus, we conclude a negative association between the accessibility being average and adherence among child on active ART drugs.

#### 4.5.2.2 High adherence vs. low adherence

The odd of accessibility being excellence is 1.875. We can therefore say that the odds of being "moderate adherence" rather than "low adherence" is increased by a factor of 1.875 by accessibility being excellence. Which implies that a one unit increase in the accessibility being excellence increases by 1.875 the odds of non-adherence to drugs by the child. The 95% Confidence Interval for odds ratio (0.875, 2.75), hence we conclude a positive association between the accessibility being excellence and adherence among child on active ART drugs. The odd of accessibility being good is 1.955. We can therefore say that the odds of being "moderate adherence" rather than "low adherence" is increased by a factor of 1.955 by accessibility being excellence. Which implies that a one unit increase in the accessibility being excellence increases by 1.955 the odds of non-adherence to drugs by the child. The 95% Confidence Interval for odds ratio (0.280, 2.242), hence we conclude a positive association between the accessibility being good and adherence among child on active ART drugs.

#### 4.5.3 ART Acceptability

This dimension of ART services sought to capture the caregivers' views on the quality-of-service provision at the health facilities as well as their confidence in the healthcare system and in antiretroviral therapy. From table 4.3., the ART acceptability and ART non-adherence among the HIV positive children under ART were strongly positively correlated and significant, r (4) = .695, p< .000. A chi-square test of independence was performed to examine the relation between ART acceptability and adherence among children under ART drugs. The relation between these variables was significant,  $\chi^2$  (1, N = 173) = 91.31,p = .056. Since ART acceptability was not statistically significant independently it was not used in the logistic regression where results indicated not statistically significant as indicated on appendix X.

The Focus group discussion (**FGD2**) on ART acceptability by the clinicians interviewed noted that: "85% of caregivers are well aware of the positive effects of ART to the child and hence strive to administer the drugs daily as well as keep clinic appointment. However, when

the child is diagnosed with any opportunistic infection which requires extra financial cost, ART acceptability becomes less"

Response for **KII5** targeting county HIV coordinator highlighted that "Children deaths related to HIV have reduced in the past years which is a clear in indication of HIV acceptability to the caregivers in charge of the children and even to some extent the community."

#### 4.5.4 Financial Cost of Accessing ART

From table 4.7, the financial cost and ART non-adherence among the HIV positive children were weakly positively correlated and significant, r(6) = .238, p < .002. A chi-square test of independence was performed to examine the relation between ART drugs cost and adherence among children under ART drugs. The relation between these variables was significant,  $\chi^2(1, N = 173) = 18.59$ , p = .06. Since ART cost was not statistically significant independently it was not used in the logistic regression analysis.

#### 4.5.5 Clinical Service Delivery per Department at the Health Care Facility

The clinical setting and service delivery is important to antiretroviral medication adherence by the children under ART drugs. The research considered the mean time taken under different services point like nutrition, clinicians, counselling services, and laboratory and pharmacy services at the health facility point (table 4.6).

The high adherence at the nutrition services took a mean time of  $13.84\pm0.46$  minutes, medium  $13.88\pm0.41$  minutes while those children with low adherence reported to have taken  $16.23\pm0.65$  minutes. The medium adherence has a mean of  $11.52\pm0.46$  minute at pharmacy,  $13.88\pm0.41$  minutes at nutrition,  $14.45\pm0.45$  minutes at Laboratory services,  $24.29\pm1.50$  minutes at clinician and a high mean of  $24.37\pm1.71$  minutes at the counselling services. From table 8, the clinical setting and service delivery and ART non-adherence among the HIV positive children were strongly positively correlated but insignificant, r(6) = .661, p < .01. A chi-square test of independence was performed to examine the relation between clinical setting and service delivery and adherence among children under ART drugs. The relation between these variables was significant,  $\chi^2(1, N = 173) = 84.18$ , p = .06. Since clinical setting and services was not statistically significant independently it was not used in the logistic regression analysis.

#### 4.5.6 Other Health system factors that contribute to ART non-adherence

Table 4.8 highlights other health system factors that hinder adherence to ART to children as expressed by the caregivers as well as the solutions as proposed by the caregivers.

Table 4.8: Health systems factors that affect drugs administration.

Health system factors that affect drugs	Solution
administration	
No nutrition supplement, support to	Provide nutritional support: Increase the number of health
the children	care workers, increase number of health care workers as
	well as provide more private rooms for counselling, make
	the facility more child friendly
	Provide refreshments to children as they come for their appointments
Consultation done in a hurry,	Extend working hours, start care givers session within the
frequency of visits,	health facilities, home visits for children with high VL
	and those who miss clinic appointments, Pairing
	caregivers for self-regulation. create Health talks, routine
	adherence counselling during clinic appointments
Different new HCWs, not enthusiastic,	Training of HCWs on children handling, being Friendly,
not friendly, attitude	
High cost of medicine, treatment	Subsidize treatments and medicine costs
High travel cost, long distance	Provide transport costs/reduce clinic visits by giving
	medication for at least 3 months
Long waiting time at the HF	Reduce waiting time at HF
Negative attitude by the staff at HF	Train staff on PR
No reminder tools, sensitization,	Eliminate language barrier, Provide alarms to caregivers
education, language barrier at HF	
No separate clinic for kids, no children	Create games and snacks, ART facilities, introduce
activities or child days within HF	pediatrics clinics

The adherence counsellors from **FGD2** noted that lack of nutrition supplements, lack of frequent support from PSSGs contributed to non-adherence among the children under ART.

