

**PREVALENCE, ASSOCIATED FACTORS AND PERCEIVED BARRIERS OF  
HIV STATUS DISCLOSURE TO INFECTED CHILDREN AGED 7-14YEARS  
AT LODWAR COUNTY REFERRAL HOSPITAL-KENYA**

**BY**

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## DECLARATION

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### Declaration by the candidate

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## **DEDICATION**

I am dedicating this thesis to my family and former employer Strategic Application International, for the support they have given me through my studies. And above all to God who has brought me this far.

## ABSTRACT

**Background:** The quality of life of Human Immunodeficiency Virus-infected children have improved significantly with the introduction of highly active antiretroviral treatment -and as a result, they are living longer. This makes disclosure of HIV very important as most survive into adolescent and are likely to involve in risky behaviors.

**Objective:** The overall objective of this study was to determine the prevalence of disclosure, associated factors and perceived barriers to HIV disclosure among HIV infected children aged 7-14 year at Lodwar County Referral hospital-Kenya (LCRH).

**Methods:** A cross-sectional study involving children aged 7-14 years and their caregivers attending Paediatric Infectious Disease Clinic of LCRH. Quantitative data was collected using a total of 99 interviewer-administered questionnaires to child/caregiver pair through systematic random sampling -and four purposively selected key informant interviews.

**Results:** Only 16.2% of HIV-infected children knew their diagnosis. The child's age was the primary predictor of disclosure (P-value 0.00). The mean age of the children was 9.97 years (SD 2.13) with a mean duration of enrollment of 77.21 (SD 34.186). The main reason for nondisclosure was that the child is too young (34.3%). Nearly half of the parent/caregivers agreed they need to disclose to children their status, 27.3% reported that they needed health care providers to help them in disclosure. Lack of knowledge on how to disclose, fear and stigma were other hindrances to HIV disclosure to children.

**Conclusion:** Few HIV-infected children in Lodwar County Referral Hospital know their HIV status.

**Recommendation:** Parents/caregiver need to be counseled by trained health professionals at Lodwar County Referral Hospital on age appropriate disclosure.

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**ABBREVIATION**

AIDS	Acquired Immunodeficiency Syndrome
AMPATH of HIV	Academic Model for Prevention and Treatment
ART	Antiretroviral Therapy
ARV	Antiretroviral
CDC	Centre for Disease Control
CD	Cluster Differential
CI	Confidence Interval
CRA	County Revenue Authority
DNA	Deoxynucleic Acid
ELISA	Enzyme Linked
G.o.K	Government of Kenya
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
KAIS	Kenya Aids Indicator Survey
KNBS	Kenya National Bureau of Statistics
KDHS	Kenya Demographic Health Survey
LCRH	Lodwar County Referral Hospital
LTFU	Loss to Follow-up
NASCOP	National STI and AIDs Control Programme
NDMA	National Drought Management Authority
NGO	Non-governmental Organization
OR	Odds Ratio
PCR	Polymerase Chain Reaction
PMTC	Prevention of Mother to Child Transmission
SD	Standard Deviation
SPSS	Statistical Package for Social Science
UK	United Kingdom
UN	United Nation
UNAIDS Syndrome	United Nation Acquired Immune Deficiency
USA	United States of America
W.H.O	World Health Organization

### **OPERATION DEFINITIONS**

- Age appropriate disclosure: It is the giving of appropriate age disclosure information for a given child.
- Caregiver: A person who lives with the child, participates in the child's daily care and is the most knowledgeable about the child's health. They were either biological parents or guardians acting as surrogate parents to the child.
- Complete disclosure: The child is told that he/she has HIV and is given disease-specific information.
- Depression: Any indication of the child depression symptoms as reported by the caregiver or the child.
- Disclosure: Where the caregiver said that the child knows his/her HIV diagnosis.
- HIV infection: Defined as having one positive HIV DNA PCR9 test or one positive HIV ELISA antibody test.
- Non-adherence: Any missed doses in the past 30 days by caregiver-report or child-report on the standard clinical encounter form or any indication of adherence difficulties reported by caregivers or children on the Disclosure Questionnaire.
- Non-disclosure: Where the caregiver said that the child does not know his/her infection or where the caregiver was unsure if the child knew his/her status.
- Partial disclosure: The child may know that he/she has an illness, but he/she has not been explicitly told that he/she has HIV infection.
- Stigma: Any indication of child- experienced stigma from the caregiver or the child.

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## CHAPTER ONE

### INTRODUCTION

#### **1.1. Background**

Human Immunodeficiency Virus (HIV) weakens people's defense system by targeting the immune system, making an infected individual immune deficient. Cluster differential four (CD4) cell count is used to measure immune functions. An average cell count ranges from (500-1600 cells/mm<sup>3</sup>). Infected individuals can have as low as (200 cells/mm<sup>3</sup>) CD4 cell count hence their susceptibility to a wide range of infections as opposed to healthy people with good immunity (British HIV Association, 2008). Acquired Immunodeficiency Syndrome (AIDS) is the advanced form of HIV infection and can have an incubation period of 2 to 15 years (W.H.O, 2008).

Globally, HIV continues to be a significant public health concern. According to a UNAIDS report 2014, 36.9 million people were living with HIV. Sub-Saharan Africa has the highest disease burden, with a total of 19.6 million cases, accounting for 70% of people living with HIV worldwide (UNAIDS, 2017). Human Immunodeficiency Virus (HIV) estimates and projections in Kenya for 2017; showed that there are approximately 1.6 million people were living with HIV, while an estimated 101,560 new HIV infections occurred in that year (UNAIDS, 2017).

The first representative population-based survey to estimate HIV prevalence among children was Kenya AIDS Indicator Survey, 2014. The study indicated HIV prevalence among children aged 18 months to 14 years old to be 0.9% (NASCO, 2014). Testing rates of HIV among children remained low at 16.4%. Regional variations were observed with highest testing rates been found among children from the Nyanza region

at 28.1%, and lowest testing rates among children in the Rift Valley Northern region at 8.3% (KAIS, 2014).

The Kenya HIV County profile in 2014; showed that Turkana County ranked seventh and tenth regarding adult and pediatric HIV prevalence, respectively. Adult prevalence was 7.6% of the total county population and 1.12% for children. Approximately 0.4% adults and 0.06% children died of AIDS-related conditions in 2013 in Turkana County, with 3,141 new infections reported (Kenya HIV estimates Technical Report, 2013).

Antiretroviral drugs can substantially reduce AIDS-related deaths, lower a person's viral load and prevent onward transmission of HIV (Williams et al., 2006). The use of highly active antiretroviral therapy (HAART) has led to increased survival of HIV infected children in high-resource settings (Brown et al., 2011). Low-income backgrounds have equally witnessed an increase in availability of HAART enabling the children to live longer because they experience fewer symptoms of the early course of the disease and survive to old age with improved quality of life (Lesch et al., 2007). As a result, the question of disclosure has increasingly become important.

Disclosure of HIV is a dynamic process that evolves and should address local socio-cultural practices (Gachanja and Burkholder, 2014). One definition of disclosure refers to a child gaining knowledge of his/her HIV status (Wiener, Melins, Marhefka, and Battels, 2007). For the purposes of this review, we focus on this type of disclosure, while acknowledging pediatric disclosure can also refer to disclosure of caregivers' HIV status to children (Rwesisis, Wolff, and Cutinoh, 2015) or a child's disclosure of his/her own HIV status to others (Hogwood, Campbell and Butler, 2012; Sherman et al., 2000). It is recommended that the disclosure is a gradual process. The process should involve giving a child age-appropriate information regarding his/her illness. This should lead

to full disclosure when the child has the cognitive and emotional maturity to process the data (Vreeman et al., 2014).

Globally, institutions such as the WHO have issued guidelines on age appropriate disclosure, but there are few published data on standardized, culturally appropriate disclosure protocols in resource-limited settings (Vreeman et al., 2014). Data still indicates low disclosure rates to children infected with HIV. In Thailand one-third of HIV-infected school children who receive HAART know their diagnosis. A disclosure rate of 13.5% was observed in a study in Nigeria, while in Uganda it was 16% (Brown et al., 2011). In Kenya studies have shown different prevalence rates; a study in Nairobi showed a prevalence of 11% (Gachanja and Burkholder, 2014) while another study in western Kenya showed a prevalence of 19% (Vreeman et al., 2014).

Caregivers and healthcare workers are presented with the challenge of deciding what is in the best interest of the child; when, why, and how much information about his/her HIV status should be shared with the child (Kiwauka et al., 2014). In Sub-Saharan Africa, the risk of loss to follow-up (LTFU) of children in HIV programs increased as children increase in age (Mannheimer et al., 2002; Vaz et al., 2008), while adherence to medical appointments to treat HIV is paramount. Contributors to non-adherence of medical visits include the following intrapersonal factors: fear of disclosure of HIV status for mother and child, and the parental perception that the child is healthy (Bigna et al., 2014). Other reasons hindering parents and caregivers from disclosing a diagnosis to children include the following; feelings of guilt, fear of stigma, shame, and social isolation that come with HIV disease (Waugh, 2003). These challenges, mostly lead to delayed disclosure. Delayed disclosure and nondisclosure are associated with



psychological problems, such as anxiety, depression, and phobias to both the child and the caregiver (Bachana, Hilo, Donna, and Krause, 2004).

Avoiding disclosure can have long-lasting effects on the child (Ferris, Burau, Schweitzer, Michael, Murray, Preda, and Kline, 2007). Nondisclosure may isolate children from potential sources of support, and there is also the risk that they may inadvertently learn the nature of their illness in a manner that is not supportive (Abebe and Teferra, 2012; Boon-Yasidhi et al., 2013; Brown et al., 2011; Oberdorfer et al., 2006).

