

**EFFECT OF PEDIATRIC HIV DISCLOSURE TRAINING ON ART ADHERENCE
BY HIV POSITIVE CHILDREN AGED 6-10 YEARS IN HOMA BAY COUNTY,
KENYA BY 2018**

**BY
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DEGREE OF DOCTOR OF PHILOSOPHY IN PUBLIC HEALTH**

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DECLARATION

By the Candidate

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DEDICATION

My husband Sammy, my daughters Melanie and Rene' and my sons; Emmanuel and Joshua.

ABSTRACT

Anti-retroviral therapy (ART) adherence by school-aged children is highly dependent on them knowing their HIV status, which can only happen by a disclosure process facilitated by their caregivers. Homa Bay County is among counties with the highest HIV prevalence currently at 19.6%. The number of HIV positive children with disclosed HIV status and those adhering to their ART were not known. Similarly, caregivers of the HIV positive children were also not trained on pediatric HIV disclosure process which was impeding pediatric HIV status disclosure. The goal of this study was to assess the effect of pediatric HIV disclosure training on ART adherence by HIV positive children in Homa Bay County. Specifically, the study aimed at comparing the ART adherence of children before and after training of caregivers on the disclosure process, determine the effect of HIV disclosure training on caregiver's knowledge of HIV disclosure process and establish the socio-demographic factors associated with ART adherence. This intervention longitudinal study had a sample size of 860 non-HIV status disclosed children from a sampling frame of 924 in ten health facilities. Eligible participants were randomly selected and assigned to either control (430) or intervention (430) groups. Caregivers in the intervention were trained on HIV disclosure process whereas control group caregivers not trained. Thereafter, caregivers in both groups performed HIV disclosure to their HIV positive children. Before the training, baseline information was gathered on children's ART adherence. Adherence to ART was measured in terms of consistencies in taking ARVs, keeping clinic appointments and viral load monitoring. Chi-square test compared adherence between the groups. Logistic regression determined the effect of disclosure training on ART adherence. Multivariate logistic regression estimated the associations between viral suppression and individual-level factors, NVivo analysed FGDs and KIIs data and Relative Risk of ART adherence calculated. Trained caregivers were 2 times (OR=2.369) more likely to disclose children's HIV status. Disclosure training had significant effect ($p < 0.05$) on children's adherence. Children of trained caregivers were nine times (OR=9.145) more likely to have good adherence. Caregiver's education ($p = 0.035$), disclosure knowledge ($p < 0.05$) and age of caregiver ($p = 0.04$) were significantly associated with ART adherence. Disclosure knowledge, HCW attitude, dosage patterns, nature of drugs and environmental factors were attributed to RT adherence from FGDs & KIIs. In conclusion, HIV disclosure training increases disclosure and subsequently improves ART adherence in children 6-10 years. The study recommends caregiver's training on HIV disclosure in order to improve ART adherence in HIV positive children.

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CARE	Cooperative for Assistance and Relief Everywhere
CASCO	County AIDS and STI Coordinator
CDC	Centers for Disease Control and Prevention
CLHIV	Children living with HIV
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FACES	Family AIDS Care and Education Services
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programs
KAIS	Kenya AIDS Indicator Survey
KCCB	Kenya Conference of Catholic Bishops
KDHS	Kenya Demographic and Health Survey
KEMRI	Kenya Medical Research Institute
KENPHIA	Kenya Population based HIV Impact Assessment
KII	Key Informant Interview
KNBS	Kenya National Bureau of statistics
LMIC	Low and Middle Income Countries
MOH	Ministry of Health
NACC	National AIDS control council
NASCOP	National HIV/AIDS and STD Control Programme
PEPFAR	President's Emergency plan for AIDS Relief
PMTCT	Prevention of Mother To Child Transmission of HIV
RA	Research Assistant
SCASCO	Sub County AIDS and STI Coordinator
STIs	Sexually Transmitted Infections
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
VL	Viral Load
VS	Viral Suppression
WHO	World Health Organization
PrEP	Pre-exposure prophylaxis
PEP	Post exposure prophylaxis

OPERATIONAL DEFINITION OF TERMS

ART Adherence	In this study, ART adherence means consistent taking of ARVs, keeping clinic appointments for drug refill and viral load level of below <1000/ml of blood.
Caregiver	Parents/guardian of the HIV positive child aged 6-10 years on ART.
Disclosure Training	In this study, disclosure training means teaching caregivers of HIV positive children 6-10 years in Homa Bay county on HIV disclosure process using a standardized CDC disclosure training guide.
HIV Status Disclosure	In this study HIV status disclosure means the process of informing the HIV positive children 6-10 years that they have HIV virus in their blood.
Pediatric	In this study context, pediatric means HIV positive children 6-10 years on ART
School-aged Children	These are HIV positive children on ART with cognitive skills and emotional maturity of a normally developing child, 6 – 10 years of age
Viral Load	The number of virus in the blood of HIV positive children 6-10 years enrolled in this study.
Intervention	Children disclosed to their HIV status through a disclosure process after training caregivers to do the disclosure.

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CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Adherence to antiretroviral therapy (ART) resulting to durable viral suppression eliminates risk of sexual transmission of HIV and is key to HIV epidemic control. Treatment efficacy relies, however, on sustained adherence, which constitutes a serious challenge to those receiving antiretroviral therapy. While the reasons for poor adherence rates in children are varied, dependence on caregivers who are frequently ill themselves for ART adherence by HIV positive children is a major contributor to low rates in ART adherence (UNICEF, 2021). Novel approaches like HIV status disclosure can make school aged children autonomous to their HIV treatment and adherence. According to (UNAIDS, 2022) report, 76% of all people with HIV world over, were accessing antiretroviral therapy (ART), while 71% were virally suppressed. Only half (52%) of the children living with HIV and accessing the life-saving medicines were virally suppressed, denoting some level of non-adherence among the children on ART. Eastern and southern Africa remained regions most heavily affected by HIV accounting for approximately 55% of all the people living with HIV (UNAIDS, 2022).

According to the Kenya Demographic and Health Survey report implemented by the Kenya Bureau of statistics (KNBS) (Kenya National Bureau of Statistics & ICF Macro, 2023), 82% HIV positive children are currently on ART while only 67.5% are virally suppressed (VLS), denoting some level of non-adherence among the children on ART in Kenya. Homa Bay County in Nyanza has been, and is currently ranked the county with the highest HIV burden county in Kenya with a prevalence of 19.6% which is 4 times the national prevalence (KNBS, 2023). Nationally, the county contributes 9.9% (128,199) of adults and 7.7% (10,722) of children living with HIV. Although the proportion of PLHIV accessing ART has greatly increased in the recent years, the UNAIDS 95-95-95 testing, treatment and viral load suppression targets are yet to be achieved. Treatment coverage in Homa Bay County is 91% among adults aged 15 years and above and 75% among children 0-14 years. Viral load suppression is 85% among children 0-14 years, which is still below the UNAIDS target of 95% for viral load suppression (Kenya National Bureau of Statistics & ICF Macro, 2023). The low viral load suppression below 95% UNAIDS target is of concern as it denotes some level of non-adherence among HIV positive children on ART in Homa Bay County.

Anti-retroviral therapy (ART) is a lifesaving treatment for HIV positive persons and adherence to treatment protocol is exceedingly important in ensuring that drug efficacy does not fail with time (NASCOP, 2022). The goal of antiretroviral therapy (ART) is to achieve and sustain viral suppression, which has both clinical and public health benefits, hence the UNAIDS 95-95-95 strategy that stipulated that, 95% of all people living with HIV (PLHIV) should know their HIV status, 95% of all people diagnosed with HIV should receive sustained ART and 95% of all people receiving ART should have viral suppression (UNAIDS, 2014). People who are virologically suppressed are very likely to remain clinically stable with no change in CD4 count. Inconsistent adherence to treatment is a contributing factor to poor health outcomes for people affected by numerous health conditions, including HIV, tuberculosis, diabetes mellitus (DM) and hypertension (NASCOP, 2022; UNICEF, 2021; Wadunde et al., 2018).

Adherence by school aged children who are HIV positive is highly dependent on them knowing their HIV status, which can only happen by a disclosure process facilitated by their caregivers. HIV status disclosure can be defined as a declaration of a person's HIV status. Pediatric HIV disclosure may be full (telling the child that they have a serious illness and the illness is HIV) or partial (telling the child that they have an illness without naming it as HIV) (Glaser, 2018). The obvious benefits of disclosure of one's HIV status is the reduction in the risk of transmission of HIV infection associated with the use of successful antiretroviral therapy. However, despite the enormous benefits attached to HIV status disclosure, global and regional countries including Kenya, have reported low rates in pediatric HIV status disclosure (Amankwah-Poku et al., 2021; Doat et al., 2019a; Melis Berhe et al., 2020). Similarly, interventions that support caregivers and healthcare providers in the disclosure process are limited, and many caregivers may feel unprepared (Lee et al., 2018; Subash, 2017). Previous studies (Amankwah-Poku et al., 2021; Kalembo et al., 2018; Vreeman et al., 2014) from sub-Saharan Africa also report about 10% prevalence of full disclosure among HIV-infected school-going children up to 10 years of age. Furthermore, no study has been found focusing on training caregivers on the disclosure process and its effect on HIV positive child's ART adherence (Amankwah-Poku et al., 2021; Doat et al., 2019a; Melis Berhe et al., 2020). The persons charged or those who should be charged with the disclosure responsibility should have proper training on the disclosure guidelines especially for children (Butler et al., 2019; Doat et al., 2019a), which informed this interventional study.