#### **CHAPTER FIVE**

#### **DISCUSSION**

#### 5.1 Introduction

This section focuses on the discussion of the findings relative to what previous researchers have found on the study variables. It correlates the findings with those of the previous literature and establishes where they are in agreement or they contradicted.

#### 5.1.1 Prevalence of ART non-adherence among respondents

The effectiveness of ART among HIV positive person is dependent on the individual's medication adherence. Currently, there are various methods being implemented to assess ART adherence among the HIV patients and they include; observing clinic appointments, provider estimation, pill counts, client self-report, this study considered patience monitoring using the Morisky Medication Adherence Scale (MMAS). Morisky medication adherence scale (MMAS-8) is one of the most used tools to assess patience adherence to ART (Aguiar et al., 2020).MMAS-8 has its advantages over other self-reported instruments used to assess adherence (Wickersham et al., 2018). From the analysis, the ART prevalence of non-adherence was 12.8% (22) with medium adherence and 32.5% (56) with low ART adherence. This gives a cumulative of 45.1% (78) non-adherence. The findings concur with (Wadunde et al., 2018) who conducted a systematic review of ART adherence studies among the children in middle- and low-income countries, the estimates of pediatric ART which ranged from 49% to 100% with 76% of articles reporting greater that the 75%. A study done by (Ssanyu et al., 2020) in Uganda also highlighted a 57.3% non-adherence rate among children receiving ART in Jinja, Uganda. In Kenya, A study was done by Vreeman et al., (2019) which found the non-adherence level among children on ART in Kenya was 31%.

# 5.1.2 The formulation and regimen specific factors that contribute to ART non-adherence among respondents

This objective was to establish the formulation and regimen specific factors that influence adherence to ART among the children in Turkana County attending level 4 and 5 health facilities. The variables assessed were palatability, number of pills, dosing complexity, side effects, intake of other medications. From analysis, whereas the formulation and regimen factors are clinically important, only ART negative side effects were statistically significant. However, on regression it did not reach statistical significance indicating potential interaction factors which were undefined in this study.

Ssanyuet al., (2020), concluded that, none of the drug regimen factors was associated with the ART non-adherence. This conclusion is similar to a study done in Uganda by Nyogea et al., (2015). However, other studies by Nasuuna et al., 2019 in Kenya attributed ART bitter taste as the major contributing factors to ART non-adherence among children. A lot of caregivers also sought various ways to mask ART bitterness through mixing it with other foods such as porridge, yoghurt to enhance palatability (Nebort et al., 2019).

Many children (32.8%) stated that they were non-adhering also due to ARV side effects. The commonly stated side effects included hallucinations, nausea, vomiting, headache, and rashes. The caregiver only solution to this problem was to deal with the various side effects by providing other medications to the child. This overlapped a study done by Ammon et al(2019), where majority of HIV positive children with ART negative side effects associated taking ART with being ill. Some of these participants perceived ART intake was reducing their quality of life hence opting to halt the medication. The study contrasts with Mehta et al., (2016) who argued that if ARV treatment is changed to a more potent regimen, the mutants will decrease again, but they are archived in memory cells and can re-emerge if ARs to which they are resistant are used in future. This was similar to Chan,(2011) who claimed that drug hypersensitivity is far more common in patients with HIV and regimen associated toxicity is a common predictor of, and reason for, non-adherence across many studies

# **5.1.3** The social-family factors that contribute to ART non-adherence among respondents

This objective was to establish the social-family specific factors that influence adherence to ART among the children in Turkana County attending level 4 and 5 health facilities. These factors include caregiver literacy level, caregiver marital status, disclosure to the child and other family members, caregiver HIV status and Caregiver form of employment. From the results, the study found that disclosing to other family members the HIV status of the child, number of days missed drugs and caregiver missing drug administration for past 3 months increased risk of non-adherence to ART.

Stigma to the caregivers may limit them from administering drugs to the children especially when family members are around while sometimes it may lead to the child not being given drugs once the caregivers is away. This relates well with Ikiara, (2022) where during his Doctoral dissertation in Embu concluded that 50% of caregivers reported fear of or experienced stigma and discrimination from family members whom they had disclosed to the HIV status of the child. This limited the caregivers from administering ART to the child in

the presence of other family members or even make it know that they are attending HIV clinic appointment. This affected adherence as well as retention in care among children below 14 years.

This study also concurs with Enane et al., (2018) who concluded that stigma and disclosure issues were among the major contributing factors to ART non-adherence contributing to nearly half of the LTFU in Botswana. Systematic review done by RC Vreeman et al.,(2018) revealed that courtesy stigma whereby caregivers my directly experience/fear stigma as a results of their child's HIV status (and not their own), is an important factor of HIV stigma which results to ART non-adherence to the child affecting both psychosocially and clinically.

From the study caregiver missing to administer drugs and missing drugs for approximately 10 days (low adherence) greatly contributed to ART non-adherence among the children. This relates well to (Naomi et al., 2018)who concluded that missing ART administration was the leading cause of ART non-adherence among children receiving ART care and treatment in Gertrude's children hospital, Nairobi.

#### 5.1.4 Health system factors that contribute to ART non-adherence among respondents

This objective was to establish the health system factors that influence adherence to ART among the children in Turkana County attending level 4 and 5 health facilities. It was a measure of the views of clients seeking services on the availability of ART at the health care facility. These factors include ART availability, accessibility, acceptability and financial cost of ART, clinical setting and service delivery and distance from health care facility.