Disclosure becomes significant both within and outside the family as sexuality becomes a dominant developmental issue during adolescence. It also becomes a significant public health issue as these children grow and become sexually active and might unknowingly transmit the virus to the uninfected population (Namulema, Seruyange, Kyazze, and Kalanzi, 2002). There is an urgent need to initiate the disclosure process as early as possible and in a correct manner. Knowledge of HIV status may have a substantial impact on disease progression and clinical management, especially the use of HAART. There is needed, therefore, to enhance the disclosure process to improve loss to follow-up (LTFU) and adherence.

Different studies have shown that; knowledge of HIV status may affect antiretroviral therapy compliance and influence a child's- participation in health decision-making. Disclosure of diagnosis to children with chronic diseases has been found to be beneficial (Ferris, Burau, Schweitzer, Michael, Murray, Preda, and Kline, 2007).

## **1.2. Problem statement**

Disclosure process of HIV status in clinics is more complicated. The process evolves from time to time and varies widely depending on socio-cultural practices. It also involves considering the child's developmental and emotional readiness to receive the information about his/her HIV status, the attitude and motivation/goal of the caregiver and healthcare worker towards disclosure (Kiwanuka, Mulogo, and Haberer, 2014).

Poor approaches to the disclosure may greatly impact how individuals will react to the stigma or perceived stigma. HIV-related stigma has been recognized as a barrier to HIV identification, prevention, and treatment (Harper, Lemos, and Hosek, 2014; Ostrom, Serovich, Lim, and Mason, 2006). Stigma and discrimination impact how communities, families, and partners interact with people living with HIV. Consequently, public health efforts to combat the HIV/AIDs epidemic are undermined. This is due to the negative impact stigma has on primary and secondary preventive behaviors such as condom use, HIV testing, engage in HIV care, and quality of care (Corbie-Smith, 2010; Harper et al., 2014; Ostrom et al., 2006).

The Kenya HIV estimates special report shows; Turkana is one of the top ten counties with the highest new infection rates. Despite the vast importance of HIV testing as a way to increase prevention and treatment, about 73 percent of people in Turkana County had never tested for HIV in 2009. In Turkana County, approximately 55 percent of individuals had their first experience of sexual intercourse before the age of 15 years, an indication of the early sexual debut (Ministry of Health, 2014). It is, therefore, a major problem if children with HIV surviving into adolescent years do not know their HIV status. This can potentially result in increased transmission of the disease.

### **1.3. Justification**

Although several guidelines and recommendations on disclosure exist, available data still show that the prevalence of disclosure of HIV status to HIV infected children in resource-limited settings is very low (John-Stewart et al., 2013; Kiwanuka et al., 2014). Infected adults have control of how and when they are informed of their status; however, this is not the case with children. Caregivers (biological, foster, adoptive or extended family) control information flow about HIV status to children and others. This is against the Convention on the Rights of the Child which states that; children under 18 years have rights to information about their health (UN Human Rights Commission).

Legal framework can hinder the process of disclosure. Some laws allow only the caregiver to disclose to the child and healthcare providers have no role to play in the process. Therefore, countries need to develop policies that are in line with international requirements. These policies need to take into account the role of healthcare providers in disclosure and how they can assist caregivers in this process. The National HIV testing and counseling guideline of Kenya, 2012 gives the sole responsibility of disclosure to caregivers. This research will partly be used to help the county develop its framework.

It is challenging to develop effectively, and appropriate local HIV disclosure interventions without sufficient data. More data is needed to create, or facilitate and support, useful and beneficial disclosure interventions in less developed settings. These interventions require the understanding of the disclosure process, factors affecting the likelihood and outcomes of disclosure and the reasons for or against caregivers' decisions to disclose or conceal HIV status to children under their care.

The Kenya roadmap for HIV, the primary focus in vision 2030 has shifted focus from regional blocks to counties in tackling HIV/AIDS. Counties have been clustered by priority, (high, medium and low) based on Kenya's geographical disparities in HIV incidence (NASCO, 2015). Among the counties that make up the North Rift region, Turkana County noted a high priority, with the highest rate of new HIV infection as well as the highest prevalence of HIV. Turkana's annual infections among children are ranked thirty-seven among forty-seven counties (the county with the lowest incidence is ranked as one). County coverage of ART among HIV-infected children in Turkana is 19% (Ministry of Health, 2014).

#### **1.4. Purpose, Outcome and Target Beneficiaries**

This study aimed to determine the prevalence of HIV disclosure among children in Turkana County, its associated factors, and perceived barriers. The research targeted children between 7 to 14 years of age attending the pediatric HIV clinic, their caregivers and healthcare workers at the Lodwar county hospital in Turkana County, Kenya. At the end of the study, I aim to understand the factors associated with disclosure and factors hindering disclosure through qualitative and quantitative analysis. The study intends to benefit the county government regarding policymaking, as well as policy reform and change in the implementation of policy. For healthcare providers and caregivers; it will help in improving disclosure approach thus increasing disclosure rates.

### **1.5. Research questions**

- a) What are the factors and barriers associated with pediatric HIV disclosure among children 7-14 years at Lodwar County Referral Hospital?
- b) Is there an association between disclosure rates and factors associated with HIV disclosure to children aged 7 to 14 years?

### **1.6. Objectives**

#### **1.6.1. Broad Objectives**

- To determine prevalence, associated factors and perceived barriers to HIV disclosures to children aged 7-14 years at Lodwar County Referral Hospital

#### **Specific Objectives**

- To estimate the prevalence of HIV disclosure to HIV infected-children 7-14 years in Lodwar County Referral Hospital.
- To evaluate factors associated with HIV disclosure to children aged 7-14 years in Lodwar County Referral Hospital.
- To evaluate barriers associated with HIV disclosure to children aged 7-14 year Lodwar County Referral Hospital.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1. Introduction**

Despite emerging evidence of the benefits of disclosure, when and how to disclose the diagnosis of HIV to children remains a clinical dilemma in the globe (Meless et al., 2013). Disclosure patterns from caregivers range from full disclosure to partial disclosure to no disclosure (Funk-Brentano, Costagliola, Seible et al. 1997).

Partial disclosure refers to the strategy whereby parents provide children with information about their illness without naming the disease correctly. It is part of a process in which gradual steps are taken towards full disclosure (Waugh, 2003). It often involves the use of metaphors to describe HIV. Therefore, the disease is characterized without attaching a name to it. For example, a parent may tell the child that she/he has 'germs in the blood' (Lesch et al., 2007).

#### **2.1. Prevalence of HIV/AIDS disclosure**

The prevalence of disclosure in children and youth varies widely across studies and settings, ranging from less than 50% to about 75% in the world. Most children know this from family members, and some from healthcare providers or even school friends (Biadgilign, Deribew, Amberbir, Escudero, and Deribe, 2011). The caregivers' understanding of 'knowing' does not always mean that the children are told the name of the disease ('HIV' or 'AIDS') or that they are informed about the particulars of the disease. Furthermore, many of these caregivers who reported that the child does not know about the disease have inaccurately explained to the child that he or she has some diseases such as an allergy, lung, or liver disease. None of the children who were

surveyed and whose primary caregiver is their biological father knew their diagnosis (Oberdorfer et al., 2006).

A shallow level (16.3%) of disclosure of HIV status to children was reported in Addis Ababa, Ethiopia, 2012. This compared to a report from Ghana (21%), 2011, but much less than Thailand (30.1%) and the USA (43%) in 2002. This might imply that parents/caregivers have a lack of knowledge about the benefits of disclosure and skills in telling the diagnosis to their children (Abebe and Teferra, 2012). A disclosure rate of 13.5% was observed in a study in Nigeria (Brown et al., 2011). It is similar to the 14% reported in India, but still lower than 30.1% mentioned earlier, among school-aged children in Thailand (Oberdorfer et al., 2006). South Africa revealed a much lower disclosure rate (9%), but their study population was much younger, 74% of the South Africa study sample was less than six years of age. A disclosure rate of 37.8% in adolescents (11 to 15 years old) was reported in South Africa (Rochat, Arteche, Stein, Mkwanzazi, & Bland, 2014).

Prevalence and correlates study of disclosure of HIV status to children in four clinics in western Kenya; found a minority of children aged 6–14 years knew their status. These findings are consistent with results from studies in Ghana, Uganda, and a previous review in Nairobi, Kenya, which found a prevalence rate of disclosure to be 19% among 271 children with a median age of nine years. The findings reveal higher rates of disclosure than a comparative study with reduced sample size, a pilot study that showed only 11% of children (median age 9.3 years) knew their HIV status (Vreeman et al., 2014).

## **2.2. Factors associated with disclosure**

Precipitating factors for disclosure include fears of accidental disclosure (Instone, 2000), illness progression and the appearance of visible signs of illness (Mellins et al, 2002), and the child persistent illness-related questions (Lester, Chesney, Cooke, Wess, Whalley, Perez, and Wara, 2002).

### **2.2.1. Responsibility of disclosure**

Most caregivers (63.5%) believe that the parents should be responsible for disclosure. This is similar to observations by (Arun et al., 2009) in India and (Oberdorfer et al., 2006) in Thailand, where 42% and 57%, respectively, of caregivers, believed the parents were the most appropriate persons to carry out a disclosure (Arun et al., 2009). However, in the study by Oberdorfer et al. (2006) 43% of caregivers preferred disclosure to be done by the healthcare provider. Another research study indicates that a quarter of caregivers agreed that support by health workers is needed in the process of disclosure. These study figures include 14.6% of respondents who preferred disclosure by parents and caregivers at the same instance and 11.5% who preferred disclosure by health workers after parental consent (Brown et al., 2011).