The Kenyan Ministry of Health through National Syndemic Disease Control Council (NASCOP, 2022) guidelines on use of antiretroviral drugs for treating and preventing HIV infections recommend that children should be counseled about the potential benefits and risks of disclosure of their own HIV status. The guidelines also recommend that all HIV positive children irrespective of their age, CD4 cell count, WHO clinical stage or co-infection should start ART immediately an HIV positive diagnosis is established. The perceived dilemma that was facing caregivers of Homa Bay County was non-disclosure to children living with HIV of their own HIV status. This was also coupled with the fact that there are challenges with voluntary counseling and testing of children. The problem was further compounded by the fact that caregivers were not trained on the disclosure process especially for HIV positive children. According to Madiba 2019 study (Madiba, 2019), lack of disclosure skills delay disclosure to Children with Perinatal HIV in resource limited communities of South Africa and Botswana. Similarly, lack of parental or guardian HIV disclosure knowledge impedes HIV status disclosure in children. According to WHO disclosure guideline (WHO, 2011), the decision on who to disclose to the child his status should be guided by the intent to improve/promote the child's welfare and minimize the risk to his or her well-being and to the quality of the relationship between child and parent/caregiver. In addition, younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure at an older age, as a way of enhancing their adherence to ART.

Challenges to disclosure are wide ranging. The caregiver may choose to delay or postpone the disclosure process out of fear of stigma, being identified as a source of HIV infection and therefore feeling guilty, being blamed, or rejected, caregiver's feelings about child's conditions to include; child is too young or not emotionally ready for disclosure, child may mistakenly disclose status to other peers with negative effects, child may react to the news in a negative manner (e.g. blame them, depression, contemplate suicide, abandon the home, stop school, etc.) or that the child will find out that the caregiver transmitted the HIV infection to the child, and will feel more guilty of that fact and this too, may make the caregiver to delay or postpone the disclosure process (Glaser, 2018). Caregivers' belief that their child is too young, both emotionally and cognitively, to understand the disease and comprehend its implications is one of the most commonly cited reasons for non-disclosure (Mphego et al., 2023).

1.2 Statement of the Problem

According to the WHO HIV status disclosure guideline (WHO, 2011), lack of disclosure affects the wellbeing of the child particularly on issues like access to pediatric HIV treatment, care and adherence to treatment. In Homa Bay County by 2014, little was known about how HIV-positive parents prepared themselves and their children for full disclosure and what resources they needed. It was also evident from the literature that up to 83% of HIV infected children were not on ART by the end of 2014. This could be partly because they were not aware of their HIV status. Additionally, the number of children on HIV treatment who were adhering to their HIV treatment was only 42% (Homa Bay County DHIS,2014), denoting high level of non-adherence. According to Gachanja and Burkholder study on ‘HIV-Positive Parents’ Accounts on Disclosure Preparation Activities in Kenya’ (Gachanja & Burkholder, 2014), limited work had explored how parents were prepared and counseled to disclose to their children their HIV status in Sub-Saharan Africa including Kenya. Additionally, such studies had not explored how incorporating a child’s caregiver in the disclosure process, might impact on HIV positive child’s treatment adherence, and so the role of disclosure training of caregivers on pediatric HIV treatment outcomes was not known. Additionally, it was also evident that gaps in knowledge remained on socio-demographic factors associated with pediatric ART adherence from a previous study (Vreeman et al., 2014), and so their significance in pediatric ART adherence remained unknown.

1.3 Broad Objective

To assess the effect of HIV disclosure training on ART adherence by HIV positive children in Homa Bay County by 2018.

1.3.1 Specific Objectives

- i. Compare the ART adherence of children before and after training of caregivers on disclosure process in Homa Bay County by 2018.
- ii. Determine the effect of HIV disclosure training on the knowledge of HIV disclosure process by caregivers of HIV positive children in Homa Bay County by 2018.
- iii. Establish the socio-demographic factors associated with ART adherence by HIV positive children after disclosure training of caregivers in Homa Bay County by 2018.

1.3.2 Hypothesis

- i. H_{1o}: There is no difference in the ART adherence before and after training of caregivers on disclosure process in Homa Bay County by 2018.
- ii. H_{2o}: HIV disclosure training has no effect on the knowledge of HIV disclosure process by caregivers of the intervention group.
- iii. H_{3o}: There is no association between socio-demographic factors and ART adherence.

1.4 Significance of the Study

Studies show that disclosure improves adherence to medication (Bernays et al., 2016; Galea et al., 2018; Letta et al., 2015; Madiba, 2019; Wadunde et al., 2018). Training caregivers of HIV positive children on the disclosure process is one way of improving caregiver's ability to disclose to their children HIV status. HIV disclosure training provides evidence – based family interventions that can guide caregivers of HIV positive children on how and when to disclose to a child who unknowingly is HIV positive his/her own HIV status. The disclosure skills gained by the caregivers after the training, has the potential of increasing involvement by caregivers at the household level in driving demand for increased uptake of ARVs and adherence to HIV treatment by children in Homa Bay County, elsewhere in Kenya and beyond. By clearly demonstrating the effect of HIV disclosure training, the findings from the study fill a critical knowledge gap of understanding HIV disclosure process and its contribution to pediatric HIV management in Homa Bay County and in Kenya

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews literature on the burden of pediatric HIV and AIDS; adherence to ART; pediatric HIV disclosure, disclosure training and socio-demographic factors associated with ART adherence.

2.2 Burden of Pediatric HIV and AIDS Globally, Regionally and Locally

The global HIV prevalence among children 0-14 years was 4% by the end of 2022 (UNAIDS, 2022). Sub-Saharan Africa accounted for almost 70% of the global total of new HIV infections. However, the global burden revealed that only half (52%) of the children living with HIV and accessing the life-saving medicines had viral suppression (UNAIDS, 2022). Eastern and southern Africa remained regions most heavily affected by HIV accounting for approximately 55% of all the people living with HIV (UNAIDS, 2022). Global HIV report (UNAIDS, 2022) further revealed that 56% of children 0-14 years from Eastern and Southern Africa were accessing antiretroviral therapy with no data on the number virally suppressed (UNAIDS, 2022).

Kenya has an HIV prevalence of 0.7% for children aged 0-14 years (Kenya National Bureau of Statistics & ICF Macro, 2023). Among children living with HIV in Kenya, 67.5% are virally suppressed (VLS), denoting some level of non-adherence to ART.

Among the counties in Kenya, Homa Bay County in Nyanza has been, and is currently ranked the county with the highest HIV burden in Kenya with a prevalence of 19.6%, which is 4 times the national prevalence (Kenya National Bureau of Statistics & ICF Macro, 2023). Nationally, the county contributes 7.7% (10,722) of children living with HIV. Treatment coverage and viral load suppression among HIV positive children in Homa Bay County are 75% and 85%, respectively, denoting some level of non-adherence among HIV positive children 0-14 years (Kenya National Bureau of Statistics & ICF Macro, 2023).

2.3 Adherence to ART

Medication adherence is important to the survival of people living with HIV as it reduces HIV viral load levels. Optimal adherence to antiretroviral therapy of above >95% is recommended for viral load suppression by the Kenya Ministry of Health (NASCOP, 2022). Treatment coverage and viral load suppression among HIV positive children in Homa Bay

County are 75% and 85% respectively. The viral load suppression rate of 85% among HIV positive children in Homa Bay county is below the stipulated 95% UNAID's viral load suppression recommendation denoting some level of non-adherence among the HIV positive children. Adherence to the recommended ARVs regimen is essential for adequate suppression of viral replication and upsurge of viremia. On the contrary, lack of adherence can lead to intermittent viremia and this may increase the chance of the development of resistant strains of HIV and consequently therapeutic failure.

Recruiting HIV positive pediatrics into ART program is recommended by WHO (WHO, 2013) and WHO strongly believes this strategy would enable them in achieving AIDS free generation. One outcome of an effective ART treatment is that it markedly suppresses the amount of the HIV virus circulating in the blood – the so-called 'viral load' – to a very low level, so that the virus is no longer detectable during routine testing (NASCO, 2018, 2022). Successful ART not only improves the health, lifespan and wellbeing of the person living with HIV and receiving treatment, but there is a growing scientific consensus that effective ART, leading to viral suppression, also means that onward transmission of HIV is eliminated (Rodger et al., 2019). This consensus in the scientific community builds on results from large multi-national research studies (Rodger et al., 2019) which involved both heterosexual and homosexual couples in which one partner was HIV-positive. These studies followed the couples over time and found no transmission from virally suppressed HIV-positive persons to their HIV-negative partner. Study results indicate that an undetectable viral load practically eliminates the risk of someone transmitting HIV once viral suppression has been achieved and maintained. These findings have now been validated by the results of the PARTNER 2 study (Rodger et al., 2019), which followed 1 000 gay male discordant couples between 2010 and 2018 and found no linked HIV transmission despite sex without condoms. Achieving and maintaining an undetectable viral load serves as a very effective prevention method to help interrupt existing transmission chains. While viral suppression means the virus is undetectable in the blood, HIV is only dormant at this stage but still present in the body. Any interruption of the treatment regimen results in viral rebound - making strict adherence to treatment essential (WHO, 2019).

Sub-optimal adherence may include missed or late doses, treatment interruptions and discontinuations and sub therapeutic or partial dosing (NASCO, 2022). Poor adherence to ART, will result in sub therapeutic plasma antiretroviral drug concentrations, facilitating the

development of resistance to one or more drugs in a given ARV regimen and possible cross-resistance to other drugs in the same class. This means that missing more than one dose of a regimen per week may be enough to cause treatment failure. In addition, leading to disease progression, this may result in the development and transmission of drug-resistant viruses which cannot be treated with first line (lower cost) medicines. Multiple factors—including regimen potency, pharmacokinetics, drug interactions, viral fitness, and the genetic barrier to ARV resistance—influence the adherence–resistance relationship (Judd et al., 2020). In addition to compromising the efficacy of the drug regimen, sub-optimal adherence can limit the options for future effective ARV drug regimens in patients who develop multi drug-resistant HIV; it also can increase the risk of secondary transmission of drug-resistant virus (WHO, 2019). Medication formulation and palatability, frequency of dosing, side effects, drug toxicities and a child’s age and developmental stage can also affect adherence (WHO, 2019). The World Health Organization (WHO) defines adherence as the degree to which a patient is able to follow a treatment schedule and take medication at recommended times (WHO, 2016). In the context of HIV, lapses in adherence to medication can lead to the development of viral rebound, which can result in immune-suppression and viral resistance (NASCO, 2022). Adherence by school-aged children who are HIV positive is highly dependent on them knowing their HIV status, which can only happen by a disclosure process done by their caregivers.