The results indicate where health system factors are vital in ensuring ART adherence among children, poor ART accessibility significantly affected ART non-adherence among children on ART receiving HIV care and treatment in Turkana County. The time taken to the health facility was a factor affecting adherence with 59.6% (84) of those taking less than 2 hours being high adherent while 37.5% (12) of those who took half a day to reach the facility had low ART adherence.

Again, the study revealed that that clinical setting significantly affects adherence to antiretroviral therapy adherence. This was similar to Paterson, (2010) who argued that the effect clinic setting has on adherence should not be underestimated where clinic characteristics that impact on adherence include: proximity to the patient's home or place of work, the expense of getting there, lengthy delays between appointments, clinic opening and closing times, long waiting times, lack of services such as childcare, privacy,

confidentiality, and unsympathetic or inconsiderate staff. A study done in Uganda by Wadunde et al., (2018)depicted that, some of the health facility reasons that contributed to ART non-adherence among children were frequent transportation to the facility for refills. The study highlighted that adherence among community-based refills was high as compared to adherence of children who visit the health facility for ART refills. A study by Sue, (2020) highlighted that, HIV infected person in ASAL areas attributed long waiting lines and long long distances to the health facility as the main reason for missing their clinic appointment. This also relates to a study done by Masaba et al.,(2022) that attributed long distances to health facility being among the major factors affecting adherence among children on ART in Turkana County as opposed to good adherence seen in Homabay county where caregivers have better access to health care.

Nonetheless, this contrasts with a study done in Kenya (Wakibi et al., 2011) which highlighted that, proximity to the heath facility predicted ART non-adherence. From the study, respondents who visited the facility within a walking distance from their homes were about two and a half times more likely not to adhere to their ARVS as compared to had to travel long distances to access the health facilities.

#### **CHAPTER SIX**

#### CONCLUSION AND RECOMMENDATION

#### **6.1 Conclusion**

The study concludes that though the formulation and regimen specific variables are clinically important and significant, only ART negative side effects was statistically significant. However, on regression it did not reach statistical significance indicating potential interaction factors which were undefined in this study. The study deduced that socio-family factors that contributed to ART non-adherence among children below 10 years on ART in Turkana County are disclosure to other family members about the HIV status of the child, number of days missed drugs and caregiver missing drug administration for past 3 months was statistically significant to ART non-adherence among children.

Health system factors that contributed to ART non-adherence among respondents according to the study is ART accessibility among the children in Turkana County attending level 4 and 5 health facilities. Thus, any change in adherence among children is affected by these 4 variables

#### 6.2 Recommendations

- i. The study recommends that sensitization the community members on the need to support caregivers within the community for enhanced adherence to drugs among the children under ART drugs.
- ii. The study recommends that the county government should take an initiative of providing ART availability to help in reducing the costs associated with the services.
- iii. Further they should be improvement of clinical settings and service delivery within the health facilities. The medics should also organize and sensitizing the caregivers on the importance of adhering to ART among children they support.

#### **6.3 Recommendation for further research**

i. Since this study was only limited to Turkana county level 4 and 5 health facilities, the study recommends that the same study should be done in other hospitals in all counties to establish the trend of adherence to ART as well as determinants of adherence of ART. The researcher should go ahead and determine the effect of the factors discussed in this study on adherence of children to ART in other counties based on the respective hospitals in those counties.

ii. The study also recommends that other factors not tackled in this study should be included in other studies such as clinical and medical factors including other related diseases affecting the child on ART including tuberculosis and malnutrition.

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#### **APPENDICES**

#### Appendix I: Informed Consent Form for semi-structured interview with

caregivers/parents of children under 10 years on ART.

Study Title: Predictors of Non-Adherence to Anti-Retroviral Therapy Among HIV Infected Children Below 10 Years Attending Level 4 and 5 Health Facilities in Turkana County

Principal Investigator: Carol Mukami Njoroge

This informed consent will be read to you, please feel free to ask for further clarification in any issue that you may not understand. Your participation in this study is voluntary; you can withdraw from the study at any time and failure to participate in this study will not affect the services you receive at this clinic.

Part 1: Information Sheet

The study is being conducted by Carol Mukami Njoroge as part of her master's degree programme at Maseno University. The study will explore various predictors that contribute to ART non-adherence among children below10 years old and also recommend possible interventions to improve ART adherence among these group.

You are being requested to participate in this study because you are caregivers/parents with children below 10 years who are HIV positive and receiving treatment at this facility which has been selected as a study site. We are also seeking consent from you to be able to use your child's patient records whereby we shall retrieve data about your child's treatment outcome We will provide information to you about this study and would like to invite you to be part of this survey.

If you accept your child to participate, this interview will take approximately 60 minutes. The questionnaire to be administered will determine the prevalence of ART non-adherence among children below 10 years through self-recall, medication and regimen specific factors, health care factors and psychosocial factors that contribute to ART non-adherence among children. I shall also be able to get your recommendations on possible interventions to improve ART adherence among children. I will also need to record the interview using an audio recorder in order to get all the information discussed with you accurately. The information recorded is confidential and no one except the researchers will access the information recorded. In order to further ensure confidentiality, I will not identify you or your child by name on the recorder and the information recorded will be destroyed after completion of the study. No one else apart from the interviewer will be present unless you would like someone else to be there.

After data collection we will prepare a report which might be shared in conferences and publications but this report will not identify you or your child in any way. Your confidentiality in participating in this research study is completely assured.