Research suggests that women want to take a leading role in disclosing to their children. They make the decision based on the child's ability to handle the information without being excessively worried or scared. Women are protective of their children and gauge disclosure decisions based on perceived maturity and emotional stability of their children. After deciding whether or not to disclose, 48.5% of the women directly disclose HIV status to their children (Ostrom et al., 2006). Among women who decided not to disclose, their stated reason was based on timing and concern for the child's well-being. Mothers are ordinarily concerned that disclosure would take away the joys of



being a child. They want to wait until the child is mature enough to handle the news, to cope without being overwhelmed and to maintain confidentiality (Delaney, Serovich, and Lim, 2008).

In rural Uganda, most reported that they perceive disclosure as a single momentous event of truth-telling that is usually preceded by a period of sustained avoidance and deliberate deception. Caregivers generally viewed disclosure as potentially beneficial to children and express desire to derive a wide range of anticipated benefits, particularly improved medication adherence and better self-care, for their children through a properly timed and managed disclosure. They also viewed the disclosure as an opportunity and framework for accounting to the child for their responsibility in the child's infection. However, most were preoccupied with the fear of negative outcome and did not feel able to disclose well. It was, therefore, easier for them to avoid disclosure, even when presented with clear opportunities to tell their children about their HIV status (Kiwanuka et al., 2014).

### **2.2.2. Age**

Age has been identified as one factor associated with disclosures of HIV status. Older children know their status more often than younger children. This is as a result of increasing maturity, independence, and responsibility for self-care that is required in knowing their status. In many studies, the older children knew their HIV status. Bor et al. (1996) reported 100% disclosure in children 16 years of age and older (Bor, 1996) likewise; Cohen et al. 1997 reported that 95% of children older than 10 years of age were aware of their HIV status in Massachusetts (Cohen, Reddington, Jacob et al, 1997). Similar findings, specifically that disclosure is higher among older children, were also documented elsewhere (Myer, Moodey, Hendricks, Cotton. 2006). Most

caregivers in various studies said that disclosure is important, but they would rather delay until the child is older. The preferred age of disclosure ranged from five to twenty years with a mean age of 13.4 years (Brown et al., 2011). Studies have found that children on ART are significantly more likely to know their HIV status, due to the responsibility following increased disease management activities like taking ART (Abebe and Teferra, 2012; Vaz et al., 2008; Vreeman et al., 2014).

### **2.2.3 Level of education**

The relationship between HIV disclosure and educational level has also been documented (Perretti-Watel, Spire, Pierret, Lert, and Obadia, 2006). Most children who know their HIV status come from families with higher socio-economic status and education is a proxy indicator of higher socio-economic status. Illiterate caregivers are more unlikely to disclose the child's HIV status than caregivers with a higher educational level. Similar findings were reported by Wiener et al., 2006 in which more children who knew their HIV status were raised in families with higher socioeconomic status (Weiner et al., 2006). In contrast, a study in Thailand found that children of caregivers who reported having financial problems knew their diagnosis more than those children whose caregivers did not report to have any financial problems (Oberdorfer et al., 2006). In the Ethiopian context, affluent families reported the desire to keep their family's status by avoiding disclosure (Biadgilign et al., 2011).

### **2.2.4. Stigma**

Research also concludes that stigma plays a large part in women's decision to disclose HIV status to their children (Forsyth, Damour, Nagler, and Adnopo, 1996). Mothers want to protect their children from discrimination because of their HIV status. As a result, they fail to disclose to the child their HIV status. However, this was contrary to

a study; using a quantitative HIV stigma scale (Berger et al, 2001) to assess the role of stigma in women decision to disclose HIV status to all, some or none of their children, as well as how stigma impacted the reasons women provided for their decision (Ostrom et al., 2006).

#### **2.2.5. Fear**

In a study in London, United Kingdom which followed 13 families with children who acquired HIV by vertical transmission. The most frequently given reason for the delay in talking to the children about HIV was fear that the children may accidentally reveal their diagnosis. Thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatization, discrimination, and prejudice (Waugh, 2003). The most common reason for non-disclosure was the fear that disclosure might have negative psychological consequences to the child (Oberdorfer et al., 2006). Despite the immediate burden of learning one's HIV diagnosis, disclosed children have better emotional health outcomes compared to their non-disclosed counterparts (Vreeman et al., 2013).

#### **2.2.6. Adherence to ART**

Limited evidence also suggests that disclosure is associated with better adherence to ART and HIV-related health outcomes, although the effect of disclosure on adherence has not been well evaluated. The relationship between adherence to ART and disclosure is not well described, and studies report mixed results (Hammami, Nostlinger, Hoeree, Lefevere, Jonckheer, and Kolsteren, 2004). There are several reasons; disclosure might be associated with non- adherence. Disclosure is a traumatic event for many children and can be accompanied by feelings of anger, hopelessness, and rebellion, which may lead to temporary or long-term adherence problems. The negative effects of HIV-

related stigma, including efforts to keep the diagnosis secret by hiding or not taking medicines, may also impact adherence to therapy for disclosed children more than non-disclosed children. Adherence issues may be compounded by other adolescent-specific factors such as increased incidence of depression and generally poorer medication adherence among this age group (Vreeman et al., 2014).

### **2.2.7. CD4**

Associations have not been found between disclosure status and clinical indicators like CD4 cell counts and WHO classified disease stage. A study among Thai adolescents found that while disclosure was associated with a CD4 percentage below 30% in multivariate analysis, disclosure status was not associated with virology outcomes (Vreeman et al., 2014). In contrast, a study in Romania found that children who did not know their HIV status were at higher risk for disease progression, measured by CD4 count decline and death compared to disclosed children. Other clinic-level factors like retention in care may also be associated with disclosure status and are important to understanding (Ferris, Burau, Schweitzer, Michael, Murray, Preda, and Kline, 2007).

## **2.3. Barriers to HIV/AIDS disclosure**

### **2.3.1. Lack of knowledge on disclosure**

The inability of most caregivers to handle disclosure has defined the three main patterns of disclosure: complete parental disclosure, partial parental disclosure, and nondisclosure. Incomplete disclosure, the child is told that he/she has HIV and is given disease-specific information. In a partial disclosure, the child may know that he/she has an illness, but he/she has not been told specifically that he/she has HIV infection. Incomplete disclosure, the child is aware and refers to his/her illness like HIV. The complete disclosure of HIV status has been associated with improved adherence to

ART (S. Kallem, Renner, Ghebremichael, and Paintsil, 2011; Wiener, Mellins, Marhefka, and Battles, 2007). Partial disclosure and non-disclosure can strain the relationship between the caregiver and the child. Force and persuasion are often used to get the child to adhere to treatment; these tactics may result in purposeful rebellion and non-adherence by the child (Kallem et al., 2011).

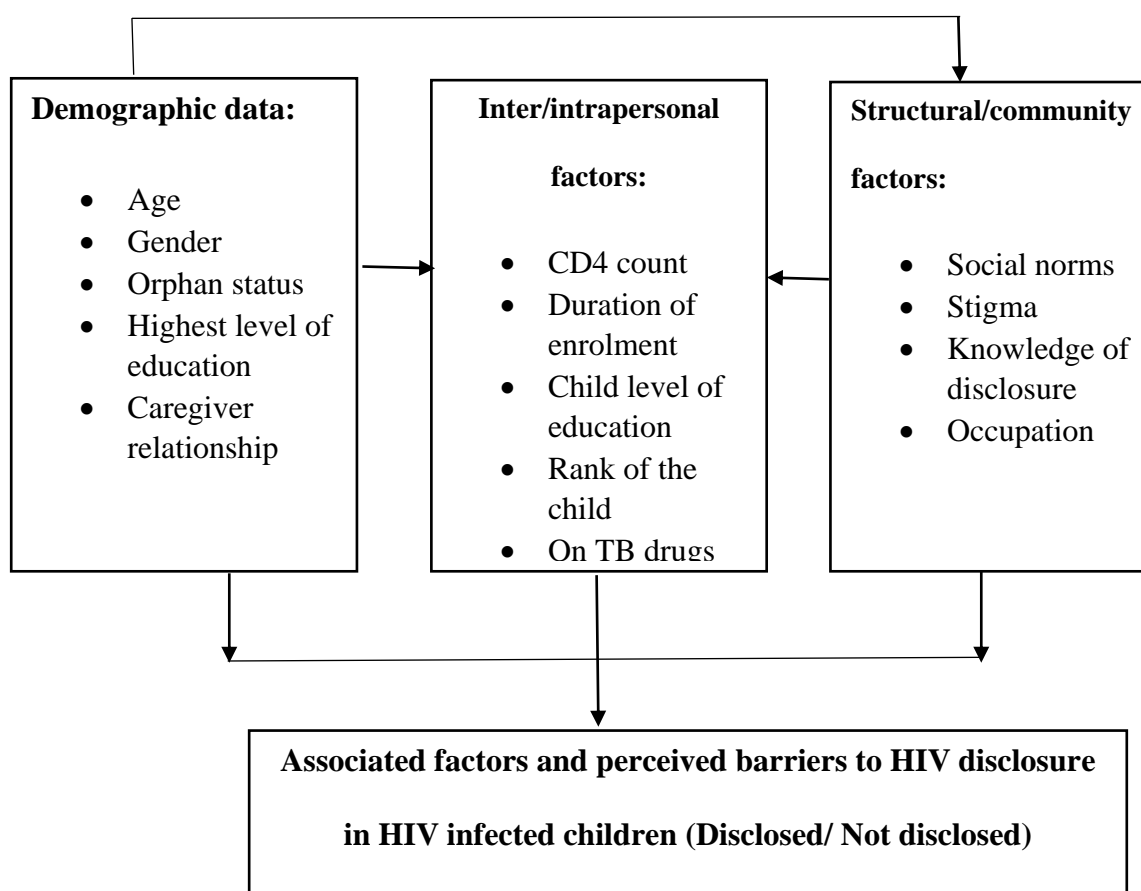
Child knowledge of HIV status is not associated with parent/caregiver characteristics (age, gender, ethnicity, educational status, HIV status), their type of placement (parent vs. caregiver) and their most recent CD4 number (Vaz et al., 2008).