Previous studies (Boender et al., 2015; Boerma et al., 2016), reported that 40% of children living with HIV (CLHIV) 0-14 years receiving antiretroviral treatment (ART) and living in low and middle income countries (LMIC) had not achieved viral suppression (ART adherence). Despite the advantages of ARVs, patients with HIV and on ARV treatment can still experience clinical, immunological or virological failures due to lapses in ART adherence (NASCO, 2022).

The Kenya Population Based HIV Impact Assessment report (KENPHIA, 2020), revealed that 98,000 children aged 0-14 years were living with HIV in Kenya in 2020. Among them, only 65% had achieved virologic suppression, translating to only 38% of the final UNAIDS 95-95-95 goal for population-level viral suppression (KENPHIA, 2020).

2.4 HIV Disclosure Training

HIV disclosure training is important as it equips caregivers with necessary skills that make them disclose children’s HIV status. To come up with disclosure training as a strategy of

promoting disclosure to HIV positive children's HIV status by their caregivers, the challenges faced by caregivers while disclosing their children's HIV status must be understood. A study (Joyce et al., 2022). conducted in South Africa at Chris Hani Baragwanath Hospital established that primary caregivers of children with HIV did not disclose HIV status to their children, despite the fact that these children often asked questions about their illnesses. The reasons that they gave for not disclosing included fear of stigma, lack of disclosure knowledge and skills, and emotional unpreparedness. They also felt uncomfortable discussing HIV and illness with children.

The perceived dilemma that was facing caregivers of Homa Bay County was non-disclosure to children living with HIV of their own HIV status. This was also coupled with the fact that there are challenges with voluntary counseling and testing of children. The problem was further compounded by the fact that caregivers were not trained on the disclosure procedures especially for HIV positive children.

Non-disclosure leads to non-adherence and consequently poor treatment outcomes such as treatment failures, increased drug resistance strains, increased viral load and associated risk of HIV transmission to the general population (Hayfron-Benjamin et al., 2018). Caregiver's 'belief that their child is too young, both emotionally and cognitively, to understand the disease and comprehend its implications is one of the most commonly cited reasons for non-disclosure (Mphego et al., 2023). Caregivers may be reluctant to disclose to their HIV-infected child's status because they view it as a distressing moment when the disease is 'named' (Namukwaya et al., 2017). When disclosure of the child's sero-status is likely to result in the exposure of the HIV-positive status of other family members, caregiver's reluctance to disclose the diagnosis may also be motivated by their fear that the child may indiscriminately disclose to others (Sumbasi et al., 2021) and their need to protect the family unit from being stigmatized becomes compromised.

Caregivers may be reluctant to disclose to their children partly because of their anxieties about having to answer questions about their own infection and how the disease entered the family (Lorenz et al., 2016). Caregivers may also be reluctant to disclose to their children due to their fears of exposing the family to stigmatization through accidental disclosure (Sumbasi et al., 2021), their own painful or disappointing disclosure experiences and their feeling uncomfortable about openly discussing HIV/AIDS and its implications with their children. Caregivers may also be reluctant to disclose the HIV diagnosis because they believe that the

child is too young to fully comprehend what being HIV-positive really means. In addition, caregivers' fears that disclosure will negatively affect their child's health by, e.g., hastening disease progression and fears that the child may suffer psychological harm may also be related to non-disclosure (Madiba & Diko, 2021). The caregiver may choose to delay or postpone the disclosure process out of fear of stigma, being identified as a source of HIV infection and therefore feeling guilty, being blamed, or rejected, caregiver's feelings about child's conditions to include; child may mistakenly disclose status to other peers with negative effects, child may react to the news in a negative manner (e.g. blame them, depression, contemplate suicide, abandon the home, stop school, etc.) or that the child or adolescent will find out that the caregiver transmitted the HIV infection to the child, and will feel more guilty of that fact and this too, may make the caregiver delay or postpone the disclosure process (Glaser, 2018).

Literature indicates that disclosure (Bernays et al., 2016; Galea et al., 2018; Letta et al., 2015; Madiba, 2019; Wadunde et al., 2018) positively affects HIV-positive children's adherence to ART. Slowing disease progression has also been observed among children who disclosed their HIV status to friends, compared with those who had not (Odiachi, 2017). The Kenya and WHO guidelines (NASCO, 2022; WHO, 2011) that support child disclosure, recommend the importance of age-appropriate disclosure according to the child's emotional and physical state. Disclosure of pediatric HIV status would enable counties to increase the number of children positive of HIV being enrolled into ART program and reduce the number of children born of HIV. The obvious benefits of disclosure of one's HIV status is the reduction in the risk of transmission of HIV infection associated with the use of successful antiretroviral therapy (NASCO, 2022).

However, persons charged or should be charged with the disclosure responsibility should have proper training on disclosure guidelines especially for children. In view of this, the current study conducted a training intervention for caregivers of children living with HIV on disclosure process in order to equip caregivers with necessary skills to be able to disclose to their HIV positive children their status.

Disclosure skills have been cited in a number of studies (Bulali et al., 2018a; Dessie et al., 2019; Madiba & Diko, 2021) to facilitate HIV status disclosure. These studies (Bulali et al., 2018b; Galea et al., 2018; Guta et al., 2020; Melis Berhe et al., 2020; Mphego et al., 2023), found that training caregivers on HIV status disclosure significantly improves caregiver's

knowledge on the disclosure process. The studies also found that caregivers of HIV positive children should be empowered with practical skills in-order to recognize opportunities to initiate the disclosure process early. This is also consistent with (Madiba, 2019) that found that lack of disclosure skills by caregivers delayed disclosure to Children with Perinatal HIV in resource limited setting.

The Centre for Disease Control supported implementing partners, led by EGPAF, had come up with pediatric HIV disclosure guide which was used for training caregivers in this study. The disclosure guide looked at; disclosure eligibility for children ages 6 – 10, child and caregiver readiness for disclosure, Disclosure –its definition and benefits, barriers to disclosure, basic HIV/AIDs information, ART adherence, child development, age-appropriate task performance, psychosocial support, role plays for caregivers and children, the execution of disclosure and post disclosure assessment.

Before the training, health facilities' own disclosure counselors were trained on pediatric disclosure who later trained the caregivers on the disclosure process. Disclosure training was conducted to caregivers as a routine procedure for three monthly clinic visits at the psychosocial support centers. After the training, the caregivers then conducted HIV status disclosures to their HIV positive children. and a period of 6 months was allowed between disclosure and 1st follow up, similarly a period of 12 months was allowed between disclosure and end-line follow up to establish the effect of disclosure training on ART adherence.

Most studies, (Ayuttacorn et al., 2019; Beima-Sofie et al., 2017; Budhwani et al., 2020; Finnegan et al., 2019) reveal improved adherence to ART following disclosure of HIV status, although no study was found focusing on training caregivers on HIV disclosure process.

2.5 Socio-Demographic Factors Associated with ART adherence

For the greatest success in antiretroviral treatment, adherence should be at 95% or greater (NASCOP, 2022). The need for near-perfect adherence to a lifelong therapy from an early age has been identified as a major challenge in the administration of ART to HIV-infected children (Tanser et al., 2019). According to (Mussa et al., 2022) study, factors associated with poor ART adherence include younger aged caregivers and child recurrent illnesses, while factors conferring good adherence include belief in ART effectiveness and lower HIV clinical stage.

According to UNICEF (UNICEF, 2021), the reasons for poor adherence to ART in children are varied, dependence on caregivers who are frequently ill themselves for ART adherence by HIV positive children is a major contributor to low rates in ART adherence. In a previous study (Haberer et al., 2017) on improving antiretroviral therapy adherence in resource-limited settings revealed that 20 children who had full HIV disclosure literacy, had optimized Art adherence than those with partial HIV disclosure, and so HIV status disclosure promotes adherence to medication. Similarly, in their study in Eastern Europe, another study (Guta et al., 2020) informed that children with disclosed status were significantly associated with ART adherence compared to their counterparts. Additionally, most HIV status disclosure studies (Bernays et al., 2016; Galea et al., 2018; Letta et al., 2015; Madiba, 2019; Wadunde et al., 2018) inform that HIV status disclosure, positively affects HIV-positive children's adherence to ART.

High education levels, have been associated with better health outcomes including adherence to antiretroviral therapy (Raghupathi & Raghupathi, 2020; Zajacova & Lawrence, 2018). Similarly, these studies (Chen et al., 2022; Fonseca et al., 2020; Raghupathi & Raghupathi, 2020; Zajacova & Lawrence, 2018) have also shown positive relationship between level of education and health outcomes. According to a previous study (Tsefahunegn & Gidey, 2023) study, high income level and knowledge of disclosure skill are facilitators of ART adherence.

According to a previous study (Adu et al., 2022) on socio-demographic factors associated with medication adherence among people living with HIV in Ghana, place of residence was significantly influencing medication adherence among people living with HIV. The study found that people with HIV who were residing in urban centers were more likely to adhere to medication as compared to those who resided in rural areas. Contrarily, another study (Tarkang et al., 2024) on socio-demographic and health systems determinants of antiretroviral therapy adherence among human immunodeficiency virus-positive patients in the Volta Region of Ghana found a different outcome; the study found that those living in the urban areas were less likely to adhere to ART than those living in the rural areas. Conversely, the study found a positive relationship between marital status, ethnicity, living place, monthly income, and distance to the ART sites.

