

**DETERMINANTS OF HIV STATUS DISCLOSURE AMONG ADOLESCENTS IN
BONDO SUB-COUNTY OF SIAYA COUNTY**

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DECLARATION AND APPROVAL

Declaration

This thesis is my original work and has not been presented for an award or conferment of a degree in any other university or institution.

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DEDICATION

This dissertation is dedicated to my brother, Mr. David Obiero and my sisters, Sophy and Mildred Obiero who have always supported my endeavors.

ABSTRACT

Disclosure of HIV status to adolescents is controversial and a sensitive issue among guardians, health workers, and parents of adolescents. However, HIV/AIDS is a chronic illness, and it's a lifelong treatment. Adolescents who are HIV positive need to know their HIV status and treatment. The World Health Organization (WHO) recommends that children should know their HIV status at the ages of 6 to 12 years. Many children living with HIV are reaching adolescence and young adulthood since anti-retroviral drugs have become more readily available (National AIDS Control Council, 2018). However, the most challenging subject among families of adolescents infected with HIV is whether or not to tell the adolescent about their diagnosis and, if they do, whether or not to allow the adolescents to say to others (Burmen *et al.*, 2017; SCHMT, 2018a). This cross-sectional study investigated the determinants of HIV status disclosure among HIV-infected adolescents. Caregivers of 209 HIV-infected adolescents (10-19 years) who have been receiving HIV care and support treatment for at least six months and are taking lifelong anti-retroviral therapy from Got Agulu Sub County Hospital, Bondo County Hospital, and Uyawu Sub County Hospital in Bondo Sub County were enrolled. A purposive and systematic random sampling method was used to select the health facilities and study participants. Data was collected using a structured questionnaire. Statistical analysis for quantitative data was done using Stata software version 15 (Stata Corp, College Station, TX). Adolescents aged 15-19 years were more likely to be fully disclosed to (aOR, 2.46, 95% CI 1.03-5.94, p-value=0.005<0.05). Those with low viral load levels were more likely to be disclosed to (aOR, 9.53, 95% CI 2.30-49.4, p-value=0.004). Adolescent caregivers who were married had significantly higher odds of fully disclosing (aOR, 5.43, 95% CI 1.25-27.5, p-value=0.030), same as caregivers who were biological parents (aOR, 4.84, 95% CI 1.34-19.5, p-value=0.019). Finally, caregivers who had been educated on HIV care and treatment package of care were significantly more likely to fully disclose (aOR, 14.1, 95% CI 4.03-62.3, p-value=<0.001). A high score in the quality of counselling results in an increased level of disclosure by 0.117. This study identified the age of the HIV-infected adolescent, the Quality of counselling service delivery offered to caregivers, current viral load levels of the HIV-infected adolescents, the marital status of the adolescent caregiver, the relation of the caregiver to the adolescent and the knowledge of the caregiver on the caregiver package of care on HIV prevention care and treatment as the factors determining the HIV status disclosure.

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LIST OF ABBREVIATIONS.

AIDS:	Acquired Immune Deficiency Syndrome.
ART:	Antiretroviral treatment.
ARV:	Antiretroviral.
PLHIV:	People Living with HIV.
NDW:	National data warehouse.
HIV:	Human immunodeficiency virus.
WHO:	World Health Organization.
HCWs:	Health care workers.
EMR:	Electronic Medical Records.
JOOUST:	Jaramogi Oginga Odinga University of Science and Technology.
JOOTRH:	Jaramogi Oginga Odinga Teaching and Referral Hospital.
ERC:	Ethics Review Committee.
CHMT:	County Health Management team.
NASCOP:	Nairobi. National AIDS & STI Control Program.
MOH:	Ministry of Health.
NACC:	National AIDS Control Council.
CCC:	Comprehensive care clinic.
KHIS:	Kenya Health Information System.
KENPHIA:	Kenya Population-based HIV Impact Assessment.
SPSS:	Statistical Package for Social Sciences.
UNAID:	United Nations Agency for International Development.
EGPAF:	Elizabeth Glaser Pediatric AIDS Foundation.
ICAP:	International Center for AIDS Care and Treatment Program.

CHAPTER ONE: INTRODUCTION

1.1: Background information

Globally, it is estimated that 81% of people living with HIV know their HIV status, and more than two-thirds (67%) are on lifelong antiretroviral therapy. This translates to an estimated 25.4 million on ART out of the 38.0 million people living with HIV. This number has more than tripled since 2010 (UNAIDS, 2019). In 2020, about 1.75 million adolescents between the ages of 10 and 19 were living with HIV accounting for 5 % of all people living with HIV and 11 % of new HIV infections worldwide (UNICEF, 2021). Adolescents represent a growing number of people living with HIV worldwide (Peralta & Rudy, 2016). In 2020 alone, 410,000 adolescents and young people between the ages of 10 to 24 were newly infected with HIV, of whom 150,000 were between the ages of 10 and 19. To compound this, most recent data indicate that only 25% of adolescent girls and 17% of adolescent boys aged 10-19 in Eastern Africa, a region with a high burden of HIV, have been tested for HIV and received the result of the last test (UNICEF, 2021).

Kenya is among the sub-Saharan countries with a high prevalence of HIV/AIDS. 1,617,707 (4.9%) people are living with HIV in Kenya. Among these are 184,700 (16%) adolescents between the age of 10-19 years (KENPHIA, 2018; NASCOP, 2018b), with a national prevalence of 0.9%. Siaya County has an HIV prevalence of 15.3%, while Bondo Sub County in Siaya County has a prevalence of 24.8% among the general population (KENPHIA, 2018; SCHMT, 2018a) with a total number of 17,355 adults and 927 adolescents living with HIV (KHIS, 2021; NDWs, 2021).

Disclosure of HIV status as part of HIV prevention is the process of telling your HIV-positive status to a Health care worker, sexual partner(s), children, family members, or other people in your social circle. The disclosure process typically occurs gradually (Dessalegn *et al.*, 2019). The method of disclosure can occur in two ways; A caregiver or a biological parent can decide to tell a child or adolescent about their positive HIV status, known as vertical disclosure, or an HIV-infected individual can choose to say to others about their HIV status is known as horizontal disclosure (Mandalazi *et al.*, 2014; Project, 2021). Disclosing HIV status to an infected child is not a one-time event. It is a continuous process which involves ongoing counselling and discussions about HIV and its treatment course as the child

grows and matures psychologically, socially, emotionally, sexually and cognitively (EGPAF, 2016).

Disclosing HIV-Positive status to children, adolescent patients, and family is a critical component of the HIV treatment cascade and crucial to the continuum of care for People Living with HIV. Despite the available documentation on the significance of disclosing HIV-Positive diagnosis, the rate of disclosure globally among pediatrics and adolescents who are infected and living with HIV remains very low (Guta *et al.*, 2020; Reif *et al.*, 2020; Vaz *et al.*, 2011). Despite disclosure being emotionally and socially complex, caregivers frequently experience uncertainty in telling their children about their HIV-positive status. This is largely due to fears about HIV-related perceived stigma and discrimination and the adverse emotional effects of disclosure due to disclosure (Toska *et al.*, 2015). Most caregivers report weighing the risks and potential benefits before deciding to disclose. This includes psychological problems, inability to comprehend and cope with the HIV diagnosis, perceived stigma and accidental disclosure to others (Wariri *et al.*, 2020). Various studies (Hatfield-TimajchyKendra *et al.*, 2016; Maseko & Madiba, 2020b) suggest that most children and adolescents who have been disclosed do not experience long-term adverse effects but benefit immensely from knowing their HIV status. A large percentage of adolescents in one study reported disclosure as a positive event for them (Beima-Sofie *et al.*, 2014; Wiener LS *et al.*, 2016). These adolescents reportedly had higher self-esteem than those not disclosed to.

Disclosure of HIV status to an adolescent has been shown to support the enrollment and uptake of lifelong ART, treatment adherence, and optimal continuum in HIV treatment (Ankrah *et al.*, 2016; Buregyeya *et al.*, 2017). Furthermore, timely disclosure of HIV - Positive status to children and adolescents presents a platform for maximized access to pediatric adherence and psychosocial support systems (PSSGs) available in the government and private health facilities and the community (Mburu *et al.*, 2014). The need for improved outcomes of treatment and high patient survival rate while on ART among vertically infected children and living with HIV has led to increased demand for the HIV -positive status disclosure from guardians, caregivers and healthcare providers (Dorrell & Katz, 2014). Caregivers who disclose HIV diagnoses to their children on time experience a positive impact from going through this process with them (Odiachi & Abegunde, 2016). Parents

who have disclosed their HIV-Positive status to their children experience less depression than those who delay telling (Lipson, 1994). Therefore, disclosure is believed to have favorable and favorable effects on all infected and affected individuals: the child, the parents, the guardian, the caregivers, the Health care worker and the family (S *et al.*, 2013).

In 2011, the WHO released a guideline on HIV status disclosure counselling for children and adolescents (WHO, 2011). This guidance is intended to be part of a comprehensive management approach to ensuring the physical, emotional, cognitive and social well-being of the developing child and adolescent following the diagnosis of their HIV-positive status. The HIV status disclosure guideline, alongside the toolkit for HIV-Positive Status disclosure targeting children and adolescents (EGPAF, 2016), recommends that the disclosure process should start when the child is six years old and be completed when the child is between the ages of 12–15 years through a structured and continuous process of engagement between the caregivers, clinical teams and professional counsellors. Before starting the process of disclosure among HIV-infected children, a readiness assessment test should be undertaken to gauge the readiness of the child for disclosure and the caregiver's willingness to disclose to undertake the process of disclosure (*Disclosure of HIV-Positive Status.*, 2015). These guidelines state that the health care worker and the caregiver should develop a disclosure plan that clearly shows the various steps to go through during the disclosure process. It says that specific factors should be considered during disclosure for each targeted child. (NHIC, 2015).

The decision of a caregiver to disclose or not the HIV diagnosis to a child or adolescent is based on several factors. Age and developmental maturity should be considered when determining whether a child is ready for disclosure, just like other chronic illnesses. Generally, older children are more likely prepared to be entirely made aware of their HIV status (Hossein Mohimani *et al.*, 2017). World Health Organization (WHO) guidelines recommend that children and adolescents of school age be fully disclosed their HIV-positive status. In contrast, younger children should be informed incrementally to accommodate their cognitive skills, and mental and emotional maturity, in preparation for full disclosure at an older age. It is also stated that before ten years, children will not be able to understand the information or deal with the stigma associated with the diagnosis (WHO, 2011). Other factors that significantly influence the decision to disclose HIV status include caregivers'

thirst to have their child improve and maintain excellent adherence to HIV treatment regimens, the level of knowledge on HIV disclosure among the caregivers, parents and guardians, The increasing age of the child, independence, concerns about adherence and sustainability of ART medication, and the general health status of the child on ART (Nzota *et al.*, 2015; Sophie Namasopo-Oleja *et al.*, 2015).

The HIV disclosure process for children who acquired HIV vertically and horizontally varies based on select contextual factors. Caregivers and parents of children who contracted HIV vertically (antenatal, perinatal and post-natal during breastfeeding) and were diagnosed with HIV at an early age are often aware of the HIV status of the child. They may decide to postpone or delay the disclosure process because they; fear the stigma associated with disclosure, not being able to discuss the infection mode, fear of being identified as the source of HIV infection and the feeling of guilt associated with it, fear of the child blaming them, or fear of rejection (Madiba & Mokgatle, 2017; Mandalazi *et al.*, 2014b). In contrast, horizontally infected adolescents (mainly through sexual activities, sharing of sharps and fluid exchange) require adequate counselling on home disclosure of their status and disclosure to their peers (Fetzer *et al.*, 2011). Despite documented evidence that HIV status disclosure is associated with improved health among children/adolescents and slowed HIV disease progression (Odiachi, 2017a), evidence from a recent systematic review shows that the majority of the children less than 18 years old living with HIV in resource-limited settings, including sub-Saharan Africa, are not aware of their own HIV status (Dellar *et al.*, 2015) with several reports indicating a deficient level of disclosure, especially in resource-limited settings (Bulali *et al.*, 2018). In one systematic review, HIV status disclosure ranged from 0% to 69% (Vreeman *et al.*, 2013a). Several barriers have been identified to be responsible for the low level of HIV status disclosure among children and adolescents by caregivers. In a study done in Malawi, despite enumerating the benefits of disclosing HIV status to infected children and adolescents, the caregivers felt unease. They were in a dilemma about disclosing (Mandalazi *et al.*, 2014). There is also evidence that parents/guardians opt not to tell because they are not sure of the child's reaction after disclosure and whether society will accept or reject them (Bulali *et al.*, 2018; Vreeman *et al.*, 2013a).

A study done in Western Kenya and Bondo SC in Siaya (Burmen *et al.*, 2017) showed that most caregivers who had delayed disclosure of HIV status to their children did so due to fears that society would judge them harshly. Equally, a report by the National Aids Control Council on Kenya's fast-track plan to end HIV and AIDs and achieve epidemic control among adolescents (NACC, 2015) conducted in Bondo Sub County recommended the need for routine caregiver education on disclosure through organized HCWs education, engagements with networks of persons living with HIV to train parents and caregivers on disclosure and treatment support for children and adolescents who are HIV infected and structured engagement of community health workers and community-based organizations to routinely providing education on young people to parents and caregivers living with HIV.

1.2: Problem statement

Disclosure of HIV status to adolescents is controversial and a sensitive issue among guardians, health workers, and parents of adolescents. However, HIV/AIDS is a chronic illness, and it's a lifelong treatment. Adolescents who are HIV positive need to know their HIV status and treatment. Failure to know this, problems with enrollment in HIV care, adherence to ART treatment and suboptimal continuity in treatment come in, which may predispose these adolescents to issues such as developing an ART drug-resistant strain of the virus and treatment failure (Peralta & Rudy, 2016).

Many children living with HIV and AIDS are reaching adolescence and young adulthood since anti-retroviral drugs have become more readily available in Bondo Sub County (National AIDS Control Council, 2018). However, the most challenging subject among families of adolescents who are infected with HIV in the Sub County is whether or not to tell the adolescent about their diagnosis and, if they do, whether or not to allow the adolescents to say to others (Burmen *et al.*, 2017; SCHMT, 2018a). In specific comprehensive treatment Centers in Bondo Sub County, some adolescent caregivers were known to request healthcare providers, not to mention HIV or AIDS, around their school-age children (Pavel, 2017).

Several documented factors affect parental disclosure of HIV status to HIV-infected adolescents in Bondo Sub County. Some of these are perceived stigma, perceptions like the anticipation of adverse psychological consequences, secrecy associated with HIV and factors that may be related to it, like mode of infection, denial by the parents of their own or

the adolescent's illness (SCHMT, 2018). Additionally, low disclosure of HIV status to children in Bondo Sub County is attributed to stigma, cultural values of the society, and service-related factors (MOH, 2019). However, it is worth noting that this report did not mention the actual disclosure rates among adolescents in each health facility in Bondo Sub County. Inadequate counselling by a professional on the disclosure process and socio-demographic factors like the educational level of the parent or guardian and the child's age are documented as some of the health healthcare-related affecting the disclosure process in Bondo Sub County (Odiachi, 2017). With the high prevalence and incident rates of HIV among adolescents living with HIV in Bondo Sub County (National AIDS Control Council, 2018), disclosure of HIV infection acquired perinatally is often delayed until the child is older enough. The anticipated problem of adverse psychological effects may manifest if the adolescent learns about their HIV status unsupportively. These include mental health issues, high defaulter rate to ART medication, lack of adherence to HIV treatment plans, rebellion, and increased school dropout cases (ICAP, 2016). The all-important psychosocial and social support may be missed by adolescents if they are not informed about their HIV status. In this regard, parents, caregivers and guardians must disclose the HIV status to the adolescents on time. However, there are available interventions to deal with the problem (ICAP, 2016). Few guidelines, policies or empirical-based interventions are available to assist parents, caregivers and providers in making decisions about disclosure (EGPAF, 2016).