There may be no direct benefit for you in participating in this research study. Though you will be able to discuss with the interviewer any adherence issues your child may have and the interviewer will provide you with the necessary counselling or referral as required.

There is no known risk in participating in this study. However, you might feel like your time is being inconvenienced while some questions may upset you mainly concerning psychological or social aspects of taking care of an HIV infected child. If you are upset,

you may choose to skip the question or stop participating and seek support from counsellors at the health facility. You therefore have a right to not answer any question you are uncomfortable with and this will neither affect services you receive at the health center nor will it interfere with your participation in other parts of this interview. Your participation is entirely voluntary and your decision to or not participate will not affected the services provided to you at this health facility.

There will be no direct monetary compensation of any kind due to participation in this research study. If you have any questions after you have been interviewed you may contact Carol Mukami on 0729829789

#### Part 2: Certificate of Consent

ask questions about it and	sent, or it has been read to me. I have any questions that I have inquire tarily for my child to participate	ed have been answered
Name of participant	Date:	Signature
If Illiterate		
	reading of the consent form to the portunity to ask questions. I confirm	
Name of participant:the participant	Date:	Thumb print of
Name of witness:	Date:	Signature
Statement of the person taking	g consent	
and all the questions asked ha	was given an opportunity to ask quave been answered correctly and to as not been coerced into giving conrily.	the best of my ability. I
Name:	Date:	Signature:

#### Appendix II: Informed Accent Form for semi-structured interview with

#### caregivers/parents of children under 10 years on ART.

Study Title: Predictors of Non-Adherence to Anti-Retroviral Therapy Among HIV Infected Children Below 10 Years Attending Level 4 and 5 Health Facilities in Turkana County

Principal Investigator: Carol Mukami Njoroge

This informed assent will be read to your child, please feel free to ask for further clarification as the caregiver in any issue that you may not understand. Your child's participation in this study is voluntary; you can withdraw from the study at any time and failure to participate in this study will not affect the services you receive at this clinic. You will also be required to sign the consent form as the caregiver once you and your child both agree to participate in the study. We will also observe your child body language to ascertain that they are comfortable to participate in the study.

#### Part 1: Information Sheet

The study is being conducted by Carol Mukami Njoroge as part of her master's degree programme at Maseno University. The study will explore various predictors that contribute to ART non-adherence among children below10 years old and also recommend possible interventions to improve ART adherence among these group.

After data collection we will prepare a report which might be shared in conferences and publications but this report will not identify you or your child in any way. Your confidentiality in participating in this research study is completely assured.

There may be no direct benefit for you in participating in this research study. Though you will be able to discuss with the interviewer any adherence issues your child may have and the interviewer will provide you with the necessary counselling or referral as required.

There is no known risk in participating in this study. If you are upset, you may choose to skip the question or stop participating and seek support from counsellors at the health facility. You therefore have a right to not answer any question you are uncomfortable with and this will neither affect services you receive at the health center nor will it interfere with your participation in other parts of this interview. Your participation is entirely voluntary and your decision to or not participate will not affected the services provided to you at this health facility.

There will be no direct monetary compensation of any kind due to participation in this research study. If you have any questions after you have been interviewed you may contact Carol Mukami on 0729829789

#### Part 2: Certificate of Assent

I have been informed that my parent(s) have given permission for me to participate, if I want to, in a study concerning ART non-adherence among children below 10 years receiving care and treatment in Turkana County. My participation in this project is voluntary and I have

participate, it will not affect my treatme	ent/care in any way.
Name:	
Date	
Name of participant/Caregiver:	Date:
Thumb print of the participant	
Name of witness:	Date:
Signature	
Statement of the person taking accent	
and all the questions asked have been	en an opportunity to ask questions about the study, answered correctly and to the best of my ability. I n coerced into giving assent and the assent has been
Name: Da	nte:
Signature:	

been told that I may stop my participation in this study at any time. If I choose not to

## **Appendix III: Caregiver Semi-Structured Questionnaire**

Study Title: Predictors of Non-Adherence to Anti-Retroviral Therapy among HIV Infected Children Attending Level 4 and 5 Health Facilities in Turkana County.

#### **Section. 1: General Information**

Section: 1. General information
Date of Interview:
County Name:
Sub-County Name:
Health Facility name:
Health Facility Code:
Consent given:

### **Section 2: Socio-demographic information**

Section 2.1: Relationship of the caregiver with the child:

Relationship	Tick Where Appropriate
Biological Mother	
Biological Father	
Stepparent	
Foster Parent/Guardian	
Sibling	
Uncle	
Aunt	
Grandparent	
Cousin	

Section 2.2: Caregiver's marital status

Caregiver's Marital Status	Tick Where Appropriate
Never Married	
Polygamous	
Married	
Separated/Divorced	
Widowed	
Widower	

Section 2.3: Caregiver's Highest level of education

Level of Education	Tick Where Appropriate
No formal education	
Primary education	
Secondary education	
Tertiary education	
College/university education	