Adherence to ART is a complex process that is affected by multiple factors. Individual-level factors such as HIV status disclosure, age, sex, and forgetfulness, have been reported as

important in predicting ART adherence (Ayuttacorn et al., 2019; David et al., 2021; Doat et al., 2019b).

2.6 Theoretical Model

Behavioral scientists working for the U.S Public Health Service developed the Health Belief Model in the 1950s. There was a parallel need to increase use of preventive services such as medical adherence in general and immunization. At the beginning, the Health Belief Model was rooted in information-giving to increase people's awareness of and concern about the serious health risks associated with certain preventable illnesses, including illnesses that could be cured if caught early enough. Health educators also wanted people to understand that they could reduce these health risks by taking certain actions. The psychologists theorized that people are afraid of getting serious illnesses, and that health-related behaviors reflect both a person's level of fear of perceived health threats and the expected fear-reduction potential of taking a recommended action. In short, individuals assess the net benefits of changing their behavior to reduce the threat to their health and decide whether to act (Murphy, 2005).

The model identifies and organizes interventions around four aspects: perceived susceptibility to ill health, or risk perception; perceived severity of ill health; perceived benefits of behavior change; and perceived barriers to taking action. Later, Health Belief theorists added the concept of self-efficacy as a factor in health behavior decision-making. Individuals' perceptions of risks, benefits, and obstacles add up to their readiness to act or lack of readiness. If a person is ready to change behavior to obtain the perceived benefits, health promotion messages—through mass media, peer education, and other interventions—act as cues to action, transforming readiness into overt behavior.

These cues are particularly important when unhealthy behaviors are habitual such as smoking. The Health Belief Model can also help identify leverage points for change. A caregiver who is fearful to disclose to a child under his/her care the HIV positive status, can be coached on proven ways to disclose child's HIV status to the child. The Health Belief Model of behavioral change was later categorized as individual centered. The model assumes that people are rational and will do the right thing once they are provided with adequate information and understand that change is in their personal self-interest. The model would be effective unless a person is neither concerned about nor afraid of negative health

consequences, or is simply not rational, or not currently in a rational frame of mind (e.g., when intoxicated).

Behavioral researchers came to realize that complex health behaviors such as those involving sexual intercourse or addiction take place in a dynamic (i.e., reciprocally influential, social and cultural context, and an individual's thinking and decision-making reflect this context (Sweat & Denison, 1995). The Health Belief Model was originally based on four cognitive constructs: a) Perceived susceptibility (individual's assessment of the risk of becoming ill, that is, realizing an unwanted outcome), b) Perceived severity (individual's assessment of the seriousness of the illness, condition, or unwanted outcome, and the potential consequences), c) Perceived barriers (individual's assessment of the influences that discourage adoption of the promoted action or new behavior), and d) Perceived benefits (individual's assessment of the positive consequences of adopting the promoted action).

The Health Belief Model has also been adapted to include the construct of self-efficacy, the belief that one is capable of carrying out the behavior change through coaching or training. Consequently, it is sometimes referred to as the Expanded Health Belief Model (Strecher & Rosenstock, 1997). Based on the afore mentioned Health Belief model constructs of; perceived severity of the condition, cues to action, perceived benefits of preventive action and self-efficacy, the study conducted an HIV disclosure training intervention for caregivers on disclosure process as a way of achieving self-efficacy to conduct HIV disclosure to their HIV positive children with an aim of making the children autonomous at taking their ART, subsequently culminating into ART adherence. Figure 2.1 shows the conceptual framework.

2.7 The Conceptual Framework

The conceptual framework that guided the study is summarized in table 2.1.

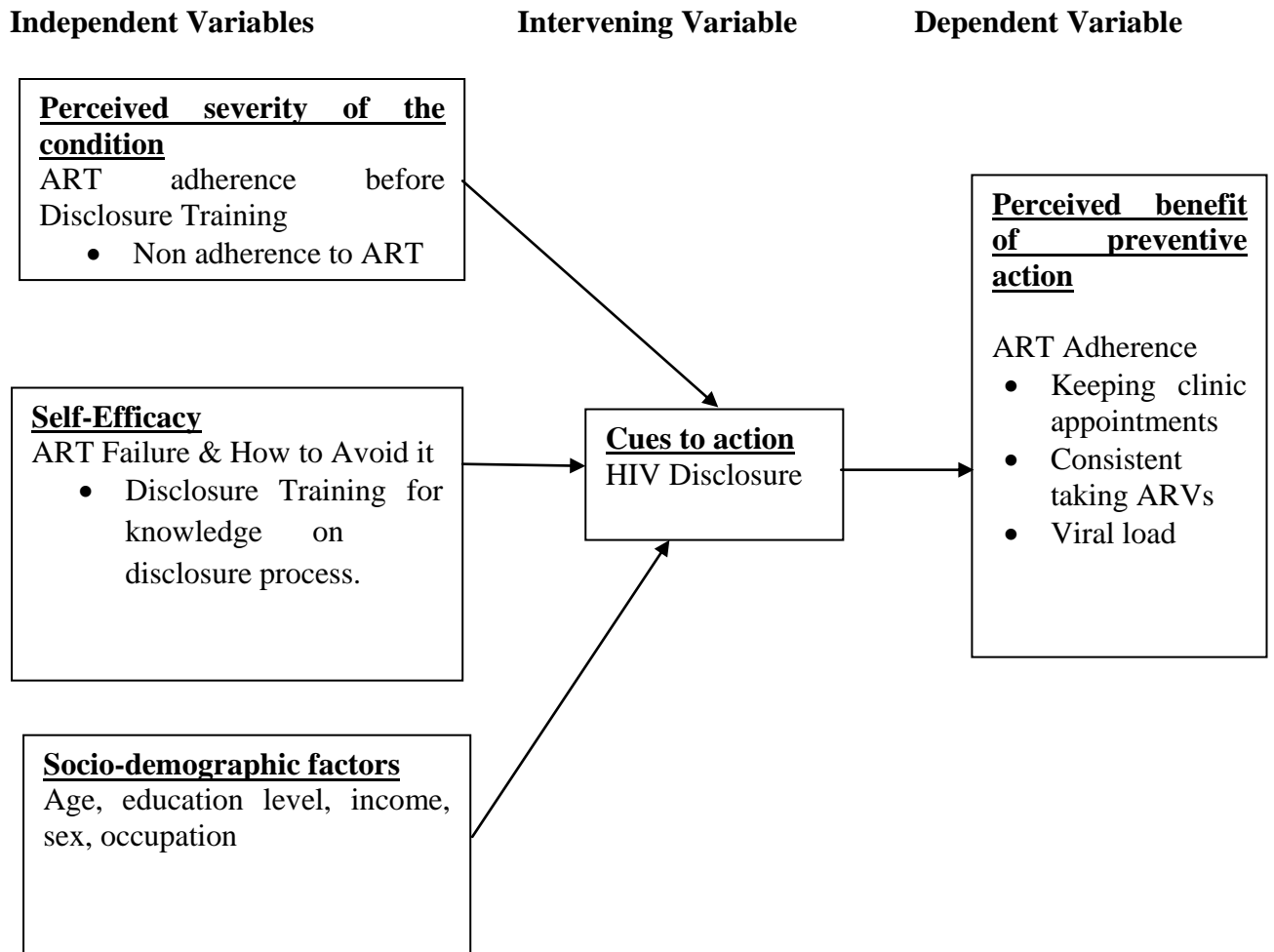


Figure 2.1: Application of the Expanded Health Belief Model to HIV Management

CHAPTER THREE

MATERIALS AND METHODS

3.1 Introduction

This chapter describes the study area, design, study population, inclusion and exclusion criteria, sample size determination and sampling strategy, data collection process, recruitment and training of research assistants and enumerators, data management and analysis, and ethical consideration.

3.2 Study Area

The study was conducted in Homa Bay County which is located in the south western part of Kenya along the shores of Lake Victoria. It borders Kasipul Kabondo and Kabondo Kasipul Sub-Counties to the North, Kisii to the East, Migori to the South and Suba to the West (Appendix 1). The county is made up of eight sub counties namely; Suba, Mbita, Kasipul Kabondo, Kabondo Kasipul, Ndhiwa, Rachuonyo North, Rangwe and Homa Bay Township. The study was conducted in ten health facilities located in six 6 out of the eight 8 sub-counties namely; Homa Bay County referral hospital, Ndhiwa Sub-County Hospital, Kendu Sub-County hospital, Rangwe Sub-County hospital, Kandiege Level 4 Hospital, Kabondo Sub-County Hospital, Kasipul Sub-County Hospital Othoro Level 4 hospital, Ober Level 4 Hospital and Nyang’iela Health Centre. The county was chosen because it is the county with the highest HIV burden among the 47 counties in Kenya, with HIV prevalence of 19.6% which is four times the national prevalence. Nationally, the county contributes 9.9% (128,199) of adults and 7.7% (10,722) of children living with HIV. The choice of the Sub-counties was based on EGPAF support as an implementing partner, and the study targeted high volume sites that could give the required sample size for generalizability. Table 3.1 and 3.2 show the health facilities with the population of HIV positive children with status non-disclosed.