1.3: Objectives

1.3.1: General objective

To determine the rate and factors affecting caregiver disclosure of HIV status to adolescents infected with HIV in Bondo Sub County.

1.3.2: Specific objectives

1. Investigate the rate of caregiver disclosure of HIV status to adolescents infected with HIV in Bondo Sub County.
2. Investigate the factors affecting disclosure of HIV status by caregivers to adolescents infected with HIV in Bondo Sub County.
3. Investigate the extent to which HIV status disclosure to HIV-infected adolescents is affected by the quality of counselling.

1.4: Research questions

1. What is the rate of caregiver disclosure of HIV status to adolescents infected with HIV in Bondo Sub County?
2. What factors affect caregiver disclosure of the HIV status of adolescents infected with HIV?
3. To what extent does HIV status disclosure to HIV-infected adolescents affected by the quality of counselling?

1.5: Assumptions of the Study

The following hypotheses guided the research; the respondents gave accurate and honest responses to the questionnaires. Secondly, the respondents provided the required information.

1.6: Significance

The findings of this study will significantly build literature for Kenya in the domain of HIV status disclosure and assist in developing knowledge on factors affecting HIV diagnosis disclosure and non-disclosure by guardians, parents and caregivers of HIV-infected adolescents in Bondo Sub County and build the foundation for more research on this matter. Furthermore, this study's findings will be used for intervention while managing HIV-infected adolescents, especially when developing age-specific and culturally relevant adolescent HIV diagnosis and disclosure guidelines in HIV comprehensive care clinics in Bondo Sub County in Kenya. The study is expected to contribute to the answers to some of the questions related to disclosing HIV diagnosis to adolescents, given the high number of adolescents who are infected and living with HIV and are taking lifelong ARTs. This will enhance interventions to improve prompt disclosure, a critical step in HIV management. Equally, understanding the barriers to the disclosure will allow stakeholders to step up efforts to circumvent the same. This will help dispel myths and negative perceptions among parents and caregivers that may hinder adequate disclosure. Finally, establishing the role of the quality of counselling on parental disclosure will improve the interaction between counsellors, parents and adolescents, further enhancing the management of HIV, especially among adolescents.

1.7: Justification

This study is the first in relation to building literature for reference in Bondo Sub County in the domain of HIV status disclosure among adolescents living with HIV by their caregivers. The HIV status disclosure process to adolescents who are infected and living with HIV in Bondo Sub County is a field that is still grossly under-studied. This has resulted in a gap in ascertaining the determinants of HIV status disclosure by the caregivers to adolescents that are infected and living with HIV. Few studies on the subject of disclosure have been done in Bondo sub-counties. A comprehensive search for the information on adolescent disclosure requested only yielded one publication time on HIV testing of sexual contacts identified by HIV-positive index clients in Siaya County, Kenya (Wekesa *et al.*, 2020). Which generally addressed the time to disclosure among newly identified HIV-positive patients in Bondo Sub County. This study, however, did not address the determinants of HIV status disclosure by caregivers among adolescents infected with HIV, both in the context of vertical or horizontal HIV infection.

It is envisaged that this research will be able to contribute valuable information that will guide the Sub County, County and national plans and strategies for effective disclosure and counselling plans for caregivers, parents, guardians and HIV-infected adolescents before and during the process of disclosure.

Additionally, the methodology and the research outputs are associated with the justification of the research. The research methodology and design used will add to the intellectual knowledge of the research, particularly for researchers who wish to conduct a similar or much wider study.

1.8: Limitations of the study

Every research has some limitations. This research had a few limitations, such as those based on the research methodology and design, that should be considered when analyzing and interpreting the study results. The study focused only on adolescents infected and living with HIV who are receiving long-acting antiretroviral therapy. Caregivers of adolescents infected by HIV who were not receiving long-acting antiretroviral therapy or had not been enrolled in the comprehensive HIV care and treatment program were not included in the reference population.

1.9: Strengths of the study

Despite these limitations, this study had notable strengths. Using Kenya EMR as a data collection tool ensured that the data generated was accurate, up-to-date, and had complete information about the adolescents and their caregivers at the point of care. In addition, it enabled the researcher to have quick access to patient records in a more coordinated manner and enhanced the privacy and security of patient data.

1.10: Definition of terms

HIV status Disclosure: Informing HIV-infected adolescents about their HIV sero -positive status by the caregiver. This involves telling them that they are infected with HIV (vertical disclosure) or encouraging them to tell others about their HIV status (Horizontal disclosure).

KENYAEMR: KenyaEMR is a customized clinical health management tool that is developed through integration and development of software modules built upon OpenMRS which is currently used as a clinical and reporting tool in Bondo Sub County. It was designed and developed by expanding on the OpenMRS platform to build an electronic medical reporting system (EMR) to collect health data and improve patient care.

Caregiver: A person, who lives with the adolescent receiving HIV care and treatment services in Bondo Sub County, participates in the adolescent's daily care and is the most knowledgeable about the adolescent's health. They were either biological parents or guardians like aunt, adoptive parent acting as surrogate parents to the child.

Vertical HIV transmission: Vertical transmission (VT) of HIV is defined as that occurring from mother to child during gestation, delivery, or breastfeeding.

Horizontal HIV transmission: Horizontal HIV transmission may be healthcare-associated (infusion of HIV-contaminated blood products, use of contaminated needles, syringes and medical equipment, or through ingestion of HIV in expressed breastmilk) or as a result of unprotected sexual intercourse.

Factors Influencing: They are the things (situations, conditions, state etc.), that contributes or has an influence on the outcome of something.

Adherence: Is taking all the ARVs in the correctly prescribed doses at the right time and in the right way observing any dietary restriction.

Health Facility: It is a place that provides health care services. In this study, Bondo County Hospital, Uyawi Sub County Hospital and Got Agulu Sub County hospital clinic where HIV infected adolescents, access psychological, social and clinical HIV treatment and care were used.

Prevalence: The number of affected persons present in the population at a specific time divided by the number of people in the population at that time.

P-Value: This is the level of significance within a statistical hypothesis test and is a representation of the probability of the occurrence of a given event.

CHAPTER TWO: LITERATURE REVIEW

2.1: Introduction

In general, the decision to disclose one's HIV status to another person or not is subjective. This is because disclosing the HIV-Positive status to others is always difficult and stressful. HIV status disclosure has been associated with improved mental health, psychological well-being, physical health, and good health-seeking behaviors. People's experiences and coping skills with diseases are reflected in their choice (Hult *et al.*, 2015). HIV status disclosure can be conducted at different stages, i.e., to family, relatives, siblings, spouses, children, employees or sexual contacts (EGPAF, 2016). The specific interest of this study is on the disclosure of HIV-Positive status by caregivers to an HIV-infected adolescent on lifelong anti-retroviral drugs. Some HIV status disclosure theories show that despite the benefits of disclosure when it is not handled well, it can be costly to family relationships, influence one's social acceptance, and elicit adverse reactions. Distressing information can particularly elicit negative judgmental thoughts and harsh responses, resulting in low social support from society. (Hult *et al.*, 2015).

2.1.1: Definitions Disclosure

WHO defines disclosure as Informing HIV-infected persons living with HIV about their HIV-Positive status. This can be done by telling them that they are infected with HIV (vertical disclosure) or the HIV-infected individual telling others about their HIV-Positive status (Horizontal disclosure). Disclosure leads to proper medication adherence and helps HIV-infected people to cope with the anxiety associated with HIV infection and its lifelong treatment. Complete HIV-Positive status disclosure process should be delayed until after ten years of age because it is believed that before this age, children cannot comprehend or deal with the stigma associated with the HIV diagnosis and treatment; however, disclosure status starts at six years (EGPAF, 2016; WHO, 2011).

WHO defines adolescence as the period when an individual is 10- to 19 years old (WHO, 2020). It also defines young people as individuals between the ages of 10 and 24. Children are defined as those who are under the age of 10 (WHO, 2014). HIV status disclosure is a continuous process and not a one-time event involving discussions about the HIV disease as the children mature cognitively, socially, emotionally, and sexually (Disclosure & You, 2021).

2.1.2: The Disclosure Process

Healthcare team and caregiver involvement form part of the general principle of HIV status disclosure. The process of disclosure should be progressive and usually flexible. It should remain sensitive to the feelings of the family and the individual needs as they navigate through the stages of disclosure. The decision on whether or not to disclose the HIV-Positive status of an adolescent to the adolescent by the caregiver should be supported by the health care providers. (Disclosure & You, 2021). HCWs should give a precise and relevant explanation of HIV illness, diagnosis and treatment during disclosure. The timing of disclosure should be different from those with critical social events such as birthdays, weddings, graduation, etc. Despite promoting sharing of feelings, disclosure should also appreciate silence. It is the role of HCWs to encourage adolescents to make inquiries during the disclosure process. Developmentally relevant educational tools should be employed appropriately if available.

2.1.3: Special Issues to be considered when Disclosing HIV status to an Adolescents

Adolescents who are HIV-infected fall into two categories that are based on the mode of HIV transmission. Some contract HIV during infancy or pregnancy, referred to as vertical or horizontal transmission, primarily through sexual contact in the teenage. Adolescence is a challenging development period marred by appreciable physical, biological, social and sexual changes. Adolescents tend to take on more life responsibilities and health during this period. They often want to assume more autonomy and adult roles and behaviors (Jameson, 2015). A typical adolescent with the normal developmental milestone should be fully aware of their HIV -Positive status and begin to address their health needs associated with it. However, it is the role of the healthcare workers to encourage adolescents to seek the support of their parents, guardians and caregivers where possible.(E Gyamfi *et al.*, 2015).

The HIV prevention care and treatment guidelines highlight that adolescents should be fully aware of their HIV-Positive status at the right time.(EGPAF, 2016; NASCOP, 2015). Proper support should be given to caregivers who find it difficult or decline to disclose their HIV-Positive status to adolescents while addressing their concerns. The HCW should assess the knowledge of the adolescent on HIV and their health or illness, which in turn will guide the discussions around the health of adolescents and sexual and reproductive health issues(Kalembo *et al.*, 2018).

2.1.4: Types of disclosure

About the HIV status disclosure tool kit for children, adolescents and adults, there are five categories of disclosure: non-disclosure, full, partial, deception and accidental (Eric Gyamfi *et al.*, 2017a). Full disclosure provides all information and knowledge about HIV disease. Complete non-disclosure is maintaining complete secrecy around the HIV disease by not disclosing the actual picture and real information regarding the illness. Accidental disclosure is telling the child about their HIV-Positive status without thoroughly preparing. It involves disclosing by accident, and it's usually done unintentionally. This can happen when the HIV diagnosis of the adolescent is being discussed among other people, and they overhear. HCWs should look at least partial disclosure to the adolescent in cases of Accidental disclosure. HCWs should appropriately undertake readiness assessments for the adolescents' parents or caregivers (Eric Gyamfi *et al.*, 2017a). Deception means ascribing the condition of the adolescent to a different disease. Sometimes it involves or links the adolescent's behavior and appearance (e.g., not getting enough rest), which are frequently associated with non-disclosure (EGPAF, 2016; Kiwanuka *et al.*, 2014).

Sometimes, disclosure was often viewed as a single binary event by researchers. However, it is now increasingly seen as a process of moving from the point of non-disclosure to full disclosure. Full disclosure may occur in a single encounter; however, it is commonly a continuous ongoing process that is undertaken as the child develops spiritually, cognitively, and psychologically and increases awareness about the meaning of death and diseases (Wiener *et al.*, 2007). Most researchers have shown that HIV status disclosure is most successful when it is mapped accurately to the emotional and cognitive development of the child. (Bibace & Walsh, 1980). When the child is younger, partial disclosure is often preferred since the specifics of HIV disease might not make sense or hold meaning to them. Children who experience developmental challenges and cognitive limitations have unique considerations when processing the diagnosis. Such cases require multiple sessions for the child to comprehend HIV disease and its consequences fully (Wiener *et al.*, 2007)). The age of the child, Its maturity, and family dynamics are not the only considerations when disclosing but the clinical context too. (Eric Gyamfi *et al.*, 2017a).

2.2: Global HIV disclosure rates of HIV-Infected Adolescents

The prevalence of HIV disclosure rates varies significantly among countries where this study has been undertaken. A study conducted in India showed a disclosure rate among adolescents living with HIV of 14% (Arun *et al.*, 2009), while in Nigeria, it showed a disclosure rate of 13% (Enobong & Ofonime, 2016). A study by Vreeman *et al.*, 2013 showed that over 77% of adolescents older than ten had been fully disclosed. Also, a prospective cohort study showed that 57% of 10–19-year-olds already knew they were HIV-infected (Baker *et al.*, 2018). Better education of caregivers on the importance of HIV status disclosure was some of the reasons for the better disclosure rate observed in resource-rich countries.

Data reviewed from the two independent studies conducted in South Africa and Ghana showed that few adolescents living with HIV were aware that they were HIV-infected (Eric Gyamfi *et al.*, 2017). In other studies, the disclosure rate is as low as 9% (Kallem *et al.*, 2011) and 21% (Madiba, 2012) in Ghana and South Africa, respectively. It is worth noting that these studies did not seek to establish the barriers to HIV status disclosure among children. Results among people living with HIV in resource limited countries show that the primary determinant of the decision to disclose the status of terminal diseases such as HIV is the thirst to protect the family from shame from society. This is because certain illnesses are traditionally considered shameful or are caused by the supernatural when one offends the ‘gods’ in some communities (Madiba, 2012).

2.3: HIV Status Disclosure rates in Kenya

Disclosure rates in Kenya are documented to vary depending on age. A study to determine HIV status disclosure among young adolescents living with HIV in Kenya revealed that the disclosure rate among adolescents between the age of 10–14 years on ARTs in the 51 considerable HIV prevention, care and treatment facilities in Kenya health facilities from November 11, 2004, through March 30, 2010, was 36.6% (Daniel E Shumer, 2017). This study gave insights into the overall full disclosure rates and the treatment outcomes of young adolescents taking ART in Kenya. The rate of HIV status disclosure among adolescents was shown to be low in Kenya. It likely reflected the lack of standard national guidelines on disclosure to be used in the earlier phases of disclosure in Kenya, where the study was conducted.

A cross-sectional study of disclosure of HIV Status to children who are HIV infected in western Kenya targeting children between the ages of 6–14 years attending the HIV clinics in western parts of Kenya showed a disclosure rate of 26%. This varied significantly by age (Vreeman *et al.*, 2014). This study concluded that few HIV-positive children living with HIV in Kenya know their HIV status. Further, the likelihood of disclosure is associated with other psychosocial and clinical factors. The study equally recommended that more data on disclosure is needed to assess its impact on children.