### **2.3.2. Laws and policies**

Other key factors shaping the disclosure process are still lacking from various compiled data. For example, government policies and guidelines in different countries may have legal implications for disclosure. The studies that I reviewed did not specifically include discussions of national laws and policies regulating disclosure in particular settings, which may influence the age for disclosure and who can be involved. In Kenya, the disclosure of HIV status to children is reserved for the parents/caregivers, rather than required by law for healthcare providers or other entities (NAS COP, 2008). In Nigeria, as another example, the laws protect the privacy of information regarding a person's HIV status and may, therefore, prevent healthcare workers from informing a child that he or she was perinatally infected with HIV. Since such disclosure would result in violating the confidentiality of the mother's HIV diagnosis (The Federal Government of Nigeria, 2003). This chosen stance presents an ethical dilemma that needs to weigh against child rights and public health implications (Brown et al., 2011).

Finally, while not significant, there is some indication that disclosure status varies by ethnic group, according to a study done in western Kenya. Therefore, more qualitative data are needed to explore further how cultural beliefs may impact decisions about how and when to disclose HIV status to children (Vreeman et al., 2014).

## 2.4 Conceptual framework



The conceptual framework shows the interplay between different factors and barriers – and how they result to either disclosure or non-disclosure. The variables have been categorized as demographic, inter/intrapersonal factors and structural/community factors.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1. Study area**

Turkana County is located in the northwest region of Kenya with a population of 855,399 people and accounting for 1.9% of the total population of Kenya. Men constitute 43%, women, 41% and children, 16% of the total population (KDHS, 2014).

Turkana people are majorly pastoralist keeping camel, cattle, goats, and sheep. The pastoral communities mostly own the livestock in Turkana. Many residents engage in complementary livelihoods, such as farming and fishing activities. The cattle and camels are significant contributors to livestock production, while sheep and goats are minor contributors of output to households (Schmidt, and Mayindo, 2006).

Regarding healthcare, Turkana County has 16 nurses, one doctor and three clinical officers per 100,000 people. There are 65 public health facilities, one nongovernmental, 41 faith-based and 21 private hospitals (Jakab, 2001).

HIV prevalence among adults in Turkana County is 7.6%, and approximately 5,736 children live with HIV (Ministry of Health, 2014).

#### **3.2 Study design**

To estimate the prevalence and understand factors associated with and perceived barriers to HIV disclosure in pediatric HIV clinic among children of 7 to 14 years of age. The study employed a cross-sectional study.

### 3.3. Study population

The study population included every second child receiving HAART at Lodwar County Referral Hospital, their caregivers and healthcare providers.

### 3.4. Sample size determination

Cochran's formula; (Cochran, W. G. 1977), will be used to calculate the sample size.

$$n = \frac{z^2 pq}{d^2}$$

n = the desired sample size

z = the value confidence level of 1.96 (95%)

p = 0.09 Proportion of paediatric disclosure (Lesch et al., 2007)

q = 1 – p

d = 0.05 (the amount of discrepancy tolerated on q)

$$\frac{(1.96)^2 \times (0.09 \times 0.91)}{(0.05)^2}$$

$$(0.05)^2$$

$$n = 126$$

### 3.5 Sampling

Systemic random sampling was used to administer interviewer questionnaires. The total number of children receiving HAART from hospital records at the HIV pediatric clinic in Lodwar County Referral Hospital is 324, and my sampling size was 126. The nth number was obtained by dividing the total number of children receiving HAART (324) by my sample size (126). The nth number was every second child accompanied by their caregiver upon returning from a clinic appointment at the HIV pediatric clinic.



Another questionnaire was administered to caregivers of children receiving HAART at the HIV pediatric clinic in Lodwar county referral hospital.

For qualitative research, four key informant interviews were conducted in each identified category of healthcare providers, namely; nurse, clinical officer, psychological counselor and social worker who offer services at the HIV pediatric clinic in Lodwar county hospital. The four healthcare providers were purposively selected from those working at the Comprehensive Care Centre.

### **3.6. Inclusion and exclusion criteria**

#### **3.6.1. Inclusion Criteria**

- The caregiver should be 18 years and above
- The caregiver should have stayed with the child for at least one year
- The child should be 7-14 years old and attending outpatient clinics at the study site

#### **3.6.2. Exclusion criteria**

- A caregiver who is not of sound mind (Legally not having the capacity to think, reason, and understand oneself.)
- Institutionalised or children living in a children's home
- Unaccompanied minors

### **3.7. Study variables**

**Child characteristics (independent variables);**

Age, weight, orphan status, medications (ART/Anti-tuberculosis), CD4 count/percentage, adherence and duration of enrolment in the clinic and the birth rank of the child.

**Caregiver's characteristics (independent variables)**

Age, sex, and the highest level of education, relationship to child, occupation

**Outcome variable (dependent)**

Disclosure status for children was described as a binomial variable disclosed or not disclosed.

During the administration of the caregiver questionnaire, if a caregiver answered "yes" (Question1) to the child knowing why she/he comes to the clinic and the child knows his/her HIV status (Question2), then the child was considered disclosed. If the child correctly named HIV as his/her illness, from the child questionnaire (Question2), then the child was deemed disclosed (Vreeman et al., 2014)

**3.8. Data collection**

Files of children who had been booked for clinic appointments, meeting the inclusion criteria, were identified through the records department. The files were marked to enable the healthcare worker to send the caregiver and every second child to the interviewing room.

Trained research assistants administered structured adult-child pair questionnaires. Questionnaires were administered in a closed room away from other clinic patients and the children, to ensure privacy and avoid unplanned disclosure to the children. Some of the content of the questionnaire was adopted from a previous study by (Vreeman et al., 2014) and others from (Oberdorfer et al., 2006). Healthcare (Clinical Officer, Nurse,

Social workers, and psychological counselor) workers were asked to send children and caregivers to the interview room after being seen. According to the individual subject's choice, interviews were being conducted in Kiswahili and Ng'turkana (the main local dialect in the region). Three sets of data were collected. One questionnaire was administered to the caregivers of children receiving HAART at a pediatric HIV clinic in Lodwar county hospital. Another questionnaire was administered to every second child between 7 to 14 years old receiving HAART at the HIV pediatric clinic in Lodwar county hospital. The four key informant interviews were conducted among purposively selected nurse, clinical officer, social worker and psychological counselor at the Lodwar county hospital.

### **3.9. Data processing and analysis**

Qualitative data analysis for key informant interview was conducted through used thematic analysis method. NVIVO software was used to analyze transcribed data. NVIVO allows for useful data review to discern themes, develop codes and align codes with data.

Words, phrases or section of the key informant interview were designated into themes and original codes by the research team. Primary codes were descriptive and labeled for subsequent reviews of the data that allowed for more analytic coding concepts and emergent thoughts.

For quantitative data, Statistical Package for Social Sciences (SPSS) version 21 was used in the analysis. Descriptive statistics were used in summarizing the results and numeric data summarized using tables. Data were analyzed using bivariate analyses

with chi-squared ( $\chi^2$ ) tests at 0.05 significant levels, and 95% confidence interval and multivariate analyses (test significance) conducted using logistic regression with odds ratios (OR) and 95% confidence intervals (95%CI) to identify the predictors.

### **3.10. Limitations and delimitations**

Essential predictor variables were not adequately studied because of funds and time. For instance, the extent of the psychological impact of disclosure was not sufficiently investigated because it requires following up time.

### **3.11. Ethical considerations**

The proposal was presented to the Institutional Research and Ethics Committee at Moi University for ethical approval and was approved by Lodwar county referral hospital to research their institution.

### **3.12 Consent and confidentiality**

Consent form one was used for both caregivers and healthcare workers (Appendix section, page 26). The child assent form was used for children (Appendix section, page33). Participants had the option of opting out of the study at any point they felt uncomfortable.

Coded participant questionnaires were kept confidential. The investigator and a data analyst who had agreed to confidentiality and nondisclosure had access to respondent questionnaires. All respondent questionnaires were locked in a secure cabinet. Data stored in electronics was stored in a password-protected Microsoft Word documents and saved in a safe and encrypted Google Drive system. Partnering agency staff will be required to sign a confidentiality agreement. After data analysis and presentation of

results, all questionnaires and responses from key informant interviews will be shredded.

### **3.12 Psychological risks**

Children were asked to leave the examination room when the research assistants were administering the questionnaire to caregivers to avoid accidental disclosure. The research assistants were trained on how best to administer the questionnaire without disclosing to the child his /her status. In the case that any questions produce negative psychological responses in the study participants. The participants had access to a counselor based at the Turkana wellness center in Lodwar county hospital.

### **3.13. Benefits of Study**

The study participants did not benefit directly, but the study provided the knowledge need to improve service delivery at HIV pediatric clinic Lodwar County Referral Hospital. The study also identify other support initiatives that the children might be missing out because of nondisclosure.

### **3.14. Statement of Non-affiliation**

The research study was conducted by me, the principal investigator who is an independent student at Moi University. There was an unpaid partnership with the County Government of Turkana and Lodwar County Referral Hospital. Both did not have access to the data, which was used solely for this study. The County Government, Lodwar County Referral Hospital, and others, however, may use the outcomes of this study to leverage broad policy changes or reforms. Finally, research results may at some point be published in full or in part.

### **3.15. Quality checks**

Translation and back translation of the questionnaires was conducted before data collection. Research assistants were trained to ensure the quality of data collected. After checking for completeness, questionnaires were put into the safe custody of filling up questionnaires. A pilot study using 10% of the desired sample size (126) was done at Kajiado County Referral Hospital before applying the final version in the study area.

## CHAPTER FOUR

### RESULTS

This chapter describes the results of data collected for this study.