Table 3.1: HIV positive children with HIV status non-disclosed (Intervention group)

Health facility	Sampling Frame (Non-Disclosed)	
	Population 6-10 years)	Sample size
Homa Bay County Referral Hospital	198	$198/473 \times 430 = 180$
Kendu Sub-County Hospital	99	$99/473 \times 430 = 90$
Ndhiwa Sub-County Hospital	75	$75/473 \times 430 = 68$
Rangwe Sub-County Hospital	49	$49/473 \times 430 = 45$
Kandiege Level 4 Hospital	52	$52/473 \times 430 = 47$
Total	473	430

Table 3.2 HIV positive children with HIV status non-disclosed (Control group)

Health facility	Sampling Frame (Non-Disclosed Population 6-10 years)	Sample size
Kabondo Sub-County Hospital	98	$98/451 \times 430 = 93$
Kasipul Sub-County Hospital	174	$174/451 \times 430 = 166$
Othoro Level 4 Hospital	80	$80/451 \times 430 = 76$
Nyang'ieia Health centre	45	$45/451 \times 430 = 43$
Ober Level 4 Hospital	54	$54/451 \times 430 = 52$
Total	451	430

3.3 Study Design

A comparative longitudinal study design was adopted for the study whereby caregivers of HIV positive children aged 6 – 10 years were grouped into two categories of control and intervention groups. One category was taken through disclosure training (intervention) while the other group (control) was not taken through a disclosure training using CDC pediatric disclosure guidelines (CDC, 2014). Baseline information on children's ART adherence was gathered and compared with mid-line (six month's ART adherence and End-line 12 month's ART adherence) after disclosure training of caregivers in the intervention group. Randomization was done by sites because the study participants were from different health facilities and could not be grouped together. Study participants from each health facility were proportionately selected from the sampling frames using simple random sampling.

3.4 Study Population

The study focused on HIV positive children aged 6-10 years plus their caregivers. This is the age recommended in the CDC pediatric disclosure guideline (CDC, 2014) and the Kenya ART guideline for HIV status disclosure in children.

3.4.1 Inclusion Criteria

- i. The children were HIV positive, 6-10 years, on ART, non-HIV status disclosed and residents of Homa Bay County.
- ii. The caregivers were of children who were HIV positive, residents of Homa Bay County for the last three months before and 1 year after recruitment into the study to allow for participation in the 1st and 2nd follow ups.
- iii. Eligible individuals who voluntarily gave consent to participate in the study.

3.4.2 Exclusion Criteria

- i. Participants who could not give consent/assent to participate in the study were excluded.
- ii. Participants who showed interest of participating in the study but had their HIV status disclosed to them were also excluded.

3.4.3 Sample Size Determination

A representative sample size at a confidence level of 95% and an error margin of $\pm 5\%$ was determined from a population of 16,500 children who were in need of ART in Homa Bay County using the sample size determination formula of Yamane *et al.*, (1967). Yamane was most appropriate because the population size was known i.e 16,500 and above 10,000. A total of 10% of the calculated sample size was added to buffer for losses to follow ups, withdrawals and missing participants.

$$n = N / (1 + N(e^2))$$

Where n = the sample size

N= total population (16,500)

e = level of precision or error margin (0.05).

$$n = 16,500 / (1 + 16,500 * (0.05)^2)$$

$$= 16,500 / 35.3625$$

=391 (+10% of the calculated sample size), the corrected sample size was 430). Because the study had both experimental and control group and children plus their caregivers, the control group had 430 HIV positive children from EGPAF's supported comprehensive care centers (CCC) in Homa Bay County. Similarly, the experimental group had another 430 HIV positive children from EGPAF's supported comprehensive care centers (CCC) in Homa Bay County.

3.4.4 Sampling Strategy

The study used simple random sampling method to proportionately select the 860 non-disclosed HIV positive children aged 6 to 10 years, from a sampling frame of 924 non-disclosed HIV positive children aged 6-10 years from Elizabeth Glaser Pediatric AIDs Foundation (EGPAF) supported comprehensive care centers (CCC) in Homa Bay County.

3.5 Data Collection Process

3.5.1 Pre-Testing of Questionnaires

A pre-test of the questionnaires and disclosure training tool were carried out in two randomly selected Sub-county not for study site with a goal of getting varied pretest experiences from different possible groups of respondents, including those who might understand or react to

the questions in different ways, with different levels of information available, or with different abilities to answer the questionnaire—different experiences (Perneger et al., 2015). After identifying and recruiting respondents to participate in the pre-testing, we made appointments with the pre-test respondents allowing about 2 to 3 times much time for the pre-test to just complete the questionnaires. When making the appointments, it was made very clear to the pre-testing respondents that it was just to pre-test the survey instruments as part of the development of planning stages. They were also informed that the study team were interested in the subject’s reaction to and understanding of the questions and so needed their assistance to help improve the instrument before sending it out to collect actual responses.

3.5.2 Baseline Information

Baseline information was gathered from patient’s blue cards on ART adherence status i.e viral load (VL) status of patients, keeping clinic appointments and consistency in taking ARVs) prior to HIV disclosure training of caregivers that formed a basis for comparison with midline and end-line ART adherence information.

3.5.3 Pilot Study

The purpose for the pilot study was to establish the study feasibility before the main study. The pilot study sample was 86 respondents which was in line with the recommendations of Morgan (2017) who asserts that sample size population should be at least 10% of the sample size of the study. The pilot study was done in two facilities not study sites. The study used Cronbach’s alpha to test the internal consistency of the questionnaires based on the pilot study data. The results for the reliability analysis for the knowledge of caregivers on the disclosure process are as shown in Table 3.3.

Table 3.3: Reliability Analysis for Knowledge of Caregivers on Disclosure Process

Item	Cronbach's Alpha if Item Deleted
Knowledge on HIV pediatric status disclosure	0.736
When is it appropriate to disclose to a child their own HIV status	0.756
What is it that is involved in child reassurance before a disclosure session may start	0.767
What do you need to prepare for a pediatric disclosure session	0.733
Who should be present during a pediatric disclosure session	0.734
Free from severe illness or abnormal behavior	0.766
At what age of the child should their own HIV status be disclosed	0.743
Child has reached the right age to know their own HIV status	0.752
In your opinion who should disclose to your child his/her own HIV status	0.735
Overall Cronbach’s Alpha	0.745

The study revealed that the items on the knowledge of caregivers on disclosure process were reliable with a Cronbach's alpha of 0.745. Therefore, these items were adopted for the questionnaire in the main study. Table 3.4 shows the reliability results for ART adherence items in the questionnaire.

Table 3.4: Reliability Analysis for ART Adherence

Item	Cronbach's Alpha if Item Deleted
The child keeps his/her appointment dates	0.858
Last time to pick her ARVs	0.837
Consistency of the child in Taking his/her ARVs	0.846
Do you always go to pick your drugs from the hospital	0.841
How do you feel when you go to pick your drugs	0.844
Does anyone accompany you to pick your drugs	0.835
How far is the health facility where you pick your drugs	0.840
Do you use some means of transport to go to the health facility where you pick your drugs	0.861
Do you always have money to use for transport	0.853
Does anyone usually remind you to take your drugs	0.841
Overall Cronbach's Alpha	0.845

The study revealed that the items on ART adherence were reliable with respect to Cronbach's Alpha test of internal consistency. With respect to this, the study revealed a Cronbach's Alpha of 0.845. Therefore, the questionnaires were adopted for the main study based on the reliability results of the pilot study.

3.5.4 Data Collection Instruments

Data collection instruments were semi-structured, interviewers-administered questionnaires, key informant interviews and focused group discussions. The instruments were pre-tested to ensure reliability. We used semi structured questionnaires to collect quantitative data from 860 participants and the questionnaires were available in both English and Dholuo translations. The questionnaires (Appendix 2) collected participants' socio-demographic profiles, caregivers' knowledge on disclosure process and information pertaining to ART adherence. Focus Group Discussion (FGD) (Appendix 3) collected data on caregivers' disclosure process, factors facilitating and hindering pediatric disclosure and ART adherence before and after disclosure training. FGD discussants were caregivers of the children selected from the study facilities. The four Sub-County hospitals gave three caregivers each, while the rest of the health facilities gave 2 participants each totaling to 24 participants. Four adult FGDs (2 control, 2 intervention), comprising of 12 males, 12 female caregivers were conducted. Key Informant Interviews (Appendix 4) focused on viral load status of HIV status

disclosed and non-disclosed children, relationship between adherence and viral load, contribution of caregiver's disclosure training to treatment adherence and viral load, barriers to HIV status disclosure and treatment adherence. Key Informant Interviews were conducted with health care providers (6 females, 6 males) from the study comprehensive care centers.

3.5.5 Recruitment and Training of Research Assistants and Enumerators

Two facility's own Disclosure Counselors (DCs) from each health facility in the intervention group were recruited into the study and trained on CDC disclosure guide (Appendix 5). A total of 10 Disclosure Counselors were trained. After which, they trained caregivers of HIV positive children on disclosure process in the intervention group. Control groups which had no disclosure training also recruited 2 facility's own Disclosure Counselors, 10 in total who provided routine literacy to caregivers on benefits of HIV status disclosure and ART adherence. The counselors were also enumerators who administered the questionnaires to the study respondents. A research assistant was also recruited and trained on the study aspects to oversee the data collection process per facility. The research assistants were clinicians at the comprehensive care centers (CCC) providing care and treatment to HIV positive clients. The research assistants verified accuracy of the collected data on-site.

3.6 HIV Disclosure Training: The Intervention

The intervention involved training of caregivers on pediatric HIV status disclosure process using a standardised CDC supported HIV partner's disclosure guideline/tool (Appendix 5). The trained caregivers under the supervision and support of a healthcare worker were then required to conduct an HIV status disclosure to their HIV positive children aged 6 – 10 years. The Centre for Disease Control supported implementing partners, led by EGPAF, had come up with pediatric HIV disclosure guide due to lack of a standardized tool to guide healthcare workers on pediatric disclosure process. The disclosure guide looked at disclosure eligibility for children (ages 6 – 10 years); child and caregiver's readiness for disclosure, the execution of disclosure and post disclosure assessment. The CDC supported implementing partner's disclosure guideline, also has components that ensure re-assurance; comfort of caregiver and the child during disclosure; safety, which is defined by the presence of conduciveness of the disclosure environment, location of disclosure room that must not be near open windows; absence of portable equipment that can be used to execute violence. The guideline also has sections that are meant to assess the knowledge of a child on basic HIV and AIDS information, knowledge of disclosure and benefits associated with disclosure.