A study on Adolescent transition to adulthood for HIV-infected adolescents in Kenya (ATTACH): study protocol for a hybrid and effectiveness in the implementation of randomized cluster trial in 11 HIV clinics with an estimated 100 adolescents and young adults who were aged 10–24 living with found that full disclosure rates among adolescents range from 0% to 62% (Njuguna *et al.*, 2020). The study recommended complete disclosure interventions for adolescents over 15 who are yet to be informed of their ailment.

2.4: Rates of HIV Status Disclosure in Bondo Sub County.

Studies on the rates, patterns or process of disclosure of HIV status among adolescents infected with HIV in Bondo Sub County could not be found after a comprehensive search. However, a study on factors influencing the management of antiretroviral in school-going children – a case of Nyang’oma Mission Health Centre, Bondo Sub County, Siaya County showed that despite ARTs being proven successful in school-going children making them live everyday life, families are still facing challenges of stigma and lack of disclosure amid other challenges leading to poor treatment outcomes among school going children (Night *et al.*, 2013). This study, however, did not evaluate determinants or rates of disclosure among the children studied.

2.5: Factors affecting Adolescent HIV status disclosure

Adolescent caregivers may or may not disclose to the adolescent their HIV -Positive status. This can be due to several factors, namely, Society, age, cultural beliefs, sex, race, gender, relationship status, socioeconomic factors, culture, educational level, perceived benefits, Perceived risks and adequacy of social support systems.

2.5.1: Benefits of HIV disclosure

A positive attitude towards HIV infection and transmission is a known benefit of disclosure. Some parents or guardians feel it is essential to let adolescents know their HIV status because they might otherwise get involved in risky sexual behavior, thereby endangering themselves and others (Mbalinda *et al.*, 2015).

Anticipation of good treatment outcomes and treatment adherence is a known benefit of disclosure. Some parents or guardians decide to let the adolescents under their custody know their HIV status in the hope that they will have better treatment outcomes. This is because, by full disclosure, they hope the adolescents will be motivated to adhere to ART and all other supporting treatments (Mengesha *et al.*, 2020).

The promotion of positive living with HIV is a known benefit of disclosure. Some parents and caregivers believe that providing relevant and truthful explanations of the illness validates the adolescent's concerns about the unknown about HIV or fears for worse diagnoses, e.g. cancer that can lead to imminent death. It also clears misconceptions about HIV disease and prepares the infected adolescent to deal with the stigma associated with it. Some of these caregivers also believe that disclosure provides ongoing support that enables planning for life with HIV productively. It also improves adherence to ART medication among adolescents likely to experience faster disease progression (Ingabire & Mutesa, 2014).

2.5.2: Risks of HIV status disclosure

Adolescents who are perceived to be young suffer adverse psychological effects regarding HIV. Some of the reasons for non-disclosure are the concerns about the impact of disclosure on the adolescent's emotional status and their ability to cope with its consequences. (Orban *et al.*, 2015). The feeling that adolescents need to be as accessible as possible has contributed significantly to non-disclosure. This is coupled with the desire not to hurt the adolescent. (WHO, 2014). Caregivers of older adolescents report that it is easier to disclose than younger ones (Nzota *et al.*, 2015). The burden imposed on adolescents since HIV is a terminal disease is a worry for many caregivers. This makes them choose to keep it a secret for fear of stigma or rejection. (Emmanuel *et al.*, 2020). Some biological parents feel guilty about being

responsible for transmitting the disease to their child, hence the reluctance to disclose.(Nabunya *et al.*, 2020).

2.5.3: Risk of HIV non-disclosure

Research conducted in some parts of the world shows that some biological parents have a firm conviction that adolescents should only be told about their HIV status by their parents. This notion has motivated many parents to offer disclosure services to their children. (Waugh *et al.*, 2010). This has resulted in adolescents learning about their HIV-Positive status in a non-supportive manner. These adolescents are also likely to lose trust in their parents if they know about the disease, they have from sources other than their parents and henceforth might not be able to confide in them. They might also need to conceal what they know from their parents.

2.5.4: Other Factors Affecting HIV Disclosure

HIV-negative caretakers and guardians usually disclose an adolescent's HIV status early (Madiba & Mokwena, 2012). HIV-negative caregivers do not have to deal with the possible guilt that they are the source of the infection or worry about their HIV status being disclosed to others by the adolescent.

Parents who deny their HIV-Positive status equally find it difficult to disclose because they still are unable with their illness (Zanoni *et al.*, 2021). Denial makes parents unable to deal with their HIV -Positive infection or that of other family members. It is difficult to carry the extra burden of disclosure and its possible consequences for parents in denial (Maseko & Madiba, 2020).

Caregivers of HIV-infected adolescents and adolescents need health education and professional counselling to be ready for HIV status disclosure (ICAP, 2016; WHO, 2011). The counselling they receive will prepare them psychologically to deal with the consequences of disclosure. Sometimes the quality of counselling they receive is never adequate for the task. In Kenya, families are encouraged to consult and engage Health care workers while preparing and during the process of disclosure of HIV(NASCOP, 2018). However, the ministry acknowledges this challenge because few specialized adherence counsellors are currently engaged (National AIDS Control Council, 2018). Some caregivers have reported that they are tired of keeping the HIV-Positive status of their children a secret

as the reasons for disclosure. However, those who feel that adolescent has a right to know about their HIV have equally disclosed it (Baker *et al.*, 2018).

In some areas, cultural factors affect HIV status disclosure, e.g. in a study conducted in Zambia; families did not disclose on time because the cultural practices dictate that elders should sensor the information they give to children(Ojikutu *et al.*, 2016). Findings from a study on HIV disclosure facilitation in diverse settings of western countries promote open communication about many issues, unlike the standard practice in most African Countries (Obermeyer *et al.*, 2011). Residential areas equally affect disclosure, with research comparing the disparity between the rural and urban settings clearly showing a difference in disclosure. People living in urban settings are more likely to disclose on time than their rural counterparts (Thior *et al.*, 2020).

2.6: The Community barriers to HIV status disclosure

Communities play a significant role in ensuring access to HIV treatment services. However, there are barriers to HIV status disclosure in the communities. These barriers include feelings of guilt by parents and more (Emmanuel *et al.*, 2020), discomfort among caregivers on disclosing Positive HIV status to children, the bad sense of hurting the innocence of childhood, the belief that some adolescents are too young to comprehend HIV disease, (Vreeman *et al.*, 2013) and the concerns of damaging the psychological status of the adolescents. Other include fear of developing low self-esteem, fears of facing rejection, fears of being able to keep the information private and fears of facing stigmatization from the society.

2.7: Conceptual Framework.

The conceptual framework was defined by Burns and Grove (2009:126) as an abstract and logical structure that provides meaning. It is deployed to guide the development of the study. It enables the researcher to link the study's findings to the empirical body of knowledge reviewed. This conceptual model (Figure 2.1) was guided by the Disclosure Processes Model theoretical perspectives (Chaudoir & Fisher, 2010) and the reviewed findings on 28 HIV disclosure studies in the adolescent population living with HIV. The relationship between predictor variables and HIV- Positive disclosure to HIV-infected adolescents living with HIV is illustrated in this model. Disclosure is the primary outcome of interest for the study.

Conceptual Framework

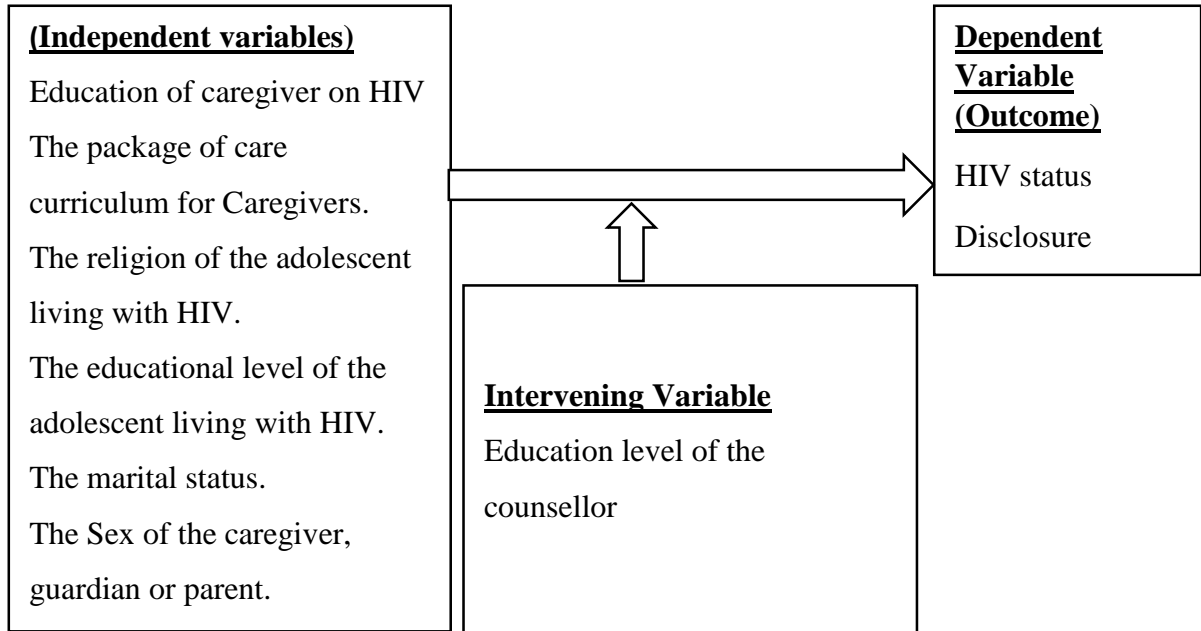


Figure 2.1: Study Conceptual Model

CHAPTER THREE: METHODOLOGY

3.1: Study design

This was a cross-sectional study. It was conducted in 3 Health facilities in Bondo Sub County in Siaya County. The three government health facilities routinely provide integrated HIV prevention, care and treatment services to PLHIV per the guidelines issued by the Ministry of Health of Kenya (NASCO, 2018). The HIV prevention, care and treatment services offered in these facilities target infants, orphaned and vulnerable children, adolescents, young people, general population pregnant and breastfeeding women, and key and priority populations.

3.2: Study area

This study was conducted at the three government Health facilities with HIV comprehensive care clinics (CCC) in Bondo Sub County in Siaya County. These facilities were: Bondo County Hospital, Got Agulu Sub County Hospital and Uyawu Sub County Hospital. Siaya County is in the southwest part of Kenya. Kakamega County and Vihiga County border it to the northeast, Busia [County](#) to the north, and Kisumu County to the southeast. It shares a water border with Homa Bay County, located south of Siaya County. The total area of the county is approximately 2,496.1 km². The County lies between latitude 0° 26' to 0° 18' north and longitude 33° 58' east and 34° 33' west with a Population of 985,400 (KNBS, 2019). Siaya County has seven sub-counties: Ugenya, Bondo, Rarieda, Alego Usonga, Gem Yala, Gem Wagai, and Ugunja sub-counties (SCHMT, 2018a).

Bondo Sub County covers an area of 1972 square kilometers. Nine hundred seventy-two square kilometers is land surface while about 1000 square kilometers is covered with water. This water body is Lake Victoria, the second-largest freshwater lake in the world. KNBS estimates the population of Bondo Sub County as of 2019 was 214 541. (KNBS, 2019). Of these, 100, 259 were males, and 114, 282 were females.

Bondo Sub County lies on the shores of Lake Victoria on the northern side. It lies within latitudes of 0.0°24' S and 0.0°02' N. It lies within Longitudes 34°0.0' W and 34°26' E. It is divided into six administrative units (wards): North Sakwa, West Sakwa, West Yimbo, Yimbo East, Central Sakwa, and South Sakwa. Lake Victoria's shores bound River Yala on the south. The river also runs its border with Alego Sub-County on the north (SCHMT,

2018a). The rain patterns in the Sub County experience bimodal rainfall. It starts with short rains between the Months of August and November, relief and altitude influencing its distribution and amount. Bondo Sub County is wet in the higher altitudes in the Eastern part and dries towards Rarieda Sub County in the western side. The sub-County has various soil types ranging from sandy loams and black cotton to laterite, including red volcanic soils.

Ferrasols are found in South Nyang'oma, West Sakwa, and Usigu locations. Central Yimbo and North Sakwa, East have luvisols with low, moderate fertility. The Sub County is divided into scattered highlands such as Got Abiero and Sirafuongo in Nyang'oma areas, Got Ramogi and Usenge in Usigu areas, the lowlands of Yala Swamp and the plains in Uyoma. These result in differences in soils, relief, and land use. These features give the Sub County an altitude rise between 1141m and 1401m above sea level. Some old exposed volcanic rocks that cover the region geologically are basalt, elite and rhyolite. The people in this Sub County are mainly subsistence farmers, livestock keepers, fishermen, and small-scale traders. The Sub County has other strengths, including natural resources like rivers, indigenous forests, fishing waters and agricultural land. The main tourist attractions include Lake Victoria.

HIV prevalence for Siaya County stands at 15.6%, while that of Bondo Sub County stands at 24.8% among the general population (KENIPHIA 2018). Seventeen thousand three hundred fifty-five adults and 927 adolescents are living with HIV (KHIS, 2021; NDWs, 2021) in Bondo Sub County. The three facilities selected for the study have a higher number of an adolescent who is living with HIV at 438, representing 47% of the total adolescents in the Sub County with facility distribution as follows; Bondo County Hospital 241, Got Agulu SCH 96 and Uyawu SCH 101 (NDWs, 2021).

3.3: Target population

Caregivers of HIV-infected adolescents (10-19 years) who have been on treatment, are infected with HIV for at least six months, and are taking lifelong anti-retroviral therapy in the three selected facilities were targeted in this study. Caregivers provide day-to-day home-based care activities for Children and adolescents living with HIV. They could be Primary Caregivers (also known as a principal caregiver) or secondary caregivers.

3.3.1: Groups of Caregivers

Caregivers are grouped as Primary Caregivers (also known as a principal caregivers) or secondary caregivers. Primary caregivers provide day-to-day home-based care activities for adolescents living with HIV. They include biological parents, relatives, spouses/partners, friends and volunteers, support group members or community health workers staying with the patient. Secondary Caregivers are people thought of as ‘specialists’ of certain types of care who are trained for the care they provide. They include; Health professionals, social workers, spiritual counsellors, behavioral specialists, and nutritionists. This study targeted primary caregivers only.

3.3.2: Role of primary Caregivers

Primary caregivers have the following roles on the adolescents who are infected and living with HIV: Providing HIV and AIDS treatment and support (feeding, bathing, toileting) where the need arises, giving medication, monitoring the use and educating on adherence to treatment, supervising ART medication and other treatments, providing education on nutrition, hygiene and preventive care, linking clients with other care members as the need arise, i.e. link with the appropriate spiritual care team, counsellor, other care members, doing Follow-ups on the children or the adolescent’s school performance. Caregivers should be staying with the adolescent.