Section 2.4: Demographics of the child:			
Date of birth (extract from the patient's clinical file):			
Gender: Male Female			
2.4.1 Does the child attend school? Yes NO NO			
Section 3: The following questions are about determining the preval	lence of A	RT non-	
adherence among the children using the Morisky Medication Scale (M	MAS-8)		
Circle the corresponding score for each response. After completion of all the points that you have circled for the total score.	questions,	add up all	
Questions	Yes	NO	
1. Do you ever forget to give the child his/her medicine?	0	0	
2. Are there times you are engaged and delay or forget administering ART to the child?	1	0	
3. Sometimes, if the child feels worse when he/she has taken medication, do you stop administering the drug to the child?	1	0	
4. When the child feels better, do you sometimes stop giving him/her medication?	1	0	
5. Did you give the child his/her medication yesterday?	1	0	
6. When you see the child's symptoms are under control, do you sometimes stop giving him/her the drug?	1	0	
7. Taking medication every day is a real inconvenience for some people. Do you feel under pressure about sticking to the child's treatment plan?	1	0	
8. How often do you have difficulty in remembering to give the child all his/her medication? Please circle the correct number	Points A=0		
A. Never/Rarely	B=1/4		
B. Once in a while	$C = \frac{1}{2}$ $D = \frac{3}{4}$		
C. Sometimes	E=1		
D. Usually			
E. All the time Total Score (sum of all items)			
Total Score (sum of an items)			
Section 4: The following questions seek to determine the formulation and regimen specific factors associated with ART non-adherence among children.			
4.1 Is the child currently on ART (extract from the patient's clinical file	le)		
Yes No			

4.2If yes, when was the child initiated on ART (extract from the patient's clinical file)?

4.3 Which ART regimen is the child currently on and how have you been administering the drugs to the child (extract from the patient's clinical file)

	S. No	Drug name	Frequency	Dosage	Formulation		
4.4	4.4Does the child at times refuse to take his/her medication? Yes No						

4.4.1 If yes, what is the main reason?

Main Reason	Tick Where Appropriate
Bitter Taste	
High ART Pill Burden	
ART side effects	
Child on other medications	
Child on new ART regimen	
Others (Specify)	

4.5 If the reason is due to bitter taste, how do you ensure that the child takes the medicines?

Action Taken	Tick Where Appropriate
Mix the drugs with other foods like porridge	
Give strong tasting foods immediately after drug administration	
Give medication plenty of water or any other fluid	
Force the child to take the medicine	
Wait until the child is willing to take the medicine	
Others (specify)	

4.6 If the reason is due to high ART burden, what do you do to ensure that the child takes the medication?

Action Taken	Tick where appropriate
Force the child to take the medicine	
Wait until the child is willing to take the medicine	
Give one type of ART withholding the rest	
Withhold ART entirely	
Others (specify)	

- 4.7. If the reason is due to ART side effect/problem,
- 4.7.1 What kind of problem/side effects?

Action Taken	Tick where appropriate							
Force the child to take the medicine								
Wait until the child is willing to take the medicine								
Wait until the symptoms have been managed to administer the ART								
Withhold ART entirely								
Others (specify)								
4.7.2 How do you deal with the problem?								
1.8 If the reason is due to other medications,								
1.8.1 What other kind of treatment is the child on?								
1.0.1 What other kind of treatment is the clind off.								
Action Taken	Tick where appropriate							
Force the child to take the ART alongside the other medication								
Wait until the child is willing to take the medicine								
Wait until the child finishes the dosage for the other medications	S							
then administer ART								
Others (specify)								
4.8.2 How do you deal with the problem?								
the state of the s								
Action Taken Tick where	appropriate							
Force the child to take the medicine	appropriate							
Force the child to take the medicine Wait until the child is willing to take the medicine	appropriate							
Force the child to take the medicine Wait until the child is willing to take the medicine Try source for the old regimen to administer to the child	appropriate							
Force the child to take the medicine Wait until the child is willing to take the medicine Try source for the old regimen to administer to the child Withhold the new ART for a while	appropriate							
Force the child to take the medicine Wait until the child is willing to take the medicine Try source for the old regimen to administer to the child	appropriate							
Force the child to take the medicine Wait until the child is willing to take the medicine Try source for the old regimen to administer to the child Withhold the new ART for a while								

## to ART non-adherence among children on ART.

5.	118	the	caregiver	HIV	positive	and	active	on .	ART:	Yes	No
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5.2Have you disclosed the HIV status to the child? (Partial disclosure to children 5-8 years

and Full Disclosure to children 9 to 10 years) Yes No:

## 5.2.1 If NO, why?

Main reason for not disclosing	Tick where appropriate
Child is not yet mature to understand his/her condition	
I do not know how to disclose to the child	
I am afraid people may be aware of the child's HIV status once I disclose	
to the child	
Others (specify)	

5.3 Have you disclosed the child's HIV status to other members of the	e family/anyone else?
Yes No	
5.4Have you ever missed administering ART drugs to the child? Yes	No No
5.4.1 If yes, how many days in the past week?	
5.4.2 What was the reason of the child missing drugs?	
Reason for missing drugs	Tick Where Appropriate
Caregiver too busy	
Time for dose administration found when the caregiver had already left home	у
There was no food to take the ART drugs with	
Child had gone to school Child was looking healthy and had no symptoms	
Child on other drugs	
ART side effects	
Others (specify)	
5.5 Have you disclosed to any teacher where the child attends sch	nool?
	ick where appropriate
Child not comfortable with the teacher knowing his/her HIV status	
I do not trust that the teacher will administer the drugs as prescribed	
I see no need since I can be able to administer ART to the child faithfully	
I am afraid my child maybe stigmatized at school once I disclose to the teacher	
Others (specify)	
5.5.1 If NO why?	
5.5.2 If yes, does the teacher at times administer the ART drugs to the second	he child?
Yes No No	
5.5.3 If yes, how many times in the past one week?	
Section 6: The following questions seek to identify the health sy	stem factors associated
with ART non-adherence among children on ART	

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6.1

What is your usual mode of transport to the health facility where the child gets his/her

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Mode of transport	Tick where appropriate
Walking	
Public transport	
Cycling	
Motorbike	
Others (specify)	

6.2	How long (	in hours)	do you	take to	travel	from	your	residence	to the	health	facility
where	the child get	s his/her A	ART usi	ng your	usual r	node (	of tra	nsport?			