Before the training, health facilities' own disclosure counselors were trained on pediatric disclosure who later trained the caregivers on the disclosure process. Disclosure training was conducted to caregivers in the intervention group as a routine procedure for three monthly clinic visits at the caregiver's psychosocial support groups in their respective health facilities by trained Disclosure counselors. The control group received routine adherence counseling sessions and taught benefits of HIV status disclosure. After the training of caregivers on disclosure process, both group caregivers performed disclosure to their HIV positive children, and a period of 6 months was allowed between disclosure and 1st follow up, similarly a period of 12 months was allowed between disclosure and end-line follow up to establish the effect of disclosure training on ART adherence.

The training covered; disclosure eligibility for children ages 6 – 10, child and caregiver readiness for disclosure, Disclosure –its definition and benefits, barriers to disclosure, basic HIV/AIDs information, ART adherence, child development, age-appropriate task performance, psychosocial support, role plays for caregivers and children, the execution of disclosure and post disclosure assessment as follows:

3.6.1 The Disclosure Training Guide

Training Objective: To know what disclosure is, when and why to disclose to HIV+ children their status.

Pre-test

Group Discussion per facility: In 5 groups, discuss the following questions (15 mins):

- Why are caregivers reluctant to tell their children their status?
- What do HIV positive children say about coming to hospital/clinic; their illness or HIV?
- Do you believe children should be informed of their HIV status-if yes/no, why?
- Define disclosure. When is the right time to tell children that they have HIV?
- How does telling a child that they have HIV differ from an adult disclosing own status?

Other training contents

- i. Child development stages (psychomotor stages, milestones and age-appropriate task performance, understanding of health and death).
- ii. Child school functionality (consistent school attendance, interacts well with the school community, able to freely discuss school activities, etc.).

- iii. Disclosure- definitions, partial disclosure and full disclosure.
- iv. Why are caregivers Reluctant to Tell their Children their status?
- v. What are the Reasons to Disclose a Child's HIV Status?
- vi. When to disclose? Disclosure readiness, availability of family, peer support or social support.
- vii. Who to disclose?
- viii. Communicating with children, Challenges of communicating with children, confidentiality of information.
- ix. HIV-definition and ART adherence.
- x. Execution of disclosure, role plays and post disclosure assessment.

Post-test:

Group Discussion per facility: In 5 groups, discuss the following questions (15 mins):

- i. Why are caregivers reluctant to tell their children their status?
- ii. What do HIV positive children say about coming to hospital/clinic; their illness or HIV?
- iii. Do you believe children should be informed of their HIV status-if yes/no, why?
- iv. Define disclosure. When is the right time to tell children that they have HIV?
- v. How does telling a child that they have HIV differ from an adult disclosing own status?

3.7 Retention Activities

The study relied on the clinic-based retention activities i.e. text message reminders, phone calls, home visits, for missed clinic appointment and loss-to-follow-up tracing. It was expected that these efforts would minimize losses to follow up and helped the research to maintain sufficient study participants to estimate the study outcomes well and lessen any bias due to missing outcomes.

3.8 Data Management and Analysis

The study used the IBM Statistical Package for Social Sciences Version 28 to analyze the quantitative data. The study provided descriptive statistics for study socio-demographic characteristics of participants. Pearson's Chi-square test was used to statistically compare adherence between intervention and control groups after disclosure training of caregivers. The study used logistic regression to establish the likelihood of either adherence or failed adherence at mid line and end-line viral loads. Additionally, multivariate logistic regression

was used to estimate associations between viral suppression and all potentially related individual-level factors (such as age, education levels, household income, occupation, gender, disclosure knowledge), in order to explore predictors of ART adherence. Additionally, relative risk of ART adherence was calculated.

For the qualitative data, the audio recordings were transcribed into MS, word transcription template with the aid of Express scribe transcription software. The English transcripts were imported into qualitative analysis software (NVivo) package for coding. The study used exploratory and inductive approaches. Requisite code sheet was then created from the participants' responses and from these, a master code sheet was developed and responses were coded using NVivo 12 PRO software. Each code and sub-code were numbered serially to reflect the analysis hierarchy.

3.9 Ethical Considerations

Ethics approval for the study conduct was granted by the Maseno University Ethics Review Committee (Ref: MSU/DRPI/MUERC/00386/17) (Appendix 6), further permission was granted by the Homa Bay county Ministry of health department permitting the conduct of the research in the specified health facilities. Caregivers of the eligible children were approached and invited to participate in the study during regular clinic visits. Caregivers expressing interest in participating in the study were given full explanation of the study and its importance. They (caregivers) were then taken through individual written consent in their preferred language by research assistant fluent in the local languages. Those who agreed to be part of the study were made either to sign or thumbprint a consent form (Appendix 7). The PI ensured that no identifiable information that could be traced to any participant was captured in the questionnaire. There were no foreseeable risks attached to this study and information generated out of the study was treated as confidential and stored in pass worded computers only accessible by the principal investigator. Families that did not wish to participate in the study, continued to receive standard HIV services at their respective health facilities.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the empirical findings from the study. First, socio-demographic characteristics of the study participants are presented. Thereafter, results are presented as per specific objectives.

4.2 Socio-demographic Characteristics of Study Participants

The socio-demographic characteristics of study participants are presented in Table 4.1. The test for the difference in distribution of categorical variables of socio-demographic characteristics between the intervention and control group, was done using Chi-square (χ^2) test. The study established there were significant differences between the intervention group and control group in the distribution of gender of caregiver ($\chi^2 = 10.367$, $df = 1$, $p < 0.05$) and their education level ($\chi^2 = 10.367$, $df = 1$, $p < 0.05$) at 5% significance level. However, the marital status of the caregivers across the two groups was not significantly different ($\chi^2 = 6.034$, $df = 4$, $p > 0.05$) at 5% significance level. It was also found that there were significant differences in the level of education of household heads ($\chi^2 = 49.361$, $df = 5$, $p < 0.05$) and their occupation ($\chi^2 = 72.217$, $df = 4$, $p < 0.05$) between the control and intervention group at 5% significance level. The size of household was revealed to be significantly different ($\chi^2 = 9.965$, $df = 2$, $p < 0.05$) across the intervention and control group at 5% significance level. At 5% significance level, the gender of the children was found to be significantly different ($\chi^2 = 16.862$, $df = 1$, $p < 0.05$) between the control and intervention group. The results imply that most of the socio-demographic characteristics of the respondents were significantly different between the control and intervention group as explained by their natural occurrence in nature such as gender and individual preferences and efforts such as education, occupation and household size.

Table 4.1: Socio-demographic Characteristics of the Study Participants

Socio-Demographic Characteristic	Categories	Group			Pearson Chi-Square
		Intervention	Control	Total	
Age of Caregivers	18-25	20	45	65	$\chi^2 = 19.546$ df = 4 p < 0.05
	26-35	198	207	405	
	36-45	143	130	273	
	46-55	42	39	81	
	Above 55	27	9	36	
	Total	430	430	860	
Gender of Caregivers	Mean Age	37.2	35		
	Male	58	93	151	$\chi^2 = 10.367$ df = 1 p < 0.05
	Female	372	337	709	
Total	430	430	860		
Level of Education of Caregivers	None	11	33	44	$\chi^2 = 56.461$ df = 5 p < 0.05
	Primary incomplete	146	74	220	
	Primary complete	139	112	251	
	Secondary incomplete	58	101	159	
	Secondary complete	65	90	155	
	Tertiary	11	20	31	
Level of Education Household Head	Total	430	430	860	
	None	9	19	28	$\chi^2 = 49.361$ df = 5 p < 0.05
	Primary incomplete	108	65	173	
	Primary complete	124	98	222	
	Secondary incomplete	61	85	146	
	Secondary complete	113	104	217	
Tertiary	15	59	74		
Marital Status of Caregivers	Total	430	430	860	
	Single, Never married	11	22	33	$\chi^2 = 6.034$ df = 4 p > 0.05
	Married	272	257	529	
	Divorced	8	12	20	
	Separated	16	10	26	
	Widowed	123	129	252	
Total	430	430	860		
Size of Household	[1-2]	29	10	39	$\chi^2 = 9.965$ df = 2 p < 0.05
	[3-5]	195	205	400	
	6 and Above	206	215	421	
	Total	430	430	860	
Occupation of Household Head	Peasant farmer	133	158	291	$\chi^2 = 72.217$ df = 4 p < 0.05
	cattle keeper	91	23	114	
	Trader	94	169	263	
	Formal employment	65	56	121	
	Others	47	24	71	
	Total	430	430	860	
Yearly income in Kshs.	0-100,000	259	245	504	$\chi^2 = 2.432$ df = 4 p > 0.05
	100,001-200,000	92	96	188	
	200,001-300,000	39	36	75	
	300,001-400,000	16	22	38	
	>4000	24	31	55	
	Total	430	430	860	
Age of the children	6	52	71	123	$\chi^2 = 16.862$ df = 1 p < 0.05
	7	66	92	158	
	8	87	96	183	
	9	108	82	190	
	10	117	89	206	
	Total	430	430	860	
Gender of the Child	Mean Age	8.4	8.06		
	Male	203	263	466	$\chi^2 = 16.862$ df = 1 p < 0.05
	Female	227	167	394	
Total	430	430	860		

The mean ages of the children in both control and intervention groups were 8 years, respectively. Children in the control group comprised of more males 263(61.2%) than those in the intervention group 203(47.2%), while the intervention group had more female children 227(52.8%) than control group 167(38.8%). Mean ages of caregivers in the study were 35 and 37 years for control and intervention groups respectively. The study had more male caregivers in the control group 93(21.6%) than intervention group 58(13.3%), while female caregivers were more 372(86.7%) in the intervention group than in the control group 337(78.4%).