3.4: Inclusion criteria and exclusion criteria

3.4.1: Inclusion criteria

1. Adolescent caregivers who were of the age of 18 and above,
2. Caregivers who were physically staying with the adolescents participated in the preparation of the adolescent treatment plan and regularly monitored the treatment of the adolescent by giving and monitoring medication
3. Caregivers who regularly followed up on adolescents’ school performance and routinely accompanied the adolescent to the clinic were included in the study.

3.4.2: Exclusion criteria

1. Adolescents’ caregivers who were below the age of 18,
2. Caregivers who did not stay with the adolescent

3.5: Sampling Procedure.

Yamane's (1967) formula was used to calculate the sample. The purposive sampling method was used to select the three facilities of study, and systematic sampling was used to determine the participants from the known population size as described below:

3.5.1: Purposive sampling.

A purposive sampling method was used to identify the three facilities among the 26 government-supported Health facilities offering HIV care and treatment services to adolescents in Bondo Sub County. This was done considering that the three facilities contributed to 47% of the total number of adolescents taking HIV care and treatment services in Bondo Sub County and hence had higher adolescent patient concentration. Additionally, these were the only facilities that had more than 70 adolescents enrolled and getting ART.

3.5.2: Determining the ideal sample size.

Of the 438 adolescents between the ages of 10 -19 enrolled in HIV care and treatment services and taking lifelong anti-retroviral therapy in the three selected facilities, Bondo County Hospital contributed a proportion of 55% (241), Uyawu Sub County Hospital 23% (101) and Got Agulu Sub County Hospital contributed a ratio of 22% (96). From the list of the 438 adolescents, 438 caregivers were enlisted, translating to 1 caregiver for each adolescent. This translated to a known population size of 438 caregivers.

Yamane's (1967) formula was used to determine the ideal sample size (Yamane, 1967):

$$n = \frac{N}{1 + N(e)^2}$$

n represents the sample size

N represents the known population size (438)

e represents the level of precision or sampling error which was set at .05

$$n=438/1+438(0.05*0.05)$$

$$n=438/1+438(0.0025)$$

$$n=438/1+1.095$$

$$n=438/2.095$$

$$n=209$$

3.5.3: Systematic random sampling

Systematic random sampling was used to select the 209 participants per the calculated sample size from the 438 caregivers in the known population size. As stated above, the 209 participants were initially assigned to the 3 facilities based on their proportional contribution to the known population size (sampling frame). Therefore, Bondo County hospital got 55% of the 209 translating to 115 participants; Uyawi got 23% translating to 48 and Got Agulu got 22% translating to 46 study participants.

All the caregivers in the known population size (sampling frame) from each facility were listed, each assigned a unique computer-generated code. After that, systematic sampling was done as follows. To get the 115 participants in Bondo County Hospital, the known population size (sampling frame) of Bondo County hospital was divided by the sample size from Bondo County Hospital I e ($241/115=2.09$); therefore, every 2nd member of the sampling frame was selected to be the study participant.

To get the 115 participants in Uyawi Sub County Hospital, the known population size (sampling frame) of Uyawi Sub County Hospital was divided by the sample size from Uyawi Sub County Hospital I e ($101/48=2.10$); therefore, every 2nd member of the sampling frame was selected to be the study participant.

To get the 115 participants in Got Agulu Sub County Hospital, the known population size (sampling frame) of Got Agulu Sub County Hospital was divided by the sample size from Got Agulu Sub County Hospital I e ($96/46=2.08$); therefore, every 2nd member of the sampling frame was selected to be the study participant.

3.6: Research instruments

A structured questionnaire containing close-ended questions to collect dichotomous and polytomous nominal data was used in this study. The questionnaires were administered to the participants through a face-to-face interview. The questionnaires were prepared in both English and Dholuo. The respondent's information sheet and the consent forms were available in English and Dholuo. The questionnaire was divided into three sections. The first section addressed the demographic characteristics of the adolescents and the caregivers, where information about age, residence, marital status, education levels, religion and caregiver /adolescent relation were collected. The second section addressed the adolescent's Knowledge of HIV status, including the information they have on HIV and who gave them

the information. The last part assesses the psychosocial, cultural and service-related factors to disclosure, including stigma, secrecy, clinical perceptions, infection prevention and availability of counselling. To assist the participants in opening up quickly, a rapport was established.

3.6.1: Pre-testing methods.

A pretest of the study questionnaire was conducted among 21 (10%) respondents in a non-sampled area two weeks before the actual data collection in a pilot study. This was to test the consistency, understandability, and flow of questions. Results from the pretest confirmed the questions were understandable, from the content and the required logistics of completing the questionnaire. The Questionnaires were thoroughly edited to ensure that relevant questions were responded to and coded according to the code designed for the study. The training was conducted for the research assistant for three consecutive days. The training mainly dealt with the purpose of the study, handling ethical issues during data collection, and the method of data collection using the structured questionnaire. The research assistants checked for the completeness of each questionnaire at the end of each interview. The researcher rechecked for completeness of the questionnaire daily of submission. The eligibility criteria were also applied to these participants during the pretest pilot study. If a participant decided they would not participate in the study, they were easily excused. The pilot study was conducted in a private room that ensured confidentiality.

3.6.2: Determining Validity and reliability

The face validity of the instruments was tested using a pretest in a pilot study. Structured questionnaires were used to obtain the required information. The document was prepared professionally and appeared uncomplicated to use and complete. The pretest pilot study results were consolidated and analyzed by a professional statistician. The statistician established whether the construct validity was usable and appropriate for statistical purposes. The statistician confirmed the statistical validity and feasibility of the final questionnaire to be used. The study data analyzed did not contain data obtained from the pilot study. The pilot study participants did not form part of the main study. Reliability was further determined after conducting the pretest and ensuring that the captured data and the questions asked were relevant. Only some changes were ultimately made to the questionnaire used in the study.

3.7: Data collection procedures

Data on the 438 adolescents between the ages of 10 -19 and their caregivers from the three health facilities were collected from the routine documentation of services which is done at the point of care through the use of an electronic medical records (EMR) system known as KenyaEMR (version 18.0.1) by the health care workers. KenyaEMR is a clinical health management tool developed through the integration and development of software modules built upon OpenMRS (OpenMRS, 2021).

Data in the EMR database was synchronized monthly to a central data warehouse for archiving and developing new program interventions. A SQL script with all the variables was created, and data were extracted from the data warehouse in an excel file. The variables extracted included: Name, gender and a unique number of adolescents, Viral load results and name and locator information of the caregiver.

Study participants were invited using the caregiver information in the locator forms. Data from the study participants were collected using a structured questionnaire. Microsoft Office Excel was used to capture the findings. The principal investigator and a qualified research assistant collected data from the study participants in a private room dedicated to the study. The private room assured confidentiality to the participants. After explaining the study to each participant, they were given a respondent's information Sheet (Appendix II). The investigator confirmed the participants that their participation was voluntary. Further, he assured them that the study would maintain their anonymity and confidentiality. The questionnaire was anonymous and coded with a participant's unique number. The participants were encouraged to make any inquiries about the study. All the consent forms were developed and presented to the participants in English or Dholuo (Appendix III and V, respectively).

After reading and signing the consent forms, all the participants were taken through each questionnaire question. They were open to the time needed to answer the questions. Most participants reportedly completed answering the questionnaire within 20 – 30 minutes. The principal investigator or research assistants were always present during the process. The research assistants were trained paramedics familiar with this study's requirements and the questionnaire. They were expected to be fluent in the study's English and Dholuo languages. They took time to explain the study to the participants whose first language was Dholuo

while trying to assist them in completing the questionnaire appropriately. The completed questionnaires were safely stored in a lockable cabinet. The principal researcher was the only person with access to the keys and completed questionnaires. The informed consent forms and the completed questionnaires were stored separately to ensure their anonymity.

3.8: Data analysis

Stata software version 15 (Stata Corp, College Station, TX) was used to analyse quantitative data. Demographic characteristics of Adolescents and Caregivers were determined. The mean (standard deviation) and proportions (counts) were used as appropriate. Data from the study period were compared to assess whether there were changes in disclosure rates.

In bivariate analysis, Chi-Square association tests were used to compare the disclosure proportions. Univariable and multivariable logistic regression analyses for key outcomes HIV Disclosure status. The odds ratio (OR) and respective 95% confidence intervals (CIs) were presented. For Likert scale responses Ordered logit model was employed to model the change among the several ordered values as a function of each unit increase in the Disclosure level; the Log-odds ratio (OR) and respective 95% confidence intervals (CIs) were presented for the logit model.

3.9: Data storage and destruction

Paper documents such as consent forms, printouts, or case tracking sheets that contain personal identifying information were stored securely in locked file cabinets when not in use. They were handled only by trained staff members when actively used during research. The consent forms will not be separated from the subject's data. Confidential data stored on transportable media such as CDs, DVDs, flash memory devices, or portable external drives were kept securely in a safe or locked file cabinet and handled only by authorized staff members. Passwords will also be used to gain access to these data records. These. Passwords were difficult to determine and will not be shared or written on slips of paper at workstations or desks. During the destruction of documents or electronic files after the project has been completed, all paper files or CDs with personal identifying information were shredded. Any electronic files on memory drives, PCs, laptops and file servers should be permanently deleted.

3.10: Data dissemination

The findings of this study will target the following audience; Hospital and community-based caregiver support groups, Faith-based HIV care and treatment organizations, Health care providers, National and County ministries of health, public health associations, ministry of education, Ministry of gender and culture and Health care providers. The study findings will therefore be disseminated through publishing programs or policy briefs, Publishing project findings in national journals and statewide publications, presenting at national conferences and meetings of professional associations, showing program results to local community groups and other local stakeholders, Hosting health promotion events at health fairs and school functions and summarizing findings in progress reports for funders.

3.11: Ethical considerations

Approval

Approval for this study was sought from the Board of Postgraduate Studies, JOOUST. Ethical approval of the study was obtained from the Jaramogi Oginga Odinga Teaching and Referral Hospital Ethics Review Committee (JOOTRH-ERC), and further authorization was obtained from the Bondo Sub County Health Management Team.

Informed Consent

All the participants of the study signed informed consent as a right that enabled the study participant to have the legal capacity to exercise the power of choice and decision without external intervention or use of force, deceit, duress, fraud, overreaching or any other form of coercion, intimidation or constrain when giving consent. The principal investigator built the capacity of the study participants with the knowledge of the elements of the study that would guide them to make informed decisions on their participation. This consent letter requires that it is made known to the participants the duration of the study, its nature, and the objective before they make an affirmative decision to participate. In addition, the means and methods of data collection and the possible inconveniences of the study were explained to the participants.

Risks

There was no form of risk or harm to the study participants that the researcher anticipated. This is because this was not an interventional study. The researcher, however, attempted to minimize cases of immediate or subsequent risks or discomforts to the study participants as

a result of participating in the study. The application of patient confidentiality dictates, and the provision of education and professional counselling for the study participants in need did this. The expectations of the study participants to the study were well explained, including the request to voluntarily answer the survey questionnaire.

Confidentiality

The study participants were duly informed that identifiers such as their names would not be written or shown on the questionnaire and that the completed study questionnaires would be destroyed after data analysis was completed. By participating in the study, they were assured that there was no possible risk directly to them or the adolescents under their custody.

The decision to quit the study

During the study, participants were informed of their right to withdraw without any sanctions or punitive measures since the study was voluntary. In addition, they were free to decline any activity that caused them discomfort or anxiety.

Rights and complaints

In case of any concerns about the study, aggrieved parties were advised to contact my supervisor (Dr Dan Onguru: 0721818368).

Expected Benefits

The study participants were informed that there were no guaranteed direct benefits such as transport advances or lunches to the study's respondents or the adolescents under their care in this study. The research findings will, however, contribute to properly managing infected adolescents living with HIV without adequate disclosure. Healthcare workers will benefit and offer professionally sound interventions targeting caregivers of adolescents in disclosure.

Questionnaire Administration

Study participants were informed that Structured questionnaires were to be used as the data collection tool. They were given an introductory letter before the study. This letter introduced the researcher and detailed the objectives and purpose of the research. After receiving signed consent from the respondents, the researcher administered the questionnaire.

CHAPTER FOUR: RESULTS

4.1: Introduction

This chapter presents the findings and interpretation of the study. The chapter has been subdivided into sections and subsections. The demographic information of the respondents (caregivers), such as age, gender, marital status, relation to the adolescent and perception on disclosure and that of adolescents, such as facility name, gender, residence, education, and viral load levels, was presented first. The quantitative data were analyzed using both descriptive and inferential statistics. Descriptive statistics were used to describe and summarize the data in charts, tables, frequencies, and percentages. Inferential statistics were used to help make inferences and draw conclusions. Statistical tests included the Chi-square test, logistic regression and logit models.

4.2: Demographics information of the adolescents

Two hundred nine adolescents had their caregivers enrolled as the study participants. Findings in Table 4.1 show that the mean of the adolescents' ages was 14.5, with an SD of 2.61. Slightly less than half of the adolescents, 63 (46.3 %), had full disclosure. Adolescents aged 15-19 had the highest proportion of adolescents with a full disclosure rate at 97 (71.3%) compared to those aged 10-14, at 39 (28.7%). The majority of adolescents who had a recent high Viral load of >1000 had a low rate of full disclosure at 14 (10.3 %) compared to those with a Viral load of <1000 at 122 (89.7%). Sexually active adolescents equally had a higher full disclosure rate of 83 (61.0%).

Table 4.1: Demographics Characteristics of the Adolescents

Factor	Disclosure			P-Value
	ALL	Partial Disclosure	Full Disclosure	
N	209 (100.0)	111 (53.1)	98 (46.9)	
Age (mean (SD))	14.5 (2.61)	12.6 (1.74)	16.7 (1.45)	
	n (%)	n (%)	n (%)	
Age group				
10-14	105 (50.2)	66 (90.4)	39 (28.7)	<0.001
15-19	104 (49.8)	7 (9.6)	97 (71.3)	
Adolescent Gender				
Females	106 (50.7)	42 (57.5)	64 (47.1)	0.194
Males	103 (49.3)	31 (42.5)	72 (52.9)	
Adolescent Education Level				
Primary/None	140 (67)	67 (91.8)	73 (53.7)	<0.001
Secondary/Tertiary	69 (33)	6 (8.2)	63 (46.3)	
Viral Load				
<1000	173 (82.8)	51 (69.9)	122 (89.7)	0.001
>1000	36 (17.2)	22 (30.1)	14 (10.3)	
Sexually Active				
No	117 (56.0)	64 (87.7)	53 (39.0)	<0.001
Yes	92 (44.0)	9 (12.3)	83 (61.0)	

4.3: Demographics information of the respondents (caregivers)

Findings in Table 4.2 shows that a total of 209 caregivers were enrolled as study participants, with the majority, 133 (64%), being females. Female caregivers had a higher rate of full disclosure among adolescents under their custody at 93 (68.4%). Caregivers who were married equally had a higher rate of full disclosure among adolescents under their custody at 107 (78.7 %). In addition, caregivers who are biological parents of the adolescents recorded a higher rate of full disclosure among adolescents under their custody at 91 (66.9%).