6.3 On average, how much fare do you spend to and from the health facility?

Average Fare (Kshs)	Tick where appropriate
0-100	
100-200	
200 and above	

6.4 How much time do you miss from home or work on average to attend the clinic

Time missed from home/work	Tick where appropriate
Less than 2 hours	
Up to half a day	
Whole day	

6.5 How long do you usually wait on queue in each of the departments listed below before being attended to by the healthcare worker?

Department	Waiting Time (minutes)
Triaging	
Nutrition	
Clinician	
Adherence Counselling	
Laboratory	
Pharmacy	

6.6 How do you feel about the following (use visuals-smileys to capture the feelings towards various services/departments),

S.NO	Departments/Services	Tick where appropriately (sm used)			(smi	ileys to be	
		Excellent	Good	Average	Poor	Don't Know	
6.6.1	ART availability at the health facility						
6.6.2	Overall charges and costs of ART therapy at the health facility						
6.6.3	Professional competence of the health care worker in handling the child's medical needs						
6.6.4	Health care worker's attitude/behavior while reviewing your child						
6.6.5	Time spent by the clinician addressing your child's needs (explaining about health and treatment, not in a hurry etc.)						
6.6.6	Laboratory services						
6.6.7	Pharmacy services						
6.6.8	Overall, how do you feel about ART services provided at the health facility to your child?						
6.6.9	Communication and information provided on HIV standard package of care						
6.6.10	Reliability of information given at the health facility to the actual experiences received?						

Yes No No		
1 2	Tick appropriate	where
The HCWs often opt to counsel us as a group		
The rooms have no privacy, anyone can enter or leave at will		
The hospital has few rooms hence one room acts as various		
departments		
The rooms are not soundproof		
Others (specify)		

Do you and your child have privacy during consultation and counselling?

6.7

6.7.1	If No, why?	
6.8	Do you feel you can confide in the health care work	ers attending to your child
regard	ling any challenges your child may experience in relation to	ART adherence?
Yes	No No	
Reason	for no privacy	Tick where appropriate
	Ws often opt to counsel us as a group	
	VCs seem too busy to have time for the child	
	trust the health care workers	
	rtain the health care worker will share with other workers (specify)	
	If no, why	
6.9 childr Yes	Are you or your child enrolled in differentiated model en at the health facility (caregiver sessions, pediatric clinic	
Reaso	n for no DMOC	Tick where appropriate
	acility has not informed me of any DMOC	Tiek where appropriate
	C suggested will inconvenience me	
I do no	ot see the need	
	fraid of being stigmatized or discriminated	
Others	s (specify)	
6.9.1	If no, why?  If yes, how often do you meet in a	·
6.10	In your own opinion, what are some of the health syst	•
prevei	nt you from administering drugs to the child as prescri	ibed and how can they be
impro	ved?	
S.NO	Health system factors causing ART no adherence among children	ons

#### **Appendix IV: Guide for FGD With Health Care Workers**

Study Title: Predictors of Non-Adherence to Anti-Retroviral Therapy Among HIV Infected Children Below 10 Years Attending Level 4 and 5 Health Facilities in Turkana County

dentification of the focused group discussion
Number of participants in the FGD
Date of the FGD/
Place of the FGD
Moderator's name
ntroduction to the study and consenting process

1. Background Information on the Health care worker

I will start by asking you some basic information about you.

- 1.1 What is your profession?
- 1.2 What specific training have you received in relation to HIV care and management specifically among children?
- 1.3 How many years of experience do you have in the HIV field?
- 1.4 What is your role in the HIV program within the clinic?
- 2. Non-Adherence in General
- 2.1 What is the ART initiation process for children in the facility?
- 2.2 Which guidelines do you follow?
- 2.3 Generally, how would you rate adherence levels to ART among children below 10 years receiving care and treatment in this health facility? (Probe whether extremely good, very good, good, fair or poor and reasons given Probe for percentages and measures used to determine adherence levels and how they monitor adherence in the facility).
- 2.4 Please give me your opinion on the following issues:
- 2.4.1 What are some of the children ART formulations or regimen factors that contribute to ART non-adherence among children?
- 2.4.2 What are some of the children's psychosocial factors that contribute to ART non-adherence among children?
- 2.4.3 What are some of the healthcare system factors that contribute to ART non-adherence among children?

- 2.4.4 Regarding children HIV care and treatment in this health facility, which costs are covered by the health facility and which ones are not? (Probe on lab tests, OI treatment and drugs, hospitalization)
- 2.4.5 How does the parent/caregiver level of education affect the child's adherence to ART?
- 2.5 What are some of the strategies the health care facility has put in place to enhance children adherence to ART?
- 2.6 As a health care worker, what are some of the strategies that can be put in place to ensure adherence to ART among children?
- **3.** Clinic Appointment
- 3.1 Approximately, what percentage of your HIV positive children keep clinic appointments?
- 3.2 What are the reasons given by caregivers of those children who do not keep appointments?
- 3.3 Do you give parents/caregivers an option of discussing the appointment scheduling?
- 3.4 What mechanisms are in place within the health facility to ensure children keep their appointments?
- 3.5 Do you have differentiated model of care for children below 10 years?
- 3.5.1 If yes, how often do they meet?
  - **4.** Could you have any additions on factors affecting ART non-adherence among children?