**Table 1: Socio-demographic caregiver characteristics (n=99)**

<b>Variable</b>	<b>Categories</b>	<b>Frequency n=99</b>	<b>Percentage (%)</b>
<b>Gender</b>	Female	89	89.9
	Male	10	10.1
<b>Marital Status</b>	Married	45	45.5
	Separated	8	8.1
	Single	4	4.0
	Widowed	42	42.4
<b>Relationship to child</b>	Father	8	8.1
	Mother	62	62.6
	Grandmother	6	6.1
	Guardian	23	23.2
<b>Occupation</b>	Employed	64	64.6
	Unemployed	35	35.4
<b>Level of education</b>	Primary	34	34.3
	Secondary	6	6.1
	Tertiary	10	10.1
	None	49	49.5

### Social demographic characteristics of the study population

Socio-demographic aspects for respondent such as gender, marital status, level of education, occupation, was assessed in 99 caregivers. The primary caregivers interviewed were biological parents (70.7%). The majority of them were women (89.9%). Nearly half of the caregivers (49.5%) had no education, (4.0%) had completed secondary school, and (34.3%) had primary education. Those with the highest level of education that is; tertiary education were (10.1%). Approximately half the caregivers, were married (45.5%), and the other half were widowed (42.4%), only (4.0%) were singles. More than half of the caregivers interviewed (62.6%) were the child's mother. Most of parents or guardians questioned in our study were people without monthly income (30%) that is homemakers while (30%) others were unemployed.

**Table 2: Measures of central tendency for caregiver (n=99)**

<b>Variable</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. deviation</b>
<b>Age (years)</b>	18	65	36.86	8.580
<b>Number of children</b>	1	9	3.71	1.848
<b>Rank of the child</b>	1	9	3.04	1.911

The average age of caregivers was 36.86 (*Range =18-65; SD = 8.580 years*). The average number of children per home was 3.71 (*Range =1-9; SD=1.848*). Most of the children who were interviewed were ranked as third in terms of birth (*Range =1-9; SD=1.911*).



**Table 3: Socio-demographic child characteristics (n=99)**

<b>Variables</b>	<b>Categories</b>	<b>Frequency (n=99)</b>	<b>Percentage (%)</b>
<b>Gender</b>	Male	55	55.6
	Female	44	44.4
<b>Orphan status</b>	Total orphan	18	18.2
	With father	8	8.1
	With mother	33	33.3
	Not orphan	40	40.4
<b>Level of education</b>	Class 1-2	45	45.5
	Class 3-4	33	33.3
	Class 5 more	17	17.2
	Not in school	4	4.0
<b>On anti TB drugs</b>	Yes	6	6.1
	No	93	93.9

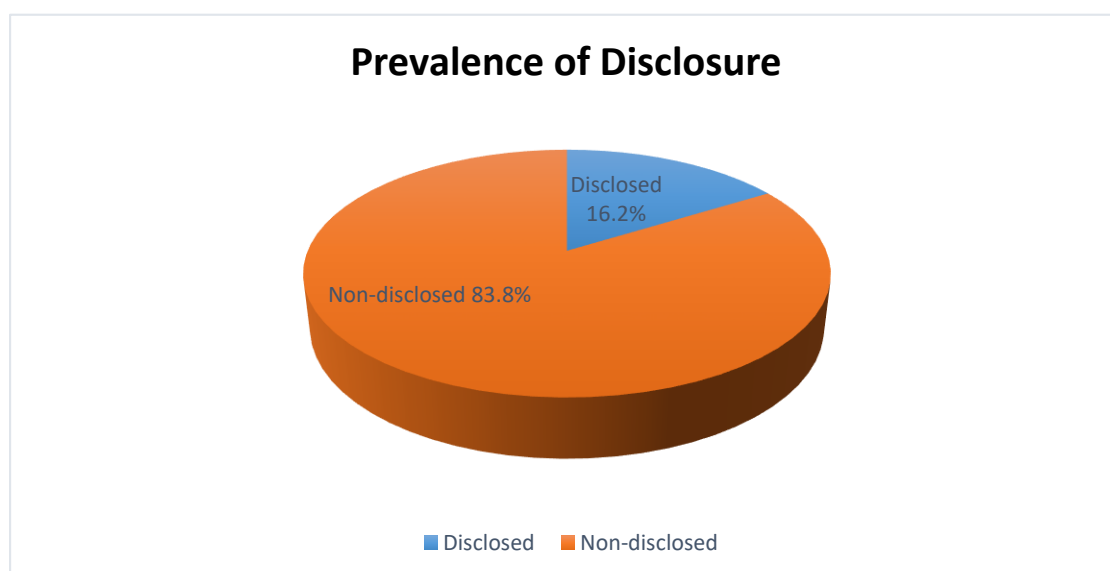
Of the 99 children who attended the clinic at Lodwar county hospital, (44.4%) were girls, and (55.6%) boys. Orphan status indicated that (18.2%) children were total orphans, (8.1%) were orphans with fathers, (33.3%) were orphans with mothers and (40.4%) had both parents. Based on their current education status, more than half of the child participants were in class four and below (78.8%). A total of (45.5%) children were in class 1-2, (33.3%) were in class 3-4, and (17.2%) were in class 5- and above, only (4.0%) were not in school. Most of them (93.9%) were not on anti-TB drugs. These child demographic characteristics were moved to the bivariate analysis to test for association to the outcome variable disclosed or not disclosed.

**Table 4: Measures of central tendency for child (n=99)**

	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>Age</b>	7	14	9.97	2.13
<b>Duration of enrolment</b>	9	156	77.21	34.19
<b>CD4</b>	583	1206	757.82	113.25
<b>Weight</b>	17.3	39.9	26.996	6.83

The average age of children is 9.97 years (*Range =7-14; SD 2.13 years*) with a mean duration of enrollment of 77.21 (*Range =9-156; SD 34.186 months*). At the time of the study, their average CD4 T-cell count was 757.82 (*Range =583-1206; 113.25*), and the mean weight was 26.996 (*Range =17.3-39.9; SD 6.83*). The preferred age for disclosure was 12.24 years (*SD1.76*) and a mode of 11 years.

#### 4.1. Prevalence of HIV status disclosure



**Figure 1: The proportion of HIV status disclosure among the respondents n=99**

Disclosure prevalence for HIV status was 16.2% (16/99) at a mean age of 9.97 years (*Range =7-14; SD 2.13 years*). To determine the prevalence of disclosure, children were asked whether they knew the name of the disease that they were being treated for or taking medication. For those children who mentioned HIV by name as the disease they were suffering from, they were considered to be disclosed. This was further confirmed through corroborated answers from the caregivers/parents questionnaires. Where both the child and caregivers/parents gave the same answers the child would be considered fully disclosed.

#### 4.2. Bivariate analysis for factors associated with disclosure of HIV status

**Table 5: Disclosure/Caregivers characteristics**

Variables	Categories	Disclosure (n=99)		P value	OR (95% CI)
		No	Yes		
<b>Gender</b>	Female	36 (81.8%)	8 (18.2%)	0.784	1.306 (0.447-3.813)
	Male	47 (85.5%)	8 (14.5%)		
<b>Duration of enrolment</b>	1-100	66 (91.7%)	6 (8.3%)	0.00*	0.100 (0.030-0.332)
	101-200	16 (59.3%)	11 (40.7%)		
<b>Age</b>	7-11	72 (96%)	3 (4%)	0.00*	0.035 (0.009-0.144)
	12-14	11 (45.8%)	13 (54.2%)		
<b>Education</b>	<=Class 5	76 (96.7%)	6 (7.3%)	0.00*	0.055 (0.015-0.198)
	> Class 5	7 (41.2%)	10 (58.8%)		
<b>On TB drugs</b>	No	78 (83.9%)	15 (16.1%)	1.00	0.962 (0.105-8.827)
	Yes	5 (83.3%)	1 (16.7%)		
<b>Orphan Status</b>	Orphan	50 (83.3%)	10 (16.7%)	0.866	0.909 (0.302-2.741)
	Not orphan	33 (84.6%)	6 (15.4%)		

Bivariate analysis using the Pearson chi-square test of association between HIV disclosure as the dependent variable and the child characteristics. According to the results, a child's education level was significantly associated with HIV status disclosure with an odds ratio of 0.055 (0.015-0.198). The results also showed that low duration of enrollment (*1-100*) had significantly fewer odds of HIV disclosure compared to the higher duration of enrollment (*101-200*) ( $OR=0.1\{0.03-0.332\}$ ,  $p=0.000$ ). Age was also found to be a significant predictor ( $p=0.000$ ) however, odds could not be tabulated due to missing values. The median age of children who have been told of their infection was 12.24 years (*range =11-14 years*) compared with years 8.5 (*range =7-10 years*) of the 99 infected children who had not been told.

#### 4.3. Disclosure Caregiver Characteristics

**Table 6: Disclosure/Caregiver Characteristics (n=99)**

Variables	Categories	Disclosure (n=99)		Odds Ratio (OR)	P value
		No	Yes		
<b>Gender</b>	Female	73(89.0%)	16(94.1%)	0.507 (0.060-4.290)	0.526
	Male	9(11%)	1(5.9%)		
<b>Age</b>	18-41	61(74.4%)	12(70.6%)	0.774 (0.243-2.466)	0.766
	42-65	21(25.6%)	5(29.4)		
<b>Level of Education</b>	Low Education	75(84.3%)	14(15.7%)	2.296 (0.529-9.965)	0.759
	High education	7(70%)	3(30%)		
<b>Occupation</b>	Employed	27(77.1%)	8(22.9%)	1.915 (0.663-5.525)	0.267
	Unemployed	55(85.9%)	9(14.1%)		
<b>Relationship to child</b>	Parent	61(87.1%)	9(12.9%)	2.582 (0.882-7.556)	0.145
	Guardian	21(72.4%)	8(27.6%)		

Bivariate analysis of caregiver's characteristics in relations to child's HIV status disclosure. All the caregiver's factors had no association ( $p > .05$ ) with the disclosure of HIV status to children; they include; the age of guardians, occupation, and level of education, marital status, and relationship to the child, gender, number of children and rank of the child. Low education include caregivers who had completed high school and below, while higher education were caregivers who had attained tertiary education.