Caregivers trained on the adolescent HIV treatment package of care recorded a higher rate of full disclosure among adolescents under their custody at 130 (95.6%). In addition, Caregivers who believed that disclosure would improve adolescent's adherence to treatment had high full disclosure rates among adolescents under their care at 135 (99.3%), while those who were not afraid that the adolescent would be stigmatized recorded a high rate of full disclosure at 80% (12/15). A higher rate of full disclosure was recorded among adolescents in cases where a professional counsellor counselling the caregiver regarding the need for disclosure at 113 (83.1%).

Table 4.2: Demographics Characteristics of the Respondents (Caregivers)

Factor	Disclosure			P-Value
	ALL	Partial Disclosure	Full Disclosure	
	n	n (%)	n (%)	
Caregiver Gender				
Female	133	40 (54.8)	93 (68.4)	0.072
Male	76	33 (45.2)	43 (31.6)	
Caregiver Marital Status				
Married	155	48 (65.8)	107 (78.7)	0.064
Single	28	15 (20.5)	13 (9.6)	
Widowed	26	10 (13.7)	16 (11.8)	
Caregiver relation to Adolescent				
Parents	101	10 (13.7)	91 (66.9)	<0.001
Siblings	46	28 (38.4)	18 (13.2)	
Uncle/Aunties	42	17 (23.3)	25 (18.4)	
Grandparents	20 (9.6)	18 (24.7)	2 (1.5)	
Education of Caregiver on HIV				
No	40	34 (46.6)	6 (4.4)	<0.001
Yes	169	39 (53.4)	130 (95.6)	
Ease of Disclosure				
Difficult	97	59 (80.8)	38 (27.9)	<0.001
Easy	112	14 (19.2)	98 (72.1)	
Fear of Stigma				
No	15 (7.2)	3 (4.1)	12 (8.8)	0.328
Yes	194	124 (95.9)	124 (91.2)	
Afraid Adolescent would lose trust				
Yes	11 (5.3)	11 (15.1)	0 (0.0)	<0.001
No	198	62 (84.9)	136 (100.0)	
Improve adherence to medication				
No	7 (3.3)	6 (8.2)	1 (0.7)	0.014
Yes	202	67 (91.8)	135 (99.3)	
Fear of Infection to others				
No	28	21 (28.8)	7 (5.1)	<0.001
Yes	181	52 (71.2)	129 (94.9)	
Quality of Counseling				
Excellent	39	0 (0.0)	39 (28.7)	<0.001
Good	73	1 (1.4)	72 (52.9)	
Fair	59	45 (61.6)	14 (10.3)	
Poor	38	27 (37.0)	11 (8.1)	
Service Provider				
Counselor	113	0 (0.0)	113 (83.1)	<0.001
HCW	96	73 (100.0)	23 (16.9)	
Facility				
Bondo	126	36 (49.3)	90 (66.2)	0.034
Got Agulu	42	21 (28.8)	21 (15.4)	
Uyawi	41	16 (21.9)	25 (18.4)	

4.4: Disclosure Rate and Pattern of Disclosure

Disclosure by Age, Gender and Education level

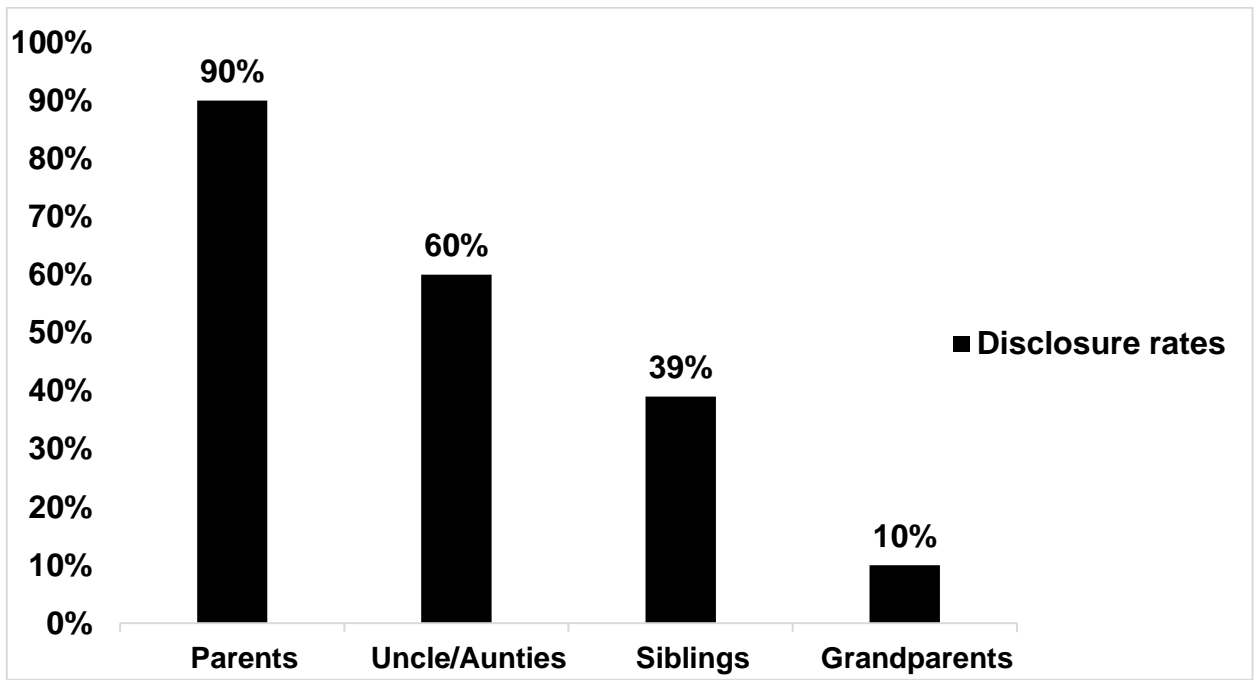
Results in Table 4.3 show that full disclosure rates were higher among adolescents aged between 15 and 19 at 97 (93.3%). In addition, adolescents with a secondary or tertiary level of education had a higher rate of full disclosure at 63 (91.4%). It is equally worth noting that full disclosure rates were slightly higher among male adolescents at 72 (70.0%).

Table 4.3: Disclosure by Age, Gender and Education Level

Factor	ALL	Disclosure	
		Partial Disclosure	Full Disclosure
Age group	n (%)	n (%)	n (%)
10-14	105 (100)	66 (62.9)	39 (37.1)
15-19	104 (100)	7 (6.70)	97 (93.3)
Adolescent Gender			
Females	106 (100)	42 (39.6)	64 (60.4)
Males	103 (100)	31 (30.0)	72 (70.0)
Adolescent Education Level			
Primary/None	140 (100)	67 (47.9)	73 (52.1)
Secondary/Tertiary	69 (100)	6 (8.60)	63 (91.4)

Disclosure by type of Relationship with the adolescent

Caregivers enrolled as study participants had different relationships with the adolescents under their care. Results from Figure 4.2 shows that a higher proportion of adolescents whose caregivers were biological parents had full disclosure at 90%, followed by uncles/aunties at 60%, siblings including brothers or sisters at 39%, and finally grandparents at 10%, the lowest.



Relationship with Adolescent	Frequency	Full Disclosure	Disclosure rate
Parents	101	91	90%
Uncle/Aunties	42	25	60%
Siblings	46	18	39%
Grandparents	20	2	10%

Figure 4.2: Disclosure by the caregivers' Relationship with the Adolescent.

Disclosure by service provider and quality of counseling

Counselling on disclosure was reported to have been provided by either a healthcare worker (HCW) or a trained professional counsellor. Results from Table 4.3 shows that all the respondents, 39 (100%), who rated counselling as excellent, had full disclosure done for the adolescents under their custody. Additionally, all the respondents, 113 (100 %) who reported that a trained professional adherence counsellor conducted the counselling sessions offered to them, recorded full disclosure rates among the adolescents under their custody.

Table 4.4: Disclosure by Service Provider and Quality of Counseling

Factor	Disclosure		
	ALL	Partial Disclosure	Full Disclosure
Quality of Counseling	n (%)	n (%)	n (%)
Excellent	39 (100)	0 (0.00)	39 (100)
Good	73 (100)	1 (1.30)	72 (98.7)
Fair	59 (100)	45 (76.2)	14 (33.8)
Poor	38 (100)	27 (71.0)	11 (29.0)
Service Provider			
Counselor	113 (100)	0 (0.00)	113 (100)
HCW	96 (100)	73 (76.0)	23 (27.0)

Disclosure by perception of the caregiver

Results from Table 4.5 shows that full disclosure rates were higher at 98 (87.5 %) among adolescents whose caregivers found it easy to disclose the HIV-Positive status to the adolescent. In addition, caregivers who did not fear the stigma associated with HIV recorded a high rate of full disclosure at 12 (80.0 %) among adolescents under their custody. The majority of the adolescents, 135 (66.8%), whose caregivers believed that the disclosure process would help the adolescent adhere to ART medication, had full disclosure done. None of the adolescents; 0 (0.00%) whose caregivers reported fear of the adolescent losing trust in them as caregivers after disclosure had full disclosure done.

Table 4.5: Disclosure by Perception of the Caregiver

Factor	Disclosure		
	ALL	Partial Disclosure	Full Disclosure
	n (%)	n (%)	n (%)
Ease of Disclosure			
Difficult	97 (100)	59 (60.8)	38 (39.2)
Easy	112 (100)	14 (12.5)	98 (87.5)
Fear of Stigma			
No	15 (100)	3 (20.0)	12 (80.0)
Yes	194 (100)	70 (36.1)	124 (63.9)
Afraid Adolescent would lose trust in them			
No	11 (100)	11 (100)	0 (0.00)
Yes	198 (100)	62 (31.3)	136 (68.7)
Believe it will Improve adherence to medication			
No	7 (100)	6 (85.7)	1 (14.3)
Yes	202 (100)	67 (33.2)	135 (66.8)
Fear adolescent might Infect to others			
No	28 (100)	21 (75.0)	7 (25.0)
Yes	181 (100)	52 (28.7)	129 (71.3)

Disclosure by training of the caregiver on adolescent HIV package of care

Caregivers of adolescents infected and living with HIV are supposed to be offered education on the basic caregiver package on HIV care and treatment. Results from Figure 4.3 show that 130 out of 169 (76.9%) caregivers who received this form of education recorded full disclosure among adolescents under their custody compared to 6 out of 40 (15.0%) caregivers who did not receive this form of education.

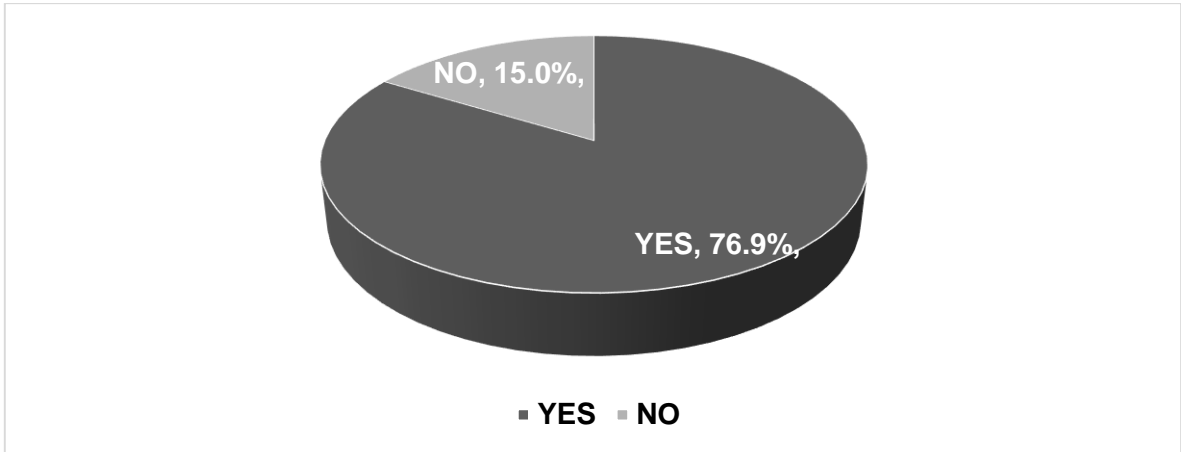


Figure 4.3: Disclosure by Training of the Caregiver on Adolescent HIV Package of Care.

Disclosure rate by Education Level of the Adolescents.

The adolescents whose caregivers formed the study participants were grouped in either primary/no school or secondary/tertiary level of education. Findings from Figure 4.4 shows that the majority, 63 out of 69 (91.3%) adolescents with secondary/tertiary education, had full disclosure compared to 73 out of 140 (52%) adolescents who had primary/no education.

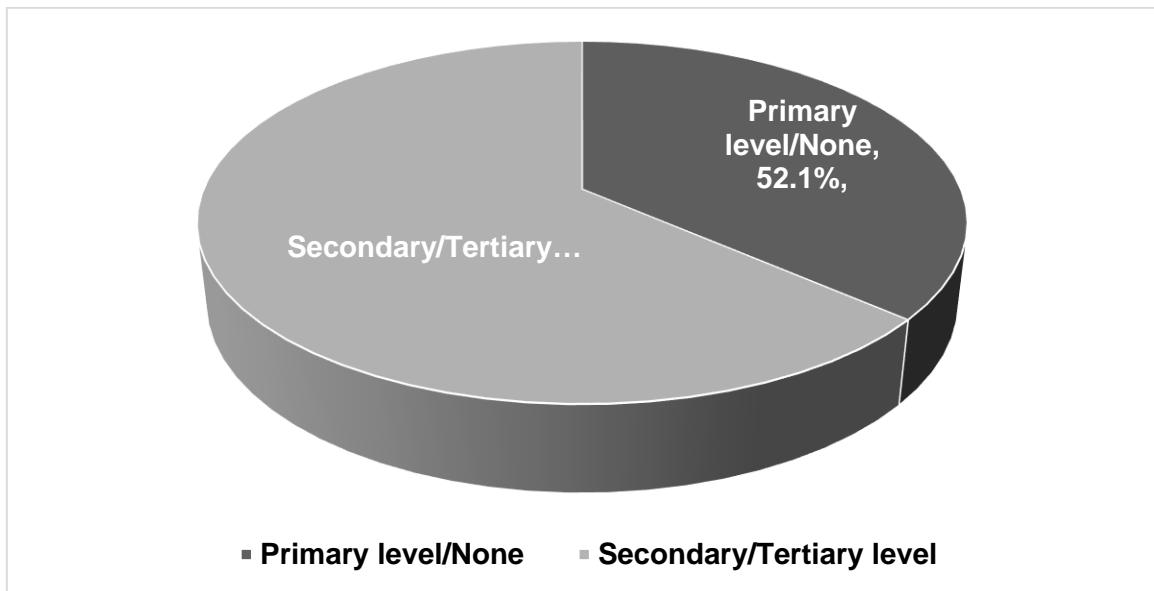


Figure 4.4: Disclosure Rate by Education Level of the Adolescents

4.5: Inferential statistics

4.5.1: Quality of Counseling and disclosure

Using the ordered logit model to model the change among the several ordered values as a function of each unit increase in the disclosure level, it was noted that for every one unit increase in disclosure level variable, the ordered log-odds of scoring in a higher category for quality of counselling services increases by 0.117 with the other factors in the model being held constant. Education of Caregivers on HIV will have a positive scoring factor in a higher category for quality of counselling services by 0.626. Caregivers seen by HCW are more likely to score in a lower category for quality of counselling services by 0.235.