Thank you for your participation.

#### **AppendixV: Guide for Key Informant Interview**

Study Title: Predictors of Non-Adherence to Anti-Retroviral Therapy Among HIV Infected Children Below 10 Years Attending Level 4 and 5 Health Facilities in Turkana County

- 1. Exploring the ART adherence problems for children under 10 years from a managerial programmatic point of view
  - i. What ART adherence problems do HIV positive children under 10 years' experience in this community?
  - ii. What contributes to the ART adherence problems?
  - iii. How can these problems be addressed?

#### 2. Exploring health seeking behavior

- i. What are your views/ opinions about the available services regarding suiting the need of the HIV positive children under 10years of age?
- ii. How can you describe the relationship/interaction between the HIV positive children under 10 years and the provider of the above services?
- iii. What are some of the reasons that make the HIV positive children under 10 years and their caretakers not utilize ART adherence services?

#### 3. Improving the System

- i. What is your source of information on HIV positive children under 10 years on ART adherence advice and care?
- ii. How can the caregivers be encouraged to access ART adherence information?
- iii. How can the existing services be made acceptable to the caregivers in the community?
- iv. What ART other additional adherence services that should be provided these cohort and why?

## Appendix VI: Morisky Medication Adherence Scale (MMAS-8)

MMAS-8: Ask the patient each question below. Circle the corresponding score for each response. After completion of all questions, add up all the points that you have circled for the total score

the total score		Vac	NIa
Questions		Yes	No
1. Do you ever forget to	take your medicine?	1	0
2. Are you careless at ti	mes about taking your medicine?	1	0
3. Sometimes if you fee you stop it?	l worse when you take the medicine, do	1	0
4. When you feel better medicine?	, do you sometimes stop taking your	1	0
5. Did you take your me	edicine yesterday?	1	0
6. When you feel your sometimes stop takin	ymptoms are under control, do you g your medicine?	1	0
<u> </u>	very day is a real inconvenience for some feel under pressure about sticking to your	1	0
<del>_</del>	ve difficulty remembering to take all lease Circle the correct number)	Points: A=0 B= \frac{1}{4} C= \frac{1}{2} D= \frac{3}{4} E=1	
Total Score (sum of all items	3)		

## **Appendix VII: Interpretation of MMAS-8 Score**

Interpretation of	MMAS-8 Score			
MMAS-8 Score	Adherence Rating	Action Required		
0	Good	Continue with routine monitoring, counselling and support		
1-2	Adequate	<ul> <li>Discuss as an MDT</li> <li>Assign a case manager</li> <li>Assess for and address barriers to adherence</li> <li>Engage treatment supporter in adherence counselling sessions</li> <li>Follow up in 2-4 weeks</li> </ul>		
3-8	Poor	<ul> <li>Discuss as an MDT</li> <li>Assign a case manager</li> <li>Assess for and address barriers to adherence</li> <li>Engage treatment supporter in adherence counselling sessions</li> <li>Implement DOTs</li> <li>Follow up in 1-2 weeks</li> </ul>		

#### Appendix VIII: School of Graduate Studies Approval Letter



## MASENO UNIVERSITY SCHOOL OF GRADUATE STUDIES

#### Office of the Dean

Our Ref: EL/ESM/01221/2017

Private Bag, MASENO, KENYA Tel:(057)351 22/351008/351011 FAX: 254-057-351153/351221 Email: sgs@maseno.ac.ke

Date: 8th January, 2021

#### TO WHOM IT MAY CONCERN

RE: PROPOSAL APPROVAL FOR CAROL MUKAMI NJOROGE — EL/ESM/01221/2017

The above named is registered in the Master of Public Health, Maseno University. This is to confirm that her research proposal titled "Predictors of Non-adherence to Antiretroviral Therapy among HIV Infected Children Attending Level 4 and 5 Health Facilities in Turkana Country." has been approved for conduct of research subject to obtaining all other permissions/clearances that may be required beforehand.

1505 MAL 80

Prof. J.O.Agure

DEAN, SCHOOL OF GRADUATE STUDIES

Maseno University

ISO 9001:2008 Certified

#### **Appendix IX: MUERC Approval Letter**



#### MASENO UNIVERSITY ETHICS REVIEW COMMITTEE

Tel: +254 057 351 622 Ext: 3050 Fax: +254 057 351 221

Private Bag – 40105, Maseno, Kenya Email: muerc-secretariate@maseno.ac.ke

REF: MSU/DRPI/MUERC/00941/21

Date: 18th May, 2021

TO: Carol Mukami Njoroge EL/ESM/01221/2017

Department of Public Health

School of Public Health and Community Development

Maseno University

P. O. Box, Private Bag, Maseno, Kenya

Dear Madam,

RE: Predictors of Non-Adherence to Anti-Retroviral Therapy among HIV Infected Children below 10 years Old attending Level 4 and Level 5 Health Facilities in Turkana County

This is to inform you that **Maseno University Ethics Review Committee (MUERC)** has reviewed and approved your above research proposal. Your application approval number is MUERC/00941/21. The approval period is  $18^{th}$  May,  $2021-17^{th}$  May, 2022.