#### 4.4. Multivariate Analysis

**Table 7: Multivariate for child and parents**

Variables	Categories	Disclosure (n=99)		P value	OR (95% CI)
		No	Yes		
Duration of enrolment	1-100	66(91.7%)	6(8.3%)	0.948	0.950 (0.206-4.383)
	101-200	16(59.3%)	11(40.7%)		
Age	7-11	72(96%)	3(4%)	0.00*	3.218 (1.898-5.457)
	12-14	11(45.8%)	13(54.2%)		
Education	<=Class 5	76(96.7%)	6(7.3%)	0.225	3.945 (0.938-16.581)
	Not orphan	33(84.6%)	6(15.4%)		

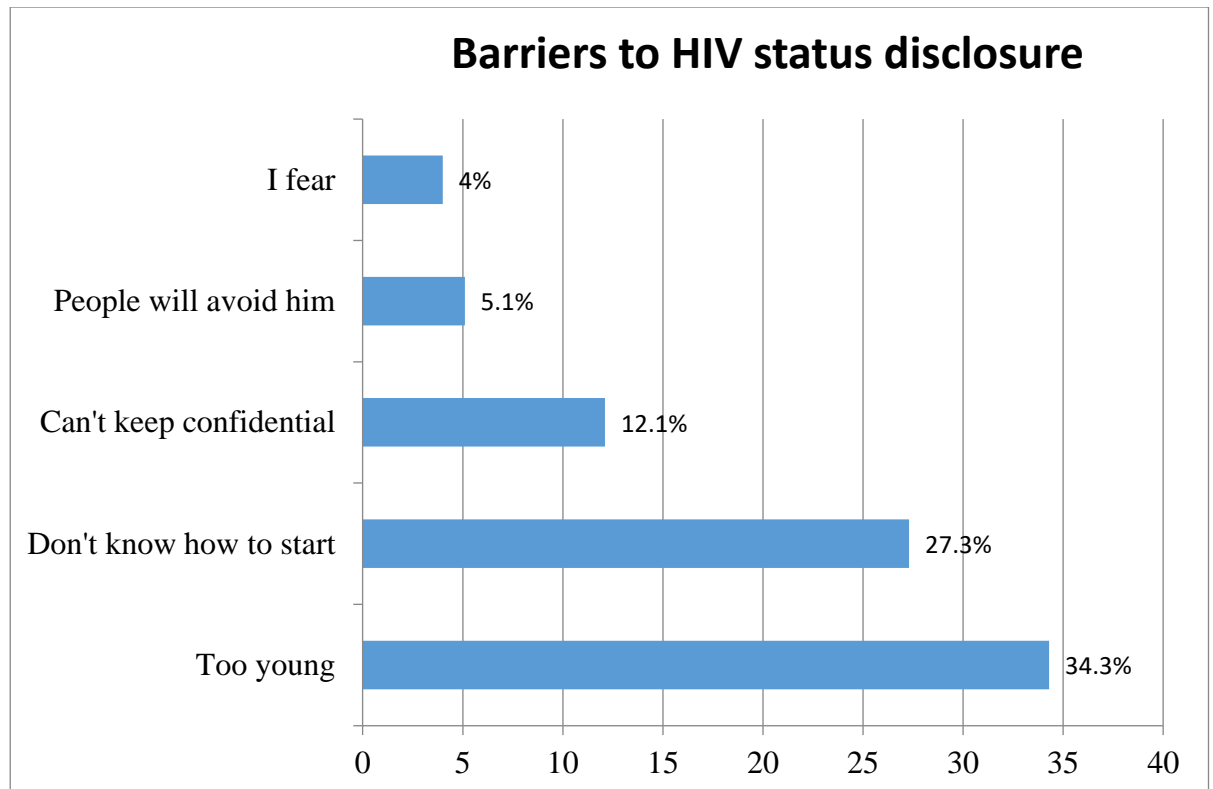
$$\text{Model } \chi^2 = 41.273 \quad p < .05 \quad n = 99$$

Although the duration of enrollment and education level were independently significant in the bivariate analysis. The model found age to be the only significant predictor of disclosure in the multivariate analysis. The logistic regression indicates that an increase

in the age of a child by one year increases the probability of disclosure by 3.22, therefore, the odds of disclosure increases by 32.2%.

#### 4.5. Perceived barriers to HIV disclosure

##### 4.5.1. Primary barriers to disclosure of HIV status



**Figure 2: Caregivers barriers to HIV disclosure**

In the graph above, the most significant barrier for parents towards disclosure is age, the majority (34.3%) of the caregivers failed to disclose to their children on the account that they were too young. This contrast with the reasons given by Key Informant Interviews on the challenges facing disclosure of HIV to HIV infected children. 'Fear' and 'stigma' were mostly used and can be linked to psychological maturity and understanding of the child.

*“Most caregivers fear not being able to maintain a relationship after disclosure due to the stigma associated with the disease especially among the Turkana.” (KII, 1)*

*“People are yet to accept the disease and sometimes even fear to call it by name.” (KII, 3)*

Inability to start disclosure by the parent/caregivers was a challenge mentioned by 27.3% of the participants. This was further supported by Key Informant Interview.

*“We’ve had challenges with accidental disclosure because most caregivers and their families don’t know how to handle the process. These have sometimes produced negative psychological effects and non-adherence.” (KII, 4)*

#### 4.5.2. Secondary barriers to disclosure

**Table 8: Responsibility of disclosure**

<b>Variables</b>	<b>Frequency (n=82 of 99)</b>	<b>Percentage (%)</b>
<b>Child support</b>	2	2.0
<b>Counselor</b>	27	27.3
<b>Father</b>	8	8.1
<b>Mother</b>	45	45.5

Approximately half of the caregivers (45.5%) thought that the mother is responsible for carrying out the disclosure. However, (27.3%) of them thought the counselor should be responsible for disclosing to children their status. KII 4 and KII 2 felt there is the need for supported disclosure by a counselor.

*“Currently the sole responsibility of disclosure is with the parents/caregivers, yet most of them don’t know how to disclose. It is important for healthcare givers to be allowed to provide supported disclosure.” (KII, 2)*

*“Although we have a guideline from the government on how disclosure is supposed to occur. It does not give healthcare providers the mandate to disclose. We often have to make tough decisions when parents/caregivers approach us to help them disclose to their children their status. The regulations need to consider this so that we can help disclose without fear”. (KII, 4)*

**Table 9: Child knowledge illness and medication**

<b>Variables</b>	<b>Categories</b>	<b>Frequency (n=99)</b>	<b>Percentage (%)</b>
<b>Reason for visiting the clinic</b>	Parent told me	47	47.5
	Doctor told me	22	22.2
	I am sick	30	30.3
<b>Name your illness</b>	Malaria	16	16.2
	Pneumonia	1	1.0
	Tuberculosis	12	12.1
	Flu	4	4.0
	None	50	50.5
	HIV	16	16.2
<b>Reason for taking medicine</b>	Parent told me	8	8.1
	Doctor told me	11	11.1
	I am sick	35	35.4
	To be strong	45	45.5
<b>Ever missed taking medicine</b>	Yes	8	8.1
	No	91	91.9
<b>Who informed you of your status</b>	Counselor	9	9.1
	Mother	8	8.1



The table shows that children have little knowledge about their ailment, which explains the low rate of disclosure. Among child participants, half (50.5%) did not know the name of their illness. Their responses described receiving either no information about their health or information that was incomplete or misleading. Some of the children reported being told commonly known diseases such as malaria and tuberculosis based on symptoms and a prior diagnosis. Adherence to medication was not based on whether the child was disclosed or not. Health care providers also play a key role in the disclosure process, more than half (52.9%) were disclosed to by counselors. The inability to link clinical visits and taking medication to their HIV status could also be indicative of the low disclosure rate. From their responses (47.5%) went to the clinic because their parents told them and (45.5%) took medication to be strong.

**Table 10: Caregiver knowledge and challenges to HIV status disclosure**

<b>Variables</b>	<b>Categories</b>	<b>Frequency</b>	<b>Percentage (%)</b>
<b>The explanation for attending the clinic</b>	Doctor said so	38	38.4
	Illness require frequent visit	44	44.4
	None	17	17.2
<b>Do you have difficulty giving medicine</b>	Yes	7	7.1
	No	92	92.9
<b>Reason for difficulty in giving medicine</b>	I forget	4	57.1
	The child doesn't like medicine	1	14.3
	I don't find time every day	1	14.3
	The child doesn't know s/he takes	1	14.3
	Don't want to give medicine in front of others	-	-

Responses from caregivers corroborate those in 4.4.2, where children were given misleading, incomplete or no information about their ailment. The explanation given to children for attending clinic indicated that approximately (38.4%) caregivers said it is because the doctor said so and nearly half (44.4%) said, it is because the child's illness required frequent visits to the clinic. This could be indicative of a lack of disclosure skills, fear or that caregivers weigh the benefits of disclosure against the social-psychological dangers.

## CHAPTER FIVE

### DISCUSSION

This study demonstrated that several factors influence whether parents/caregivers' disclosure or not disclosure HIV- positive status to children under their care. These factors included caregivers' levels of knowledge by caregivers about disclosure strategies, the age of the child, fear of blame and social and psychological acceptability by the child and the community of the child HIV status and lastly, support from the health care providers.