Although not significant, the odds of scoring higher on the positive quality of counselling services were higher among those clients who had fully disclosed their status than those who had not [aOR= 1.12 (95% CI 0.44-2.91)]. Caregivers who reported somewhat difficulty in disclosing to the adolescent their HIV status were significantly likely to score lower on the quality of counselling services [aOR= 1.72 (95% CI 1.05-3.09)]. Clients who reported believing that disclosure of HIV status to adolescents would greatly improve their medication adherence were significantly likely to rate the quality of counselling services highly [aOR= 1.93 (95% CI 1.11-9.99)]. Clients who had fears that adolescents would infect others were significantly likely to rate the quality of counselling services highly [aOR= 2.68

(95% CI 1.14-6.45)]. The odds of poorly rating the counselling services were higher among clients who were seen by HCWs [aOR= 0.79 (95% CI 0.15-0.98)].

Table 4.6: Quality of Counseling and Disclosure

Quality of Counseling	Estimate	Std.Error	Multivariable aOR (95% CI)	P value
Disclosure				
Partial Disclosure	Reference	Reference	Reference	
Full Disclosure	0.117	0.484	1.12 (0.44-2.91)	0.809
Education of Caregiver on HIV				
Yes	Reference	Reference	Reference	
No	0.626	0.391	1.87 (0.87-4.06)	0.11
Ease of Disclosure				
Easy	Reference	Reference	Reference	
Difficult	0.541	0.300	1.72 (1.05-3.09)	0.031
Fear of Stigma				
No	Reference	Reference	Reference	
Yes	-0.282	0.479	0.75 (0.29-1.95)	0.556
Afraid Adolescent would lose trust				
No	Reference	Reference	Reference	
Yes	-0.942	0.752	0.39 (0.08-1.60)	0.210
Improve adherence to medication				
No	Reference	Reference	Reference	
Yes	0.656	0.826	1.93 (1.11-9.99)	0.043
Fear of Infection to others				
Yes	Reference	Reference	Reference	
No	0.984	0.440	2.68 (1.14-6.45)	0.026
Service Provider				
Counselor	Reference	Reference	Reference	
HCW	-0.235	0.409	0.79 (0.15-0.98)	0.039
Intercept				
Excellent fair	-1.604	1.191		
Fair good	-0.219	1.187		
Good poor	1.512	1.192		

4.5.2: Factors affecting caregiver Disclosure

Factors affecting caregiver disclosure in univariate analysis

Findings in Table 4.7 shows that adolescents aged 15-19 years had higher odds of being fully disclosed to [OR= 3.45 (95% CI 1.05-6.03)] compared to those aged 10-14 years. Similarly, adolescents with secondary/tertiary level of education were more likely to be fully disclosed to [OR= 9.64 (95% CI 4.20-26.2)] compared to those with primary or no level of education. In addition, adolescents who were reportedly sexually active were more likely to be fully disclosed to [OR= 11.1 (95% CI 5.34-25.7)] than those who were not.

Caregivers who had been educated on basic caregiver HIV care and treatment package of care were significantly more likely to fully disclose [OR= 18.9 (95% CI 7.88-53.0)] compared to those who had not. In addition, caregivers who were biological parents had higher odds of fully disclosing [OR= 6.19 (95% CI 2.57-15.7)] compared to those who were uncles or aunties. It is worth noting that caregivers whose adolescents were seeking care and treatment at Bondo Sub County hospital were two times more likely to fully disclose [OR= 2.50 (95% CI 1.22-5.16)] compared to those who were seeking services at Got Agulu Sub County Hospital.

Factors affecting caregiver disclosure in multivariate analysis

Findings in Table 4.7 show that five factors significantly affect caregiver disclosure of HIV to an infected adolescent. These factors are; Age of the adolescent, current viral load levels of the adolescent, the caregiver's marital status, the relation of the adolescent to the caregiver and the caregiver's knowledge of the HIV package care and treatment for caregivers.

Adolescents aged 15-19 years have significant odds and are two times more likely to be fully disclosed to (aOR, 2.46, 95% CI 1.03-5.94, p-value=0.005<0.05) compared to those aged 10-14 years. In addition, adolescents living with HIV who had a low viral load level (<1000) copies per ml were significantly more likely to be disclosed to (aOR, 9.53, 95% CI 2.30-49.4, p-value=0.004<0.05) compared to those who had high viral load levels (>1000) copies per ml.

Adolescent caregivers who were married had significantly higher odds of fully disclosing an HIV-infected adolescent to the adolescent under their care (aOR, 5.43, 95% CI 1.25-27.5, p-value=0.030 <0.05) compared to those who were single. Similarly, caregivers who were biological parents were more likely to fully disclose (aOR, 4.84, 95% CI 1.34-19.5, p-

value=0.019<0.05) compared to those who were uncles or aunts. Finally, caregivers who had been educated on basic caregiver HIV care and treatment package of care were significantly more likely to fully disclose (aOR, 14.1, 95% CI 4.03-62.3, p-value=<0.001) compared to those who had not been educated.

Although not significant, the odds of caregivers who were widowed fully disclosing were high (aOR, 5.43, 95% CI 0.64-58.0, p-value=0.136) compared to those who were single.

Table 4.7: Factors Affecting Caregiver Disclosure.

	Univariable		Multivariable	
	OR (95% CI)	P value	aOR (95% CI)	P value
Age group				
10-14	Reference		Reference	
15-19	3.45 (1.05-6.03)	<0.001	2.46 (1.03-5.94)	0.005
Adolescent Gender				
Females	Reference			
Males	1.52 (0.87-2.72)	0.150		
Adolescent Education Level				
Primary/None	Reference		Reference	
Secondary/Tertiary	9.64 (4.20-26.2)	<0.001	1.44 (0.17-12.0)	0.736
Viral Load				
>1000	Reference		Reference	
<1000	3.76 (1.80-8.08)	0.001	9.53 (2.30-49.4)	0.004
Sexually Active				
No	Reference		Reference	
Yes	11.1 (5.34-25.7)	<0.001	0.64 (0.09-3.88)	0.636
Caregiver Gender				
Female	Reference			
Male	0.56 (0.311-1.01)	0.053		
Caregiver Marital Status				
Single	Reference		Reference	
Married	2.57 (1.14-5.90)	0.023	5.43 (1.25-27.5)	0.030
Widowed	1.85 (0.63-5.59)	0.268	5.43 (0.64-58.0)	0.136
Caregiver relation to Adolescent				
Uncle/Aunties	Reference		Reference	
Parents	6.19 (2.57-15.7)	<0.001	4.84 (1.34-19.5)	0.019
Siblings	0.44 (0.18-1.02)	0.058	0.75 (0.24-2.32)	0.618
Grandparents	0.08 (0.01-0.31)	0.001	0.15 (0.01-1.00)	0.074
Education of Caregiver on HIV				
No	Reference		Reference	
Yes	18.9 (7.88-53.0)	<0.001	14.1 (4.03-62.3)	<0.001
Facility				
Got Agulu	Reference		Reference	
Bondo CH	2.50 (1.22-5.16)	0.012	0.90 (0.29-2.76)	0.853
Uyawi	1.56 (0.66-3.78)	0.316	0.88 (0.23-3.25)	0.845

CHAPTER FIVE: DISCUSSION

5.1 Discussion

This is the first study on HIV status disclosure among adolescents infected with HIV to be undertaken in Bondo Sub County, Siaya County in Kenya, to investigate the determinants of HIV status disclosure among adolescents living with HIV and not how disclosure decisions are made. Despite the majority of caregivers understanding the importance of HIV status disclosure to maximize HIV treatment outcomes and the life and health care options of children, majority still require counselling and continued support to enable them to assess the potential consequences and cope with the stress associated with HIV status disclosure (Dellar *et al.*, 2015; Peter Mwangi Mugo *et al.*, 2015).

Most of the adolescent caregivers' descriptions of the reasons for fully disclosing HIV status to adolescents under their care reflected weighing of cost and benefits of full disclosure and how to apply the criteria regarding the appropriate time and place for disclosure. Most of the caregivers who decided against full disclosure of the HIV status of the adolescents under their care attributed the decisions to emotional and intuitive processes, which they described as the sole criteria for disclosure (E Gyamfi *et al.*, 2015). This reflected their appraisal of the anticipated negative consequences anticipated with disclosure than concrete reasoned actions. These caregivers were less likely to disclose the HIV-Positive status to the adolescents than those who gave other categories like full disclosure as the response (Wariri *et al.*, 2020).

In this study, we found that slightly over half of adolescents living with HIV and enrolled on HIV care and treatment services in three select facilities in Bondo Sub County were not aware of their HIV status. These results are consistent with the findings of other research conducted in low-and middle-income sub-Saharan countries where, generally, low disclosure rates of HIV status ranging from 15% to 31% were described (Eric Gyamfi *et al.*, 2017; Sophie Namasopo-Oleja *et al.* 2015). The variations in disclosure rates largely depend on the age of the adolescents whose caregivers were assessed. In this study, adolescents aged 15-19 had a higher disclosure rate of 93% compared to those aged 10-14. Those who reported a full disclosure rate were 37%. A study on disclosure and Knowledge of HIV status among children, adolescents and young adults attending an adolescent HIV clinic in Accra, Ghana, found a disclosure rate of 53% among 13 to 22-year-olds, which was still suboptimal,

considering that older adolescents and young people were part of the study (Kenu *et al.*, 2015).

This study recorded the average age of full disclosure among adolescents at 16.7%. This is relatively different from other studies, such as (Britto *et al.*, 2016; Sophie Namasopo-Oleja *et al.*, 2015,) which reported that the mean age of full HIV status disclosure was 9.6% and 9.2%, respectively. This can be explained since this study only considered adolescents, while the others equally included children from the age of five. This age is significant because it is at this age that the cognitive development of illness begins (Aderomilehin *et al.*, 2016). This study's youngest age of disclosure was five years, which is in line with what most professionals and experts advise, which is as early as 5 to 7 years (WHO, 2011). Similarly, the adolescent caregivers suggested that discussions with children regarding HIV infection and treatment plans should be delayed until the child attains a median of 10 years. It is also in line with the modelled theory of a child's cognitive understanding of the disease process, which considers the ages of 9 and 10 years and the appropriate time for HIV-infected children to know about their illness. At this age, children can understand the causes of diseases, their treatment plans and their consequences (Lester *et al.*, 2002).

Findings in this study show that caregivers who were biological parents and those who had been trained on the adolescent HIV treatment package of care recorded a higher rate of full disclosure among adolescents under their custody. These findings are similar to results in two studies (Lee & Rotheram-Borus, 2002; Sophie Namasopo-Oleja *et al.*, 2015) that determined the factors affecting the disclosure of serostatus to children attending Jinja hospital pediatric HIV clinic in Uganda and assessed the determinants of parental disclosure of HIV to their children respectively. This is mainly because biological parents feel more obligated to the welfare and well-being of the adolescent under their care, feel no need to maintain secrecy, have potentially fewer behavioral problems with the child or adolescent, can openly discuss the disease with the adolescent and can quickly obtain treatment and other health support for the child at school and during clinical visits in hospital (ICAP, 2016; International & Agency, 2014). On the other hand, caregivers trained in the adolescent package of care are more likely to understand the benefits of HIV status disclosure on adolescents and the expected treatment course. This basic understanding of HIV helps these caregivers navigate fears associated with stigma, self-esteem, self-management and societal

discrimination related to HIV diagnosis, as described in the disclosure of the HIV Status toolkit for pediatric and adolescent populations (EGPAF, 2016).

Most adolescent Caregivers prefer the active involvement of trained HCWs in the disclosure process. In most cases, HCWs play a decisive role in the caregivers' decision to disclose (Nwoyeocha & Brown, 2020) fully. HCWs usually provide counselling, supportive discussions and education that are crucial after disclosure by the caregiver. In the absence of a steady and responsible caregiver or in cases where the caregiver requests, the HCW assumes the primary role in disclosure as described in the perspectives and practice of HIV disclosure to children and adolescents by healthcare providers and caregivers in sub-Saharan Africa (Aderomilehin *et al.*, 2016). In this study, we equally found that a higher rate of full disclosure was recorded among adolescents in cases where a professional counsellor counselled the caregiver regarding the need for disclosure. In addition, caregivers who believed that disclosure would improve adolescents' adherence to treatment hence better treatment outcomes, had high full disclosure rates among adolescents under their care. These findings are similar to the ones in a study (Nwoyeocha & Brown, 2020) that established the Impact and psychosocial outcomes of disclosure of pediatric HIV status to infected children and significant others focusing on adherence to treatment and better long-term treatment outcomes considering that HIV is a chronic disease.

Some of the barriers to caregivers' HIV status disclosure noted included; perceptions that adolescents are too young to understand HIV and its treatment options, that adolescents are not emotionally ready for HIV status disclosure, or that caregivers are worried that the adolescent might disclose HIV status to other peers by accident hence generating negative psychological effects, or that the adolescents might negatively react to the news of HIV infection (e.g. blame the caregivers, develop depression, suicidal thoughts, abandon the house, disengage from school, etc., or that the adolescents might find out they transmitted to them the HIV infection hence the feeling of guilt (Cervia, 2013; Heeren, 2011). Findings in this study showed that full disclosure rates were higher among adolescents whose caregivers found it easy to disclose HIV-Positive status to them. In addition, caregivers who did not fear the stigma associated with HIV recorded a high rate of full disclosure among adolescents under their custody.

Caregivers who reported fear of the adolescent losing trust in them as caregivers after disclosure failed to disclose at all. These findings are similar to those in studies (Exavery *et al.*, 2021; Madiba, 2016), which determined factors influencing caregiver disclosure and the strategies to increase the readiness of caregivers to disclose HIV-Positive diagnoses to children and adolescents. This could be due to a lack of a system to minimize the feeling of guilt by the biological parents and caregivers by providing the best possible explanation of HIV transmission and treatment to adolescents and to protect the privacy and maintain the confidentiality of the biological parents and caregivers while supporting disclosure (EGPAF 2016). HCWs should counsel and discourage feelings of guilt that the biological parent may have by keeping the caregiver in finding the appropriate language that helps avoid attributing blame to the caregiver (Wariri *et al.*, 2020).

Caregivers should be adequately educated and counselled on the benefits of HIV status disclosure to enable them to foster psychosocial support from the family while attempting to address the adverse effects and reported emotional challenges that are associated with HIV status disclosure (ICAP, 2016) if the HCW discovers that a caregiver is reluctant to disclose HIV status to the child, they should employ some approaches which include understanding the caregivers' reasons for failing to disclose, try to understand the challenging factors associated with their reluctance, work with the caregiver to create a disclosure plan which will address their complex concerns and with an acceptable and realistic timeline for future disclosure. In addition, referral to a professional counsellor should be done. Professional counselling can be conducted by a trained HCW or a professional counsellor (NASCOP, 2015).