This approval is subject to compliance with the following requirements;

- . Only approved documents including (informed consents, study instruments, MTA) will be used
- All changes including (amendments, deviations, and violations) are submitted for review and approval by Maseno University Ethics Review Committee (MUERC).
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to Maseno University Ethics Review Committee (MUERC) within 24 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to Maseno University Ethics Review Committee (MUERC) within 24 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- Submission of an executive summary report within 90 days upon completion of the study to Maseno University Ethics Review Committee (MUERC).

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <a href="https://oris.nacosti.go.ke">https://oris.nacosti.go.ke</a> and also obtain other clearances needed.

Yours sincerely

APPROVED 18 MAY 2021

Prof. Philip O. Owuor, PhD, FAAS, FKNAS

Chairman, MUERC

MASENO UNIVERSITY IS ISO 9001:2008 CERTIFIED

#### **Appendix X: NACOSTI Research Permit**



Appendix XI: Bivariate Analysis, Likelihood Ratio Test and Multiple Logistic Regression Results

Bivariate analysis

Factors affecting non-adherence to ART drugs among HIV Positive children	Pearson Correlation (p)	df	p-value
ART formulation and regimen specific factors			
Bitter taste (Palatability)	0.001	2	.987
High ART pill burden (No of Pills)	-0.143	2	.111
ART negative side effects (Side effects)	-0.092	2	.307
Child on other medication (Other medication)	0.208	2	.020*
Child on new ART regimen (Complexity)	0.081	2	.370
Social/family factors			
Literacy level of the caregiver	0.117	6	.127
Marital status of the caregiver	0.035	8	.647
Caregiver HIV positive and active on ART?	0.026	2	.734
Disclosed to the child about his/her positive HIV status?	-0.019	2	.801
Disclosed the Child's HIV status to other family members	0.185	2	.015*
Missed administering drugs to child in past 3 months?	0.797	2	.010*
Days missed in the past 3 months?	0.701	2	.010*
Health care system factors			
ART availability	0.229	6	.002*
Financial cost of ART	0.238	6	.002*
Clinical setting and service delivery	0.661	6	.010*
Acceptability	0.695	4	.010*
Accessibility	0.692	6	.010*

<sup>\*</sup>Correlation is significant at the 0.05 level (2-tailed).

## Multiple Logistic Regression

Model	Model Fitting Criteria	Likelihood Ratio Tests		
	-2 Log Likelihood	Chi-Square Df Sig.		Sig.
Intercept Only	229.105		•	•
Final	71.388	157.717	36	.000

## Pseudo R-Square Model Output

Mc Fadden	Cox & Snell R Square	Nagelkerke R Square
0.746	0.779	0.898

Likelihood Ratio Tests

Effect	Likelihood Ratio Tests		
	Chi-Square	Df	Sig.
Intercept	0.000	0	•
Missed days	128.439	38	.010*
Bitter taste of ART drugs	1.234	2	0.987
ART negative Side effects	4.969	2	0.083
Child on other medication	5.531	2	0.063
High ART Pill Burden	2.990	2	0.224
New ART Regimen	1.026	2	0.599
Literacy level of Caregiver	6.600	6	0.359
Marital status of Caregiver	17.245	8	0.280
Caregiver HIV status	0.791	2	0.673
Disclosure to the child	0.094	2	0.954
Disclosed to other family	6.673	2	0.036**
Missed ART Drugs	110.900	2	0.000**
ART Availability	15.507	6	0.077
ART Cost	18.589	6	0.055
Clinical Setting	84.183	6	0.057
Acceptability	91.313	4	0.056
Accessibility	99.331	6	0.000**

<sup>\*\*</sup> Significant at 0.05

### Parameter Estimates

Levels	Modeling	β	Std. Error	df	Sig.	Exp (β)	95% Confidence Interval for Exp (β)	
			Litoi				Lower Bound	Upper Bound
Medium Adherend e	Intercept	-18.714	1.723	1	0.998	•		
	Missed ART days	-0.018	.094	1	0.008**	0.982	0.978	0.986
	[Disclosed to other family=No]	-1.927	0.033	1	0.021**	0.146	0.141	0.151
	[Disclosed to other family =Yes]	$0_{b}$		0	•			
	[Missed ART Drugs=No]	0.714	0.012	1	0.019**	2.042	2.018	2.067
	[Missed ART Drugs=Yes]	$0_{b}$		0	•			
	[Accessibility=Excellent]	-24.700	0.055	1	0.001	1.875	1.774	1.981
	[Accessibility=Good]	0.670	0.015	1	0.758	1.954	1.925	1.984
	[Accessibility=Average]	-0.896	0.055	1	0.632	0.408	0.386	0.431
	[Accessibility= Poor]	$0_{\rm p}$		0	•			
High Adherence	Intercept	-31.683	2.689	1	0.996			
	Missed ART Days	-0.465	0.027	1	0.093	0.628	0.611	0.645
	[Disclosed to other family = No]	-1.785	0.052	1	0.018	0.168	0.159	0.177
	[Disclosed to other family =Yes]	$0_{\rm p}$		0	0.000			
	[Missed ART Drugs=No]	0.502	0.024	1	0.074	1.652	1.613	1.692
	[Missed ART Drugs =Yes]	$0_{\rm p}$		0	•			
	[Accessibility=Excellent]	-11.561	0.159	1	0.999	9.529	9.157	9.930
	[Accessibility=Good]	-16.028	0.018	1	0.989	1.094	1.075	1.114
	[Accessibility=Average]	-12.785	0.610	1	0.991	2.802	1.523	5.158
	[Accessibility= Poor]	$0_{\rm p}$		0	•		·	<u>.                                    </u>

Appendix XII: Turkana County Study Map

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