4.3 Comparing the ART Adherence of Children Before and After Training of Caregivers on Disclosure Process in Homa Bay County

4.3.1 Viral Load of the Patients

Viral load was used as the proxy for ART adherence. The proportion of children with suppressed viral load (<1000 copies) increased in the control group from 279(64.9%) at baseline to 287(66.7%) within a period of six months (mid line) and to 296(70.1%) within a period of 12 months (end line). Similarly, the proportion of children with suppressed viral load (<1000 copies) increased in the intervention group from 345(80.2%) at baseline to 357(83.0%) within a period of six months (mid line) and to 384(90.1%) within a period of 12 months (end line). The difference between the improvement in viral load levels between baseline, mid line and end-line for both control and intervention group gives the effect of training of caregivers on disclosure aspect as shown in Table 4.2.

Table 4.2: Changes in Viral Load of the Patients Following Disclosure Training:

	Control n(%)	Intervention n(%)	Total n(%)^a
Baseline Viral Load of patient			
<1000copies	279(64.9)	345(80.2)	624(72.6)
>1000copies	151(35.1)	85(19.8)	236(27.4)
Total	430 (100%)	430 (100%)	860 (100%)
Mid line Viral Load of patient			
<1000copies	287(66.7)	357(83.0)	644(74.9)
>1000copies	140(32.3)	71(16.5)	211(24.5)
Missing (Lost to follow-up)	3(0.7)	2(0.5)	5(0.6)
Total	430 (100%)	430 (100%)	860 (100%)
End line Viral Load of patient			
<1000copies	296(70.1)	384(90.1)	680(79.1)
>1000copies	126(29.3)	42(9.8)	168(19.5)
Missing (Lost to follow-up)	8(1.9)	4(0.9)	12(1.4)
Total	430 (100%)	430 (100%)	860 (100%)

^aProportionality test performed using Chi-square

Disclosure training had significant effect on ART adherence of children. Children whose care givers were trained (intervention group) were nine times (OR=9.145) more likely to have good adherence to ART (suppressed viral load) with respect to HIV disclosure training for caregivers. Additionally, in terms of relative risk (RR), the control group had a comparatively higher risk of viral non-suppression than the intervention group (6 months: RR = 1.96, 95% CI = 1.536 – 2.583; end line: RR = 3.028, CI = 2.194 – 4.180). Indeed, these results were also supported out by KIIs and FGDs as reported below.

“Before disclosure, viral load was high, after disclosure, the viral load went down” [FGD-INT-01]

“Before disclosure, the viral load was high, after disclosure, the viral load reduced and I just encouraged him to continue with the medicines in time.” [FGD-CNT-04]

A participant reported to have been relieved from frequent visits to the hospital after disclosure since the child gained knowledge and understanding of why he was taking the drug;

” After disclosure I got relief because we could come to the clinic quite often before because viral load was worse, virus level increased so much, after we had the reasons why the viral load was high, we rectified the problem, the child now takes the medicine well and was given longer return date period to the clinic because the viral load was good. This also reduced burden on transport costs to the clinic. The viral load is good; the child is very healthy.” [FGD-INT-05]

One participant clearly elaborated how the child turned out to be responsible after disclosure and attributed a decrease in viral load due to disclosure.

“Before disclosure, the child could miss doses due to lack of understanding as to why he should take the medicines and so the viral load was high, after disclosure the viral load reduced” [FGD-CNT-05].

This finding concurred with responses from the KII where most HCWs reported a decrease in the viral load after disclosure of the HIV status of children;

“Those who know their HIV status, they do better as oppose to those who don’t know why they are taking drugs. Sometimes they think they are taking drugs for somebody, when someone knows why he/she takes drugs, he tends to take his life seriously and will take the drugs as is wanted, automatically the outcome of the viral load will be good as opposed to one who doesn’t know status.” [KII-CNT-01]

Health care workers clearly stated the comparison between viral load status for children whose status are known and those unknown.

“Children who understand their status and know why they are taking drugs have their viral load suppressed. For the disclosed cohort, we have good adherence and good viral suppression achieved compared to the children who have not been disclosed.” [KII-CNT-02]

The themes and sub-themes of the discussants views are depicted below in table 4.3

Table 4.3: Themes and Sub-Themes

THEMES	SUB-THEMES
1.Viral load status among children with HIV	Comparing viral load before and after disclosure
2.Factors associated with adherence	Knowledge on disclosure Drug side effects HCWs attitude Dosage pattern Environmental factors Pill burden Change in caregiver
3.Process of Disclosure	<u>Trained Caregivers</u> Considered age of child Ensured privacy Disclosed in stages Introduced red and green germs
10.Factors hindering disclosure	<u>Untrained Caregivers</u> Reported accidental disclosure Consulted clinician Child learnt on their own Psychosocial support groups Lack of Disclosure knowledge Age of a child Disability among children Culture and religion Fear amongst caregivers

Summary of themes and sub-themes considered in the study.

4.3.2 Consistency in Taking ARVs and Keeping Clinic Appointments between Intervention and Control Groups

Consistent taking of anti-retroviral drugs of >95% is recommended by National Syndemic Disease Control Council (NSDCC) as good adherence. Consistency in taking ARVs was determined through pill count at the pharmacy during drug refill. Consistency in taking ARVs improved overtime in both control from 281(65.3%) at baseline to 286(66.5%) within a period of six months (mid line) and to 301(70.0 within a period of 12 months (end line).

Intervention group improved from 347(80.7%) at baseline, to 369(85.8%) within a period of six months (mid line) and to 411(95.6% within a period of 12 months (end line). Keeping clinic appointments dates also improved in both control from 351(81.6) at baseline to 359(83.5) within a period of six months (mid line) and to 398(91.6) within a period of 12 months (end line). Keeping clinic appointments within the intervention group improved from 349(81.2%) at baseline to 421(97.9%) within a period of six months (mid line) and to 425(99.1) within a period of 12 months (end line). Table 4.4 indicates comparison of keeping clinic appointments and consistency in taking ARVs by HIV positive children in Homa Bay County.

Table 4.4: Consistency in Taking ARVs and Keeping Clinic Appointments

	Baseline		6 month's FU		End-line	
	Control n(%) ^a	Intervention n(%) ^a	Control n(%) ^a	Intervention n(%) ^a	Control n(%) ^a	Intervention n(%) ^a
Keeping clinic appointments						
Yes	351(81.6)	349(81.2)	359(83.5)	421(97.9)	398(92.5)	425(99.1)
At Times	79(18.4)	81(18.8)	68(15.8)	7(1.6)	24(5.6)	1(0.0)
Missing (LTFU)	0(0.0)	0(0.0)	3(0.7)	2(0.5)	8(1.9)	4(0.9)
Consistency in taking ART						
Consistent	281(65.3%)	347(80.7%)	286(66.5%)	369(85.8%)	301(70.0)	411(95.6)
Not Consistent	149(34.7)	83(19.3)	141(32.7)	59(13.7)	121(28.1)	15(3.5)
Missing (LTFU)	0(0.0)	0(0.0)	3(0.8)	2(0.5)	8(1.9)	4(0.9)

^aProportionality test performed using Chi-square

Pearson's Chi-square test was used to compare adherence levels between intervention and control groups. Pearson Chi-square tested whether the difference caused by the training of care givers was significant and whose results are shown in Table 4.5. Chi-square test established significant difference in adherence levels between the intervention and control group (p-value <0.001). Based on regression analyses, the risk of non-adherence to ART in control was twice and eight times higher at 6 months and 12 months than in the intervention group (6 months: RR= 2.395, 95% CL = 1.884-3.147: end line: RR=8.143, 95% CL= 4.844-13.688).

Table 4.5: ART Adherence between the Control and Intervention Groups

	Category	Type Intervention ^a	Control ^a	P-value
The end-line viral load of patient	Viral load > 1000 copies	42(25.0%)	126(75.0%)	<0.001
	Viral load < 1000 copies	384(56.5%)	296(43.5%)	
	Missing (LTFUP)	4(33.3%)	8(66.7%)	
	Total	430(50.0%)	430(50.0%)	

^aProportionality test performed using Chi-square

4.3.3 Keeping Clinic Appointments

Based on regression analyses, the risk of not keeping clinic appointments were 10 times and 24 times higher after 6 months and 12 months in the control group compared to the intervention group (6 months: RR = 9.737, 95% CL = 4.525-20.953; end line: RR = 24.227, 95% CI = 3.292-178.276).

4.4 Effect of HIV Disclosure Training on the Knowledge of HIV Disclosure Process by Caregivers of HIV Positive Children in Homa Bay County

Knowledge on HIV disclosure process was comparatively measured after the training of caregivers in as shown in Table 4.8. The results in Table 4.8 indicate that trained care givers on HIV disclosure were 1.486 times likely to have good knowledge on appropriate time to disclose to a child his/her own HIV status (OR=1.486; 1.225-1.801) at 95% confidence interval. The study further noted that at 95% confidence interval, training care givers on HIV disclosure process increased the odds of understanding what is involved in child reassurance before a disclosure by 4.972 times OR=4.972; 3.860-6.405). At 95% confidence interval, HIV disclosure training also increased the knowledge on what is needed to be prepared for a pediatric disclosure session by 18.545 times as shown by OR=18.545 with lower bound as 12.076 and upper bound as 28.480. However, at 95% confidence interval, training of care givers on HIV status Disclosure did not increase the odds of understanding on who should be present during a pediatric disclosure session, understanding severity of illness or abnormal behavior, the age at which a child should be disclosed to their own HIV status and the level of understanding on who should disclose to a child his or her own HIV status. This is evidenced by OR below 1.0 and negative beta coefficients (B). This therefore implies that training of care givers on HIV disclosure process helps in improving knowledge on appropriate time to disclose to a child their own HIV status, what is involved in child reassurance before a disclosure and knowledge on what is needed to be prepared for a pediatric disclosure session as shown in Table 4.6.