#### **5.1. Prevalence of HIV status disclosure**

Different studies show that the prevalence of disclosure varies widely across settings. This was similar in our study where the rate of HIV status disclosure was meager (16.2%). It was comparable to a report from Ethiopia (16.3%), and Ghana (21%), but much less than Thailand (30.1%) and the USA (43%) (Abebe & Teferra, 2012). The different findings in the level of disclosure in our study and Thailand are because in our study we confirmed with both the child and caregivers/parents that the child knew they have HIV/AIDS. However, in the latter study, the caregivers' understanding of "knowing" did not always mean that the children were told the name of "HIV" or "AIDS" unlike in our study in which all the children to whom their HIV status had been revealed were told they had HIV infection (Brown et al., 2011). The high level of disclosure in the United States may be due socio-cultural differences showing higher levels of expressiveness within the family and more intensive child-parent interactions, which is not the case in most African countries, including Kenya (Mumburi et al., 2014). This is a clear indication that disclosure is not a straightforward, linear process; it is instead a complex, interlinked, non-linear and dynamic process driven by contexts and constructs at both individual and community level (Mweemba et al., 2015).

## **5.2. Factors associated with disclosure of HIV status**

Mean age of disclosure was 12.4 years which was different from 9.2 years, reported in Uganda (Bagenda & Ekirapa-kiracho, 2015) and 8.7 years found in Nigeria (Brown et al., 2011). The reason for this age in disclosure in our set up may be because parents/caregivers reluctance to initiate disclosure. The youngest age of disclosure in this study was 11 years, and this is not in line with what some experts are advocating for, that disclosure starts as early as 5 to 7 years.

In this study, most of the caregivers thought that younger children did not seem to understand the implications of HIV diagnosis. Most of the caregiver/parents thought the optimal age for specific discussions about an HIV infected child's health should be conducted at an average age of 12years. This is similar with findings from a study in Nairobi (John-Stewart, 2014) where the median age of preferred disclosure was 12 years. It is also in agreement with the theory of child's cognitive understanding of illness, which considers the age from 9 to 10 years and older as the best time for HIV infected children to know about their sickness as at this age children can understand about causes of illness and its consequences (Bagenda and Ekirapa-kiracho, 2015).

However, our findings differ from those in India and Ethiopia, which showed that the majority of the caregivers wanted disclosure to take place during the mid-teenage (14-18 years). Caregivers who proposed mid-teenage believed that it is the age at which children become emotionally mature enough to cope with chronic disease and need sex education to prevent the spread of infection (Mumburi, Rune, and Kapanda, 2014).

From the analysis, the child's age was a significant predictor of whether the child had been told about his or her HIV status or not. Older children knew their status more frequently than younger children, likely as a result of increasing maturity,

independence, and responsibility for self-care that required knowledge of their status (Vreeman et al., 2014). The findings were in agreement with those documented by Cohen, 95% of children older than 10 years were aware of their status, but differed in that, unlike the Cohen study where 30% of children aged 5-10 years knew about their diagnosis and at least 5.9% of children age 8-9 knew their status with no disclosure at all at age 7 years (Cohen et al., 1997). In our study, no child age 10 years and below knew their HIV status.

Other factors like level of education of the child and duration of enrollment were also independently associated with disclosure at the bivariate level. These findings are consistent with other studies where older age, level of education and duration of enrollment were associated with disclosure. The duration of enrollment of the child made a significant contribution to prediction, consistent with other studies (Melins et al. 2002). This could be because a higher level of education and longer duration of enrollment are associated with cognitive maturity. However, we did not find any association between the orphan status of the child and disclosure. Some studies indicated that children with deceased biological fathers had higher odds of being disclosed to their HIV status compared to another orphan status (Kallem et al., 2011). However, weight and CD4-T lymphocyte count were not associated with the disclosure; this is similar with findings from other studies (Kallem et al. 2012).

Child knowledge of HIV status was not associated with parent/caregiver characteristics such as (age, gender, marital status, level of educational status, occupation, number of children, the rank of the child), their relationship to the child (parent vs. caregiver). Adherence to medication was not affected by disclosure this can be explained by the fact that caregivers were responsible for the child's medication.

While this study did not find any significant association between levels of education of the parent/caregiver to disclosure of HIV status to the child; this is not supported by other studies which found the educational status of the caregivers was statistically significantly associated with disclosure. And children with caregivers that had an education at or above primary level were statistically significantly less likely to be informed of their result than those with illiterate caregivers (Biadgilign et al., 2011).

### **5.3. Perceived barriers to HIV/AIDS disclosure**

On the disclosure process, our findings appeared to contradict the four stages of disclosure put forward by Tasker (Mweemba et al., 2015). These stages comprise, a) secrecy stage, where parents want to keep all knowledge about the illness from the child; b) exploratory phase, where they will begin to give some explanations to their child; c) readiness stage, when they provide further information and prepare more fully; and lastly, the disclosure stage, when the adolescent is told the name of the virus (Mweemba et al., 2015).

The findings suggest that caregivers encounter challenges in disclosing the HIV status to the child. From the analysis, 27.3% of the parents/caregivers did not disclose to their children because they didn't know how. This implies they lack knowledge and skills in telling the diagnosis to their children. This could partly be due to their overall low level of education, or that they had never been trained how to disclose the HIV status to the child or lack of knowledge about the benefits of disclosure. Disclosure is not a straightforward process; it is, therefore, vital that caregivers have adequate skills to disclose to facilitate the process adequately.

Also, it could be the case that health care providers are unsure as to how to approach disclosure in their setting as evident in the key informant interviews. Having disclosure

guideline is not enough, health care providers need to be trained on how to utilize it in their settings (Ledlie, 1999) (Abebe & Teferra, 2012). Health care providers can aid with disclosure issues in several ways. First, providers can help parents think about disclosure as a process, rather than a single event or point in time. In this regard, caregivers may require education about the possibility of partial disclosure, gradually increasing the child's understanding over time (Kiwauka et al., 2014). Parents may also benefit from peer support, speaking with other caregivers concerning disclosure to an HIV-infected child; either individually or in a group (Klitzman, Marhefka, Mellins, and Wiener, 2008). There is, therefore, need for specific programmes to prepare families and children for disclosure (Brown et al., 2011).

The lower prevalence of disclosure in our study was also be due to fear of stigma and discrimination as caregiver's perceived lack of emotional preparedness of the children and if the child is told he/she will not keep it confidential leading to stigma and discrimination by others (John-Stewart, 2014). This is also evident from the key informant interview, where health care provider strongly felt that fear and stigma played a major role in nondisclosure. This is comparable to other studies done both in low-income and high-income countries (Biadgilign et al., 2011).

Generally, caregivers perceived themselves as primarily responsible for telling the child about the HIV diagnosis. This is consistent with previous studies conducted with caregivers and healthcare providers (Madiba, 2016). In our study (61.7%) caregivers believed that parent/caregivers should be responsible for disclosure. This is similar to observations by Arun et al. (2009) in India and Oberdorfer et al. (2006) in Thailand where 42% and 57% respectively believed the parents/caregivers were the most appropriate persons to carry out the disclosure. Moreover, caregivers felt that disclosure

should be a shared responsibility of both the caregiver and the healthcare provider. In the present study about 27.3% of caregivers agreed that support by health workers is needed in the process of disclosure unlike 43% in the survey by Oberdorfer et al. This point to the need for closer working relationship between healthcare providers and the parents/caregivers to identify the best probable options and processes of disclosing HIV status to the child.

The caregiver also agreed that the primary responsibility of disclosure was with the mother, with most stating the close relationship between mother and child as the reason. This is supported by other research findings which indicated mothers as the most preferred person for disclosure because of closeness to the child (Oberdorfer et al., 2006).

This study also suggests that barriers to disclosure of HIV status to the child are not mutually exclusive. They are interrelated, and some may intersect and coalesce to undermine disclosure. For instance, while the perception of the young age of the child reduces motivation to inform the child of his/her HIV status, fears about stigma, sometimes influenced by parent/caregiver's attempt to preserve their social image, may undermine disclosure of HIV status to children. Similarly, although lack of disclosure skills may undermine disclosure of HIV status to a child, concerns about the young age of a child may also dissuade caregivers from telling children their HIV- positive status (Mweemba et al., 2015). From these findings, we cannot, therefore, conclude that there is one single barrier to disclosure of HIV status to children. As a result, there is a need for a multi-pronged approach to addressing these barriers.



There is no evidence to suggest that disclosure negatively affects HIV-positive children. Mellins et al. (2002) reported a non-significant trend toward less depression among children who knew their HIV status compared with those who did not (Lesch et al., 2007). On the contrary, the disclosure of HIV status helps the child to gain a better understanding of the need to adhere to the HAART regimen. It also provides an opportunity for parents and health care providers to wean children from their dependence on parent supervision and support in taking medicine (Brown et al., 2011). The study was limited in that it did not attain the required sample size due to unforeseen challenges.

## CHAPTER SIX

### CONCLUSION AND RECOMMENDATION

#### 6.1 Conclusion

In conclusion, few HIV-infected children in Lodwar County Referral Hospital know their HIV status. The major significant hindrance was age as caregivers thought the child was too young for disclosure. However, lack of knowledge and skills, fear and stigma seem also contributed to non-disclosure.

#### 6.1 Recommendation

It is recommended that children of school going age (6 years) be disclosed. The research recommends aided disclosure from healthcare providers. Parents/caregivers need to be counseled by trained health professionals at Lodwar County Referral Hospital, about age-appropriate disclosure to children receiving treatment at the hospital. This counseling may need to be repeated throughout the course of the child's illness. The county needs to develop her own policy on disclosure following the WHO and Kenya HIV disclosure guidelines, but specific to socio-cultural practices in the County. Further studies involving children living with HIV should be done to assess their perceptions of and allow them to provide insight into their lived experiences and articulate their needs and preferences.