In this study, counselling on disclosure was reported to have been provided by either a healthcare worker (HCW) or a trained professional counsellor. The study revealed that all the caregivers who rated counselling as excellent had full disclosure done for the adolescents under their custody. Additionally, all the caregivers who reported that a trained professional adherence counsellor conducted the counselling sessions they offered recorded full disclosure rates among the adolescents under their custody compared to those counselled by a trained HCW. The findings in this study are similar to the research of (Nzota *et al.*, 2015; Sowell *et al.*, 2003), which affirmed that the caregivers' knowledge of the HIV status disclosure process primarily drives successful disclosure. It further suggested that there is a

need to provide caregivers with adequate knowledge about the approaches of HIV status disclosure to improve HIV status disclosure to adolescents infected and living with HIV through systematic professional counselling.

Despite the call for support, many PLHIV feels uncomfortable telling relatives, friends or children about their HIV-Positive status for fear of rejection and perceived stigma. If they reveal their HIV-Positive status, they might still not receive the required information, psychosocial and emotional support and information. Over time they may be overwhelmed by the negative thoughts and fears concerning the future, the possible negative consequences associated with them, and feelings of guilt, anger, shock and absolute despair (International & Agency, 2014). Caregivers may need support to disclose the HIV status to the adolescents under their custody, and their families should help them to cope with their feelings following disclosure. Despite being advocated for as a way to reduce stigma and protect uninfected partners, disclosure of HIV status is complex, with many factors to consider before the disclosure process can begin. This is why counselling is essential to disclosure (EGPAF, 2016; International & Agency, 2014).

The ongoing nature of parents or guardians' struggle with disclosure is complex, with issues to be addressed; education and counselling support from HCWs is essential to help caregivers realistically appraise disclosure-related concerns. This will enable them to access the needed support for the services (Kiwauka *et al.*, 2014; Peter M. Mugo *et al.*, 2016; Nicastro *et al.*, 2013; Okatch *et al.*, 2020; Wariri *et al.*, 2020). Counselling is a conversation between two or more parties structured to assist the participants in working on particular challenges they face during the HIV status disclosure process. Counsellors encourage parents and caregivers to develop and reorganize their coping abilities and effectively deal with problems (International & Agency, 2014). This study revealed that parents and caregivers who reported full disclosure received quality counselling services from a professional provider.

Likewise, caregivers who had a positive attitude towards disclosure and believed the benefits of disclosure on adherence to care and treatment outweighed the risks reported receiving quality adherence counselling. These findings are similar to the ones from studies (Aderomilehin *et al.*, 2016; Nwoyeocha & Brown, 2020) which revealed whether caregivers decide to disclose or not or the adolescents experience involuntary disclosure, they must

cope positively with stress and anger associated with it. This can only be achieved by adopting a coping mechanism that can be achieved through proper counselling by a trained professional. Through professional counselling, more adolescents can know their HIV status, get accurate information on HIV transmission, have a better understanding of their own risk or vulnerability to HIV infection, have access to information about care and treatment and have access to information and services leading to better treatment outcomes.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Because of the complexity and the ongoing nature of an HIV-infected person's struggle with disclosure issues, counselling support from professional health providers is critical to help caregivers realistically appraise their disclosure-related concerns so they can access needed support and services. Even though most caregivers described the importance of disclosing to maximize the life, health care options and treatment outcomes of their children and adolescents under their custody, many caregivers still need continued support and counselling to be able to assess the impending consequences of HIV status disclosure and deal with the complex nature of the disclosure. The findings of the low disclosure rate in this study show that adolescent caregivers may have a severe need for routine health education and individual counselling in developing an HIV status disclosure plan for the children in their custody and how to effectively cope with people's adverse reaction and attitudes towards individuals living with HIV infection.

Based on this study's findings, conclusions can be confidently drawn that it demonstrates the emerging and existing challenges of HIV status disclosure faced by caregivers of adolescents infected and living with HIV in Bondo Sub County. In addition, this study describes the challenges in Siaya County, which has rapidly scale-up up HIV/AIDS treatment services and wide roll-out of ART services to all adolescents living with HIV. We can conclude that full diagnosis of HIV diagnosis is low among caregivers of adolescents living with HIV in Bondo Sub County and that most cases of full disclosure reported occurred among relatively older adolescents in puberty and beyond. This is consistent with other studies on disclosure among adolescents and young people.

From this study, we can conclude that caregivers who disclose HIV status to adolescents infected and living with HIV are motivated primarily by the feeling that HIV status disclosure may improve the acceptance of their HIV-Positive status by the adolescent hence improving adherence to, quality of life and continuum of treatment. Other reasons that motivate them to do so include; the belief that the child has a right to know about their HIV status, the fear that the child would lose trust in them if they don't disclose, fear that the adolescent might unknowingly or knowingly infect other people and fear that the adolescent might learn of their HIV status accidentally or from unauthorized sources. Therefore, this

study concludes that six factors significantly affect HIV status disclosure by the caregiver of HIV-infected adolescents. These factors are; Age of the adolescent years, the Quality of counselling service delivery by the health care worker, the current viral load levels of the adolescent, the marital status of the caregiver, the caregiver's knowledge of the HIV caregiver package of care and the relation of the adolescent to the caregiver.

The decision to disclose the HIV status to an adolescent depends on the personal perceptions of the caregiver on the self-readiness to tell the adolescent, the adolescent's age, the adolescent's maturity level, fear of causing emotional stress to the adolescent by the caregiver and fear of the adolescent blaming all or one the biological parents for the infection. Caregivers who are not ready for the disclosure process often resort to the use of inaccurate information, continuous lying, substituting names of the illness, selective telling on HIV when explaining the condition, particularly telling when explaining the lifelong medication and HIV-positive diagnosis to the HIV-infected adolescent.

6.2 Recommendations.

The researcher has the following recommendations based on this study's findings:

1. The National AIDS and STIs Control Program (NASCO), and all non-Governmental organizations that partner in running the HIV/AIDS programs in the country, should domicile HIV-Positive status disclosure to adolescents living with HIV in the HIV/AIDS Policy and strategic framework and standardize the practice of HIV diagnosis disclosure in the management of adolescents living with HIV as opposed to the current practice where disclosure is done at will by the health care providers.
2. The National AIDS and STIs Control Program (NASCO) should develop
3. standard HIV disclosure guidelines targeting adolescents that will guide caregivers and healthcare workers on the disclosure process. This will show the precise steps to be followed and w t information to give to make disclosure easy and practical. Non-governmental partners involved in implementing HIV care and treatment should work closely with the Ministry of Health to assist in the implementation of this guideline through the printing of age-specific disclosure guide standards of procedures, Capacity building of Health care workers on the standard disclosure modules through didactic training, mentorships and on the job training.
4. A specific module on disclosure counselling should be domiciled in the curriculum offered by the Kenya Association of Counselors (KAPC) as opposed to the current practice where qualified counsellors have to undertake an additional HIV disclosure course offered by NASCO. This curriculum will enable trained adherence counsellors to cope with the difficult and distressing disclosure task and continuously support adolescent caregivers with disclosing HIV-Positive diagnoses to adolescents. This will empower parents or guardians of HIV-infected children with the best knowledge of the best time to tell the HIV status of the HIV-infected child under their custody. The components of counselling should address anticipated barriers to disclosure at pre-HIV testing sessions, such as physical, emotional and sexual abuse, self-stigma, anxiety, self-blame depression and suicidal ideations, poor adherence in some instances (due to loss of hope) and loss of economic/subsistence support from family members, post HIV testing sessions and at ART initiation addressing the benefits of disclosure such as good adherence to care and medications reduction of

anxiety, self-stigma and depression, partner awareness, partner notification services such as testing and to enable one to access peer support groups and community.

5. Healthcare workers must continuously offer counselling, education, and encouragement to adolescent caregivers because this could benefit parents, guardians, and children in the disclosure process. All caregivers should be educated on the standard package of care curriculum designed by NASCOP. This will enable them to gain in-depth knowledge and a better understanding of HIV, including transmission, care and treatment, since the current command is insufficient in determining whether the choice and time of HIV disclosure are appropriate.

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APPENDICES

APPENDIX I: PERMISSION TO UNDERTAKE STUDY (BONDO SCHMT)

The Sub County Medical Officer of Health,
Bondo SC Health Management Team,
Dear Sir/Madam,

RE: PERMISSION TO CONDUCT RESEARCH IN BONDO SUB COUNTY

I am a student at Jaramogi Oginga Odinga University of science and technology pursuing a master's degree program in Public Health. I am currently conducting the second part of the coursework, which involves research.

I seek permission to conduct the study. The study is titled "Determinants of HIV status disclosure among Adolescents in Bondo Sub-County of Siaya County". I want to conduct it at the following health facilities: Usigu SCH, Uyawi SCH, and Bondo County Hospital. Below are some details about the study:

Sample:

1. Caregivers of adolescents who are HIV infected and are receiving ART services in the three health facilities.

Data collection tools:

1. Structured questionnaire.
2. EMR

The duration of the study will be six months.

I have attached for you a copy of my proposal for your perusal. In addition, I have applied to the Jaramogi Oginga Odinga teaching and referral hospital ethics and review committee (JOOTRH-ERC) and Jaramogi Oginga Odinga University of science and technology Research Ethics Committee for ethical clearance. Should you require further information regarding the study, I shall be most grateful to oblige.

Thank you in advance for your cooperation.

Yours sincerely,

Julius Obiero.

APPENDIX II: RESPONDENT'S INFORMATION SHEET

Study number.....

Introduction

My name is Julius O Obiero. I am a Jaramogi Oginga Odinga University of Science and Technology student pursuing a master's degree. I am asking for your help concerning my study for my thesis. I want to find a few essential facts on “**Determinants of HIV status disclosure among Adolescents in Bondo Sub-County of Siaya County.**” I shall explain the study to you in detail should you find the information contained here insufficient.

This letter has been sent to you and some other people. Please try and ensure I hear your views concerning the adolescent living with HIV whom you are taking care of. I have provided a copy of the consent certificate for you to sign as an acknowledgement of your participation. Be kind enough to read and sign it. I hope your participation will contribute immensely towards this cause. This study will inform decisions, guidelines, policies and approaches to improve disclosure management among adolescents living with HIV in the community.

This study will not interfere with the clinical intervention of the adolescent. All the information you share with me will be helpful and appreciated. Should you help me carry out this study, I will be indebted to you and your support.

Description of the study

You have been asked to participate in the study to find out the Determinants of HIV status disclosure among Adolescents in Bondo Sub-County of Siaya County.

How will it be done?

Study participants were informed that Structured questionnaires were to be used as the data collection tool. They were given an introductory letter before the study. This letter introduced the researcher and detailed the objectives and purpose of the research. After receiving signed consent from the respondents, the researcher administered the questionnaire.

Potential Risks

There was no form of risk or harm to the study participants that the researcher anticipated. This is because this was not an interventional study. The researcher, however, attempted to minimize cases of immediate or subsequent risks or discomforts to the study participants as a result of participating in the study. The application of patient confidentiality dictates, and the provision of education and professional counselling for the study participants in need did this. The expectations of the study participants to the study were well explained, including the request to voluntarily answer the survey questionnaire.

Expected Benefits

The study participants were informed that there were no guaranteed direct benefits such as transport advances or lunches to the study's respondents or the adolescents under their care in this study. The research findings will, however, contribute to properly managing infected adolescents living with HIV without adequate disclosure. Healthcare workers will benefit and offer professionally sound interventions targeting caregivers of adolescents in disclosure.

Confidentiality

Participation in this study is confidential as per the provisions of the law. All the information provided by you will be kept safe and confidential. There will be no information in the script that can be traceable to you. You will not be identified by name but by a unique identifier. This will guarantee that no unauthorized person will have access to information about you or the adolescent.

Decision to Quit

The decision to participate in this study is voluntary. You can say no now or leave the study at any time later. You can also refuse to answer any question asked. You shall tell Julius Ooko Obiero (the lead researcher for the study) that you cannot go further hence quitting the interview. You are free to withdraw or stop anytime. This will not affect or jeopardizing the current treatment of the adolescent under your custody. You are also free to decline to answer questions you don't feel comfortable responding to.

Questions

If you have any further questions, you can call Julius Ooko Obiero (Principal Researcher of the study, on 0728018978). If you have questions regarding the study's success, don't hesitate to contact the University Supervisor (Dr Dan Onguru: 0721818368).

APPENDIX III: RESPONDENT'S CERTIFICATE OF CONSENT

The parent statement: I being the parent or legal guardian, have read and understood/it has been explained about the study. I confirm that I have been allowed to ask questions, which were answered to my satisfaction. I confirm that I have not been coerced/forced into giving consent to participate in the study and that permission has been given voluntarily.

.....
Participant's signature/thumbprint Date

.....
.....
Witness signature/thumbprint Date

.....
.....
Researcher/Research Assistant signature Date

APPENDIX IV: RESPONDENT'S INFORMATION SHEET (DHOLUO VERSION)

Okang' mokuongo

Nyinga en Julius Obiero. An japuonjre e Mbalariany Mar Jaramogi Oginga Odinga University of science and technology. Akwayo kony mari kuom nonro ma atimo. Adwaro ngeyo adier kuom weche mamiyo nyithindo kata rowere ma odak kod kute mag ayaki ok fulnegi chal margi mar kute ayaki e wang sa ma owinjre e gweng ma Bondo. Abiro lero ni matut e wi nonro ni.

Barua ni andikoni ka achiel kod jomamoko bende. Mondo ayud ler ma kori kendo makende. Ibiro yudo oboke moro ma ibiro goyoe koki ka ichiwo go ayie mari mar bedo e nonro ni. Yie mondo isom oboke ni matut ka pok igoyo koki. An gi geno ni ibiro konya e nonro ni mondo duoko mare okony e thieth mag nyithindo kata rawera masani odak gi kute mag ayaki ni e piny wa ka. Nonro ni ok bi donjre e yo moro amora kod thieth ma rawera gi iyudo e kart thieth ka. Omiyo akwayo mondo ikonya e nonro ni ka igolo ayie mari kendo igoyo koki e oboke ni. Erokamano

B. Ratiro mar nonro ni

Akwayi mondo ibed achiel kuom joneno marwa e nonro mar ngeyo adier kuom weche mamiyo nyithindo kata rowere ma odak kod kute mag ayaki ok fulnegi chal margi mar kute ayaki e wang sa ma owinjre e gweng ma Bondo.

Nonro ni itime nade?

Ka iyie bedo janeno e nonro ni, ibiro penji penjo mag ratiro to dwoko mari indiko e oboke machielo. Japenj penjo nyalo kao nyaka saa achiel. Dwoko ma ichiwo ibiro ndiko piny maler e oboke machielo. Ber ka ingeyo ni nyingi ok bi land ne ngato kata ok bi ndik kamoroamora.

Kit gik manyalo hinyi

Onge kido mar gimoro amora manyalo hinyi sama itimo nonro ni. Kapo ni openji penjo ma ok lerni kata ok iikori chiwo dwoko ne, in thuolo mar tamori kendo nyiso Julius O Obiero kwedo ma in go. Kapo ni ikwedo penjo kata itamori dwoko penjo, thieth mari rawera ma idak godo kar thieth biro dhi mbele mana kaka pile.

Yuto moro amora e nonro ni.

Daher yango ni adiera ni nonro ni onge yuto moro amora ma ibiro miyi kapo igoyo ayie mari mar bedo janeno. Ber ng'eyo bende ni kuom konya e nonro ni, dwoko biro konyo jothieth e ngeyo kaka ginyalo tayo thieth mar nyithindo kata rawere ma odak gi kute mag ayaki.

Maling'ling mar nonro

Daher mar nyisi ni weche duto, kata dwoko duto kata neno duto ma iwacho e nonro ni ibiro kano maling'ling kendo onge kama ibiro fulie wachni. Nyingi bende ok bi ndik kamoramora. Ma ingo ni onge nga'to machielo mabiro yudo weche ma oa kuomi.

Kwedo nonro

Kapo ni ok idwar dhi mbele gi nonro ni kata bed mana ni penjo ma ipenji ikwedo kendo ok idwar chiwo dwoko, in kod thwolo mar tamori kendo Julius O Obiero biro miyi thuolo mar weyo e thuolo no. Agoyo erokamano.

Penjo Kuom nonro

Kapo ni in gi penjo moro amora, in thuolo penjo Julius Obiero (Principal Researcher of the study, e ong/we yamo 0728018978) kata japuonj maduong e Mbalariany (University Supervisor Dr. Dan Onguru: 0721818368).

**APPENDIX V: RESPONDENT’S CERTIFICATE OF CONSENT (DHOLUO
VERSION)**

Afulo ni asomo oboke ni te kendo penjo moro amora ma ne bed ni an godo olerna e ratiro maber. Afulo ni yie bedo janeno e nonro ni kendo onge ng’ato ma ochuna godo. Erokamano

.....

Kogno ja gol neno

.....

Tarik

.....

Kogno jasir janeno

.....

Tarik

.....

Kogno jatim nonro

.....

Tarik

APPENDIX VI: QUESTIONNAIRE (ENGLISH VERSION)

(Health facility interview schedule for caregivers)

Participant Number:

Instructions:

1. Kindly respond to all questions
2. The interview schedule consists of 4 sections.
3. Mark with an “X” where relevant

NB: All information gathered will be kept confidential.

Section A: Demographic characteristics

Health Facility:
1. Age of the caregiver (in years):
2. Sex a. I am Male <input type="checkbox"/> b. I am Female <input type="checkbox"/>
3. Residence a. I am from Uyawi <input type="checkbox"/> b. I am from Got Agulu <input type="checkbox"/> c. I am from Bondo Township <input type="checkbox"/> d. I am from Gobei <input type="checkbox"/> j. I am from Others <input type="checkbox"/> State.....
4. What is the Marital status? a. I am Single <input type="checkbox"/> b. I am Married <input type="checkbox"/> c. I am Divorced <input type="checkbox"/> d. I am Widowed <input type="checkbox"/> e. I am Separated <input type="checkbox"/>

5. The level of education?

- a. I never ever went to school ()
- b. I reached Primary ()
- c. I reached Secondary ()
- d. I reached College ()
- e. I reached University ()

6. Your religion?

- a. I am a Catholic ()
- b. I am a Protestant ()
- c. I am a Muslim ()
- d. I am a Hindu ()

7. The age of the adolescent? (years).....

9. What is the sex?

- a. The adolescent is a Male ()
- b. The adolescent is a Female ()

10. How are you related?

- 1. The adolescent is my Son ()
- 2. The adolescent is my Daughter ()
- 3. The adolescent is my Nephew ()
- 4. The adolescent is my Niece ()
- 5. The adolescent is my Grandson ()
- 6. The adolescent is my Granddaughter ()
- 7. The adolescent is my Brother ()
- 8. The adolescent is my Sister ()
- 9. The adolescent is my Cousin ()

Section B: Child's Knowledge of HIV status

11. Does the adolescent know their HIV-positive status? a) The answer is Yes <input type="checkbox"/> b) The answer is No <input type="checkbox"/> c. I do not know <input type="checkbox"/>
12. If yes, who informed them? a. I did <input type="checkbox"/> b. The counsellor did <input type="checkbox"/> c. The counsellor and I <input type="checkbox"/> e. Someone else did <input type="checkbox"/> f. I do not know <input type="checkbox"/>
13 If yes, at what age did they know? (in years)
14. What is the current knowledge of the adolescent on the illness? a) They only know other illnesses, e.g malaria, <input type="checkbox"/> b) I haven't told them anything <input type="checkbox"/> c) I don't know <input type="checkbox"/>

Section C- Psychosocial, cultural and Service-related factors

I) Psychosocial and cultural factors

(For each option tick only one answer)

a. Age of the child

15. How did you feel disclosing at the age of the adolescent? a. The adolescent was not old enough <input type="checkbox"/> b. The adolescent was old enough <input type="checkbox"/>

b. psychological effects

16. Did you feel the adolescent would react angrily after disclosure? a) The answer is Yes <input type="checkbox"/> b) The answer is No <input type="checkbox"/>
17. Did you feel that the adolescent would feel they will die soon? a) The answer is Yes <input type="checkbox"/> b) The answer is No <input type="checkbox"/>

18. Did you feel the adolescent would be ashamed of themselves?

a) The answer is Yes ()

b) The answer is No ()

C. Stigma

19. Did you feel the adolescent would be rejected by the community?

a) The answer is Yes ()

b) The answer is No ()

20. Did you feel that the adolescent would be isolated in the community?

a) The answer is Yes ()

b) The answer is No ()

d. secrecy

21. Did you feel that the adolescent may reveal the secret to others?

a) The answer is Yes ()

b) The answer is No ()

22. Did you want the adolescent to know the truth?

a) The answer is Yes ()

b) The answer is No ()

23. How did you feel about the secret?

a. I was comfortable keeping it ()

b. I got tired of keeping it ()

24. What was your concern about the adolescent?

a. I was afraid they would hear about the disease someone else. ()

b. I was not afraid they would hear about the disease someone else. ()

e. clinical perceptions

25. Do you think the adolescent will improve the way they take drugs?

a) The answer is Yes ()

b) The answer is No ()

f. infection prevention concerns

26. Do you think the adolescent will infect others if not disclosed to?

a) The answer is Yes ()

b) The answer is No ()

II) Availability and Quality of Counseling

27. Have you ever talked to a counsellor on disclosure?

a) The answer is Yes ()

b) The answer is No ()

28. Rate the counseling quality.

a) It was Excellent ()

b) It was Good ()

c) It was Fair ()

d) It was Poor ()

29. Who offered you the counselling?

a) It was a HCW ()

b) It was a Counsellor ()

30. Did the counseling help you disclose to Adolescent their HIV status?

a) The answer is Yes ()

b) The answer is No ()

31. Dd you talk to the counsellor in a private room?

a) The answer is Yes ()

b) The answer is No ()

32. Did you feel the counsellor was polite?

a) The answer is Yes ()

b) The answer is No ()

APPENDIX VII: QUESTIONNAIRE (DHOLUO VERSION)

(Penjo mag nonro ma watimo)

Namba ja gol neno:.....

Yore mogo luu:

1. Yie iduok penjo te ma opeji

2. Nonro ni opog ding'wen.

3. Nik "X" kama iyiego e nonro ni.

NB: Weche te ma wafwambo ok bi ket e lela.

Section A: Chal mar kar dak,somo kod lemo

Nying Od thieth:
1. Higni mag janyuol kata jarit):
2. Ng'at ma itimo nonro kuome a. Dichuo () b. Dhako ()
3. Kar dak a. Uyawi () b. Got Agulu () c. Bondo Township () d. Gobei () j. Moko () ful
4. Ise dhi ka tedo kata kendo? a. podi () b. asetedo/kendo () c. wawere () d. jaot onindo () e. wapogre e dak ()
5. Kiwango ni mar somo? a. Ok ne adhi skul () b. Klas aboro ()

c. Klas apar gi ario	()
d. Mbalariany/College	()
e. Mbalariany/university	()
6. Ilemo kanye?	
a. Catholic	()
b. Protestant	()
c. Muslim	()
d. Hindu	()
e. Mamoko (ful)	()
7. Nyathi ma ikelo yudo thieth en ja higni adi?	
9. Nyath ma ikelo yudo thieth en?	
a. Nyako	()
b. Wuoyi	()
10. Nyathi ma ikelo yudo thieth en ang'oni?	
1. Wuodi	()
2. Nyari	()
3. Sang'ni	()
4. Nyakwari	()
5. Owadu	()
6. Nyameru	()
7. Moko	()

Section B: Ng'eyo mar nyathi/rawera kuom chal mare mar Ayaki

11. Be nyathi ma ikelo yudo thieth ongeyo ni en gi kute makelo Ayaki?	
a. Ongeyo	()
b. Okia	()
c. Akia	()
12. Kapo ni ong'eyo,ng'ano mane onyise?	
a. An awuon	()
b. Kansela mapimo e od thieth	()
c. Kansela kachiel kod an	()

d. Kansela kende	()
e. Ng'ato moro machielo	()
f. Ok ang'eyo	()
13 Kapo ni ong'eyo,ne onyise ka en ja higni adi ?.....	
14. Ang'o ma nyathini ong'eyo kuom tuo mar Ayaki?	
a) Ong'eyo mana kuom malaria gi kahera	()
b) Podi ok anyise kuom tuo mar Ayaki	()
c) Ok ang'eyo	()

Section C- Chal mar dak,kido mar timbe kod gweng.

I) Kit dak kod timbe oganda

a. Higni mar nyathi

15. Ineno nadi puonjo nyathi kuom ng'eyo kute mag ayaki?	
a. Aneno ni nyathini pod tin	()
b. Aneno ni nyathini osechopo higni ma onego ong'e	()

b. Weche mag paro

16. Be ne in gi luoro ni nyathi ne nyalo kuno ka ngeyo chalne mar Ayaki?	
a. Ne ok awinjo luoro	()
b. Ne awinjo luoro.	()
17. Be ne iwinjo luoro ni nathi ne nayalo bedo gi paro ni ochiegni tho?	
a. Ne ok awinjo luoro	()
b. Ne awinjo luoro.	().
18. Be ne iwinjo luoro ni nyathi ne nyalo winjo wich kuot gi ngimane?	
a. Ne ok awinjo luoro	()
b. Ne awinjo luoro.	()

C. Stigma

19. Be ne in gluoro ni Oganda nyalo thegore gi nyathi/rawera kuom chal mare mar Ayaki?

a) Kamano ()

b) Dawe ()

20. Be ne in gluoro ni Oganda nyalo kwedo nyathi/rawera kuom chal mare mar Ayaki?

a) Kamano ()

b) Dawe ()

d. Siri kuom tuo mar Ayaki

21. Be ne in gi luoro ni nyathi/rawera ne nyalo fulo siri ni jok mamoko kuom chal mare mar Ayaki?

a) Kamano ()

b) Dawe ()

22. Be ne idwaro ni nyathi/rawera obed gi adier kuom tuo mar ayaki?

a) Kamano ()

b) Dawe ()

23. Ineno nade kano siri?

a. Ayudo ka yot kano siri ()

b. Ne awinjo pek kano siri ()

24. Be ne in gi luoro ni nyathi/rawera biro winjo wach kuom chal mare mar Ayaki ka owuok kuom jok mamoko?

a) Kamano ()

b) Dawe ()

e. Paro kuom thieth

25. Be iparo ni wacho ni nyathi/rawera chal mare nyalo miye odak e ng'ima maber kendo omuonyo yath maber?

a) Kamano ()

b) Dawe ()

f. Geng'o landruok tuo

26. Be iparo ni nyathi/rawera nyalo miyo jok mamoko tuo mar ayaki ka po ni okia chal mare?

a) Kamano ()

b) Dawe ()

II) Puonj ma kare

27. Be nyamrerua osega miyi puonj ni onego iler ni nyathi/rawera chal mare mag kute Ayaki?

a) Kamano ()

b) Dawe ()

28. Inyalo puoyo punj makawuono nadi

a) Ber Kabisa ()

b) Ber ()

c) Ber ber ()

d) Rach kabisa ()

29. Ngano ma ne owuoyo kodi?

a) Ajuoga ()

b) Nyamrerua ()

30. Bende nyamrerua ne okonyi fulo ni nyathi/rawera chal mare mar Ayaki?

a) Kamano ()

b) Dawe ()

31. Bendo nyamrerua ne owuyo kodi e ot mantie gi thoulo kendo opondo?

a) Kamano ()

b) Dawe ()

32. Bende Nyamrerua ne owuoyo kodi gi mwolo?

a) Kamano ()

b) Dawe ()

EEROKAMANO!

APPENDIX VIII: BPS APPROVAL



JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE & TECHNOLOGY

BOARD OF POSTGRADUATE STUDIES

Office of the Director

Tel. 057-2501804

Email: hps@jooust.ac.ke

P.O. BOX 210 - 40601

BONDO

Our Ref: H152/4130/2015

Date: 28th May 2019

TO WHOM IT MAY CONCERN

RE: OBIERO JULIUS OOKO – H152/4130/2015

The above person is a bona fide postgraduate student of Jaramogi Oginga Odinga University of Science and Technology in the School of Health Sciences pursuing Master of Public Health. He has been authorized by the University to undertake research on the topic: *"Determinants of HIV Status Disclosure among Adolescents in Bondo Sub-County of Siaya County"*.

Inbox (34)

Any assistance accorded to him shall be appreciated.

Thank you

Prof. Dennis Ochuodho

DIRECTOR, BOARD OF POSTGRADUATE STUDIES

APPENDIX IX: PROTOCOL/ETHICAL APPROVAL



COUNTY GOVERNMENT OF KISUMU
DEPARTMENT OF HEALTH

Telephone: 057-2020801/2020803/2020321

Fax: 057-2024337

E-mail: medsuptrspch@yahoo.com
ceo@jaramogireferral.go.ke

Website: www.jaramogireferral.go.ke

When replying please quote
IERC/JOOTRH /223-/20

Ref:

JARAMOGI OGINGA ODINGA TEACHING &
REFERRAL HOSPITAL
P.O. BOX 849
KISUMU

3rd September, 2020

Date.....

To: Julius Ooko Obiero

Dear Julius,

RE: **STUDY TITLE:**
DETERMINANTS OF HIV STATUS DISCLOSURE AMONG ADOLESCENTS IN BONDO SUB-COUNTY OF SIAYA COUNTY

This is to inform you that JOOTRH IERC has reviewed and approved your above research proposal. Your application approval number is IERC/JOOTRH/223/20. The approval period is 3rd September, 2020 – 3rd September, 2021. This approval is subject to compliance with the following requirements;

- i. Only approved documents including (informed consents, study instruments, MTA) will be used
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by JOOTRH - IERC.
- 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 JOOTRH - IERC within 72 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 JOOTRH - IERC within 72 hours
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. 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.
- vii. Submission of an executive summary report within 90 days upon completion of the study to JOOTRH - IERC.

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

In case the case of study site is JOOTRH, kindly report to Chief Executive Officer before commencement of data collection.

Yours sincerely,

SECRETARY, IERC



APPENDIX X: RESEARCH PERMIT FROM NACOSTI

REPUBLIC OF KENYA
Ministry of Education, Science and Technology
National Commission for Science, Technology and Innovation

Ref No: 309745

RESEARCH LICENSE

Date of Issue: 25 September 2020

License No: NACOSTEP/20/0057

309745
Applicant Identification Number

Director General
NATIONAL COMMISSION FOR
SCIENCE, TECHNOLOGY &
INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.



APPENDIX XI: MAP OF THE STUDY AREA