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## APPENDICES

### APPENDIX 1: CAREGIVER CONSENT FORM

**BRIAN ODUOR OMBAKA**

**MOI UNIVERSITY**

**Dear Sir/Madam**

**Re: Consent Form**

I am a student at Moi University pursuing a master of public health. As part of the program, I am required to research partial fulfillment of master of public health program.

I am therefore interested in establishing; prevalence, associated factors and perceived barriers to Human Immunodeficiency Virus (HIV) disclosure to HIV infected children between 7 to 14 years. The evidence-based information will add to the pool of knowledge in improving pediatric disclosure hence improving the disclosure process.

You are invited to participate in this study by answering a one-time questionnaire. If at any point you feel uncomfortable with the questions and would like to withdraw from the interview, you are free to do so without any repercussions.

The questionnaire will be administered by a trained research assistant. The information provided will be treated as confidential and will not be used for any other purpose other than this study.

Although you may not benefit directly from participating in the study; your contribution by filling this questionnaire will make a significant contribution to the knowledge known about disclosure.

A research assistant will keep a record of all the questionnaires in a closed cabinet. Only the professional staff at the pediatric clinic will know the identity of study participants. If you feel that you have been affected as a result of participating in the study directly, please contact **Mr. Brian on 0727726470 or ombakabrian@gmail.com.**



Your signature on this form means that you understand the information presented and that you want to participate in the study. You understand that participation is voluntary, and you may withdraw from the study at any time.

.....  
Name of participant                      Signature/thumbprint                      Date and Time

.....  
Name of person obtaining consent                      Signature                      Date

**APPENDIX 2: Caregiver questionnaires****PART A: Demographic data****CODE****Gender** (tick the appropriate)Male  Female Age **Relationship Status**Married  Single  Widowed  Seperated **Relationship to child**Father  Mother  Guardian  Grandmother  **Grandfather**Number of Children  Rank of the child Occupation **Level of education** (tick the appropriate)None  some primary  Completed primary  some secondary Completed secondary  Tertiary education  Vocational training Adherence to clinic visits  out of Duration of enrolment (Months) **PART B: Disclosure status and patterns of disclosure**

1. Does the child know s/he has HIV?

- a. Yes
- b. No

***IF NO MOVE TO QUESTIONS 11-14***

2. What name does the child know of his/her illness?.....

3. Does the child know s/he is taking medicine for HIV?.....

- a. Yes
- b. No

4. At what age did the child know his/her HIV status?.....

5. Who told the child of his/her HIV status? .....

6. How did you disclose to the child his/her HIV status?.....

7. Did you experience any challenges before disclosure?.....

- a. Yes
- b. No

If yes, what challenges did you experience?

- a. S/he was too young
  - b. I did not know how to start
  - c. I fear of blame
  - d. Others.....
- .....

8. What was the response of the child when s/he was told about his/her HIV status?

.....

9. Who referred you to HIV screening?

- a. Community clinic
- b. Hospital- inpatient ward
- c. PMTCT programme
- d. Private practitioner/NGO

***A child does not know his/her HIV status***

10. If the child does not know s/he has HIV, what explanation did you give for coming to the clinic for taking medication?

- a. The doctor said so
  - b. His/her illness require a frequent visit to the doctor
  - c. Others.....
- .....

11. If the child does not know his/her status, what has hindered you from disclosing to the child his/her HIV status?

- a. I do not have the know how
- b. I fear
- c. S/he is too young
- d. S/he cannot keep it confidential
- e. Other people will avoid him/her
- f. Others

12. Do you plan to tell the child about his/her HIV status, and at what age?

13. Do you have difficulty giving the child medicine s/he is supposed to take?

- a. Yes
- b. No

If Yes, why?

- a. I do not want to give it in front of other people.
- b. The child does not know why s/he is taking medicine.
- c. I do not find time giving him/her every day.
- d. S/he does not like it.
- e. I forget.
- f. Others

14. What challenges has your child faced because of his/her HIV status?

- a. Other children avoid playing with the child.
- b. Other children tease or call the child hurtful names.
- c. The child has been rejected by friends and family.
- d. The child seems to have little interest or pleasure in doing things lately.
- e. The child has been feeling down, depressed or hopeless.

15. Who do you think should be responsible for HIV status disclosure?

- a. Family (Father/Mother)
- b. Health work (Doctor/Councillor)
- c. Child supporter

**Thank you for your time!**

**APPENDIX 3: ASSENT FORM****BRIAN ODUOR OMBAKA****MOI UNIVERSITY****Dear Sir/Madam****Re: Assent Form**

I am a student at Moi University pursuing a master of public health. As part of the program, I am required to research partial fulfillment of master of public health program.

You are invited to participate in this study by answering a one-time questionnaire. If at any point you feel uncomfortable with the questions and would like to withdraw from the interview. You are free to do so without any repercussions.

The questionnaire will be administered by a trained research assistant. The information provided will be treated as confidential and will not be used for any other purpose other than for this study.

Although you may not benefit directly from participating in the study; your contribution by filling this questionnaire will make a major contribution to the knowledge known in this area of research.

A research assistant will keep a record of all the questionnaires in a closed cabinet. Only the professional staff at the pediatric clinic will know the identity of study participants.

If you feel that you have been affected as a result of participating in the study directly, please contact Mr. Brian on 0727726470 or [ombakabrian@gmail.com](mailto:ombakabrian@gmail.com).

Your signature on this form means that you understand the information presented and that you want to participate in the study. You understand that participation is voluntary, and you may withdraw from the study at any time.

.....	.....	.....
Name of participant	Signature/thumbprint	Date and Time
.....	.....	.....
Name of person obtaining consent	Signature	Date

**APPENDIX 4: Child questionnaire items****PART A: Demographic****CODE**

Gender (tick the appropriate)

Male  Female Age 

Orphan status (tick the appropriate)

Total orphan  Orphan (with mother)  Orphan (with father) Duration of enrolment in months CD4 count/ percentage Weight **Education of the child**Class 1-2  Class 3-5  Class 5 more  Not in School On anti-TB drugs Yes  No **PART B: Disclosure status***Items 1-4 will be administered to ALL respondents*

1. Why do you come to visit the clinic?

- a. My parents told me so
  - b. The doctor told me I have to come
  - c. I am sick
  - d. Others.....
- .....

2. Do you know what your illness is called?

- a. Malaria
- b. Diabetes
- c. Pneumonia
- d. Tuberculosis
- e. Others (Specify)

3. Why do you have to take medicines?
  - a. My parents told me
  - b. The doctor told me I have to
  - c. I am sick
  - d. To be strong
  - e. Others
4. Do you ever miss to take medicines you are supposed to take?
  - a. Yes
  - b. No

If yes why?

- a) I refuse /I do not feel like?
- b) I do not want to take it in front of other people?
- c) I do not know why I am taking medicine?
- d) I do not find the time of taking them every day?
- e) I forget
- f) Others

### **PART C: Challenges to disclosure**

*Item 5-9 will be administered to ONLY disclosed children (Answered HIV question 1-3)*

5. Have you been told that your illness is HIV? If yes, who informed you of your HIV status?
6. Before you knew that you had HIV, did you ask questions about why you take medicine?
7. Do you still have questions about why you have to take medicines? If yes, which questions?
8. What challenges have you experienced since knowing your HIV status?
  - a) Children avoid playing with me
  - b) Friends or family have rejected me?
  - c) I have little interest or pleasure in doing things lately
  - d) I feel down, depressed or hopeless.
  - e) Others.....

**Thank you for your time!**



**APPENDIX 5: Prevalence, associated factors and perceived barriers to HIV disclosure among HIV infected children 7-14 years**

**Key informant interview (Healthcare providers)**

My name is Ombaka Brian Oduor from MOI UNIVERSITY. I am a student pursuing a master in public health and would like to understand associated factors and perceived barriers to HIV disclosure among HIV infected children in Lodwar. \_\_\_\_\_ hoped you would be willing to answer a few questions.

Anything you tell me is confidential. Nothing you say will be personally attributed to you in any reports that result from this interview. All of our reports will be written in a manner that no individual comment can be attributed to a particular person.

Are you willing to answer my questions?    **Yes**     **No**

Do you have any questions before we begin?    **Yes**     **No**

**Question:**

1. How are you currently approaching the disclosure process?  
(Which guidelines are you using? Apart from the ones you are using are there any other guidelines you know?)
2. What challenges do you think is facing HIV disclosure among HIV infected children?  
(What is preventing disclosure from happening?)
3. What needs to happen to help address the above challenges?
4. What do you think the national/county government can and should do to help meet these needs?  
(If you were charged with being the head of county health, what do you think needs to be done? As the county health officer what plans do you have in place?)
5. In the future, how would you like to approach the disclosure process as a healthcare provider?

**Thank you for your time!**

## APPENDIX 6: IREC APPROVAL



MOI TEACHING AND REFERRAL HOSPITAL  
P.O. BOX 3  
ELDORET  
Tel: 334711/2/3  
Reference: IREC/2015/254



MOI UNIVERSITY  
SCHOOL OF MEDICINE  
P.O. BOX 4606  
ELDORET  
13<sup>th</sup> July, 2016

### INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

Ombaka Brian Oduor,  
Moi University,  
School of Public Health,  
P.O. Box 4606-30100,  
ELDORET-KENYA.



Dear Mr. Ombaka,

#### RE: PROVISIONAL APPROVAL

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

***"Prevalence, Associated Factors and Perceived Barriers of Human Immunodeficiency Virus Disclosure to Children Aged 7-14 Years at Lodwar Hospital - Kenya."***

Your proposal has been granted **one month provisional approval** from 13<sup>th</sup> July, 2016 subject to ratification by IREC Full Board. Note that this is a preliminary approval and you are only allowed to set-up in readiness for the study but no recruitment should take place within this period until formal approval is granted.

Sincerely,

*For Signature*  
PROF. E. WERE  
CHAIRMAN

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

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

**APPENDIX 7: Map of the study area**