Table 4.6: Effect of HIV Disclosure Training on Knowledge of Disclosure Process

Variable	Level of Knowledge	Group		B	S.E.	Wald	df	Sig.	OR	95% CI	
		I	C							Lower	Upper
When is it appropriate to disclose to a child their own HIV status	Good Knowledge	430	173	0.396	0.098	16.197	1	<0.001	1.486	1.225	1.801
	Poor Knowledge	0	257								
What is it that is involved in child reassurance before a disclosure session may start	Good Knowledge	430	72	1.604	.129	154.200	1	<0.001	4.972	3.860	6.405
	Poor Knowledge	0	358								
What do you need to prepare for a pediatric disclosure session	Good Knowledge	360	22	2.920	.219	178.011	1	<0.001	18.545	12.076	28.480
	Poor Knowledge	70	408								
Who should be present during a pediatric disclosure session	Good Knowledge	270	285	-.676	.102	43.886	1	<0.001	0.509	0.417	0.621
	Poor Knowledge	160	145								
Free from severe illness or abnormal behavior	Good Knowledge	429	312	-0.972	.108	80.944	1	<0.001	0.378	0.306	0.467
	Poor Knowledge	1	118								
At what age of the child should their own HIV status be disclosed	Good Knowledge	429	276	-0.583	.101	33.649	1	<0.001	.558	0.458	0.680
	Poor Knowledge	1	154								
Child has reached the right age to know their own HIV status	Good Knowledge	426	410	-3.020	.229	173.973	1	<0.001	0.049	0.031	0.076
	Poor Knowledge	4	20								
In your opinion who should disclose to your child his/her own HIV status	Good Knowledge	430	428	-5.366	.709	57.320	1	<0.001	0.005	0.001	0.019
	Poor Knowledge	0	2								

OR=Odd Ratio, CI=Confidence Interval

4.4.1 Effect of HIV Disclosure Training on HIV status Disclosure

Table 4.7 shows logistic regression analysis and proportional comparison of knowledge among caregivers in the control and intervention group to determine the effect of HIV disclosure training on HIV Disclosure. Trained caregivers were two times more likely to disclose children's HIV status (OR=2.369).

Table 4.7: Effect of HIV Disclosure Training on HIV status Disclosure

	Intervention, N=430 n(%)	Control, N=430 n(%)	Bivariate logistic analysis			
			OR	SE	DF	P-value
Overall knowledge						
Poor knowledge	21(4.9%)	314(73.0)	ref	-	-	-
Good knowledge	409(95.1%)	116(27.0)	2.369	0.109	1	<0.05

OR=Odd Ratio; SE=Standard Error; DF=Degree of freedom

4.4.2 HIV Disclosure Rate

Table 4.7 shows the disclosure rates in both groups. Most untrained caregivers 323(75%) felt that disclosure was complex and difficult and were concerned that they did not have the necessary skills to disclose and so requested counsellors and clinicians to disclose to their children their HIV status on their behalf. Almost all trained caregivers (98%) disclosed to their children their HIV status. The reasons that they gave are cited in both FGD and KIIs.

“These virus needs openness (disclosure), tell everybody you stay with that you have HIV. It also comes with some forgetfulness. Like me, in my house everybody knows when I take my medicines. Sometimes I’m still busy in the kitchen and all over sudden the child comes and signals me even if the visitor is in the house when the time for taking medicines reaches (FGD1,R2)”

“We should know our HIV status early enough especially pregnant women to know their HIV status early to prevent giving birth to child with HIV. We should be free and disclose in the house and share freely on HIV (FGD, 1R1)”

“Disclosure was abit easy following the disclosure training we had received. I was confident answering child’s questions because I had answers (FGD1, R3)”.

“Most of these children start treatment at an early age, so if you will have captured caregivers training at an early age as they continue with treatment then it becomes easier (KII,1)”

Table 4.8: HIV status Disclosure Rates

	Control	Intervention
Disclosure by Caregivers	99(23%)	422(98%)
Assisted Disclosure by HCWs	323(75%)	4(1%)
Missed (Lost to follow ups)	8(2%)	4(1%)
Proportionality determined using Chi-square		
Total	430	430

4.5 Socio-demographic Factors Associated with ART Adherence for HIV Positive Children in Homa Bay County

Table 4.9 shows logistic regression analysis for factors associated with ART adherence. All socio-demographic factors showed no significant relationship except age of the caregiver (p=0.041) and level of education of the household head (p=0.035). However, the level of knowledge of care givers on the disclosure process was significantly associated (P=0.049) with ART adherence.

Table 4.9: Factors Associated with ART Adherence after Disclosure Training

Variable	Category	B	S.E.	P-value	OR	95% CI	
						Lower	Upper
Age of care giver	18-25						
	26-35	0.768	0.68	0.259	2.155	0.568	8.171
	36-45	0.138	0.614	0.822	1.148	0.345	3.821
	46-55	-0.096	0.614	0.041	0.908	0.272	3.028
Sex of care giver	Above 55	0.222	0.629	0.724	1.249	0.364	4.285
	Female						
Level of education-caregiver	Male	0.303	0.298	0.308	1.354	0.756	2.426
	None						
	Primary incomplete	1.402	0.941	0.136	4.064	0.643	25.688
	Primary complete	0.788	0.748	0.293	2.198	0.507	9.532
	Secondary incomplete	1.224	0.691	0.076	3.401	0.879	13.164
	Secondary complete	0.432	0.689	0.53	1.541	0.400	5.942
	Tertiary	0.702	0.65	0.28	2.017	0.565	7.206
Level of education of Household Head	None						
	Primary incomplete	-1.197	0.951	0.208	0.302	0.047	1.946
	Primary complete	-0.635	0.569	0.265	0.530	0.174	1.617
	Secondary incomplete	-0.851	0.487	0.081	0.427	0.164	1.109
	Secondary complete	-0.819	0.478	0.087	0.441	0.173	1.125
Marital status caregiver	Tertiary	-0.866	0.411	0.035	0.421	0.188	0.942
	Single, Never married						
	Married	-0.007	0.585	0.991	0.993	0.316	3.124
	Divorced	-0.253	0.238	0.286	0.776	0.487	1.236
	Separated	0.066	0.684	0.924	1.068	0.279	4.08
Occupation of caregiver	Widowed	-0.833	0.685	0.224	0.435	0.113	1.664
	Informal employment						
	Formal employment	-.632	0.430	0.141	0.531	0.229	1.233
Sex of the child	Others	0.232	0.527	0.660	1.261	0.448	3.544
	Male						
Knowledge on Disclosure	Female	-0.066	0.207	0.751	0.936	0.624	1.404
	Poor knowledge						
Knowledge on Disclosure	Good knowledge	1.047	0.235	0.049	2.849	1.799	4.516
	Good knowledge						

OR=Odd Ratio; CI=Confidence Interval; SE=Standard Error

In addition to socio-demographic factors, other factors associated with ART adherence were revealed in the FGDs and KII. Figure 4.1 illustrate themes for factors associated with ART adherence.

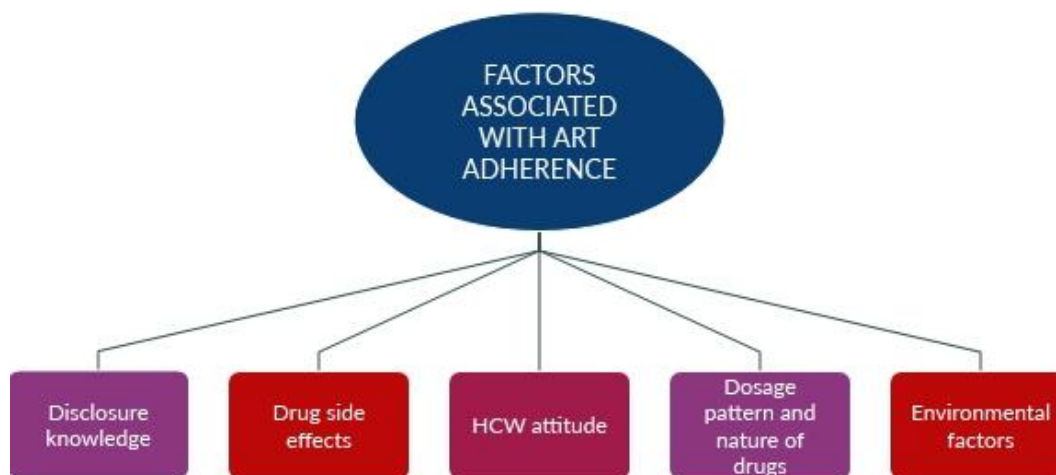


Figure 4.1: Themes for Socio-demographic Factors Associated with ART Adherence

Knowledge on Disclosure

Participants from both intervention and control reported that knowledge on HIV disclosure is paramount;

“The caregivers are the ones to do disclosure to the children. When the caregivers do disclosure, the children will take it very seriously as opposed to the HCW. The caregivers contribute to 100% in terms of adherence. When they have disclosed, the viral load which is the end result, will be good. Training makes caregivers understand the importance of disclosure hence disclose, after disclosure, then we don’t have problems with adherence which eventually leads to viral suppression. The training is good because it leads step by step into good adherence and then into viral suppression.”[KII-CNT-01]

Health care workers appreciated the need for caregivers to be trained on disclosure as stated;

“Caregivers training and viral load suppression and adherence, some children do not have real parents with understanding of HIV and reasons why they have to take drugs. Kids are playful, if a caregiver with understanding is lacking, then it is not easy to call the child for medication when the time reaches.”[KII-CNT-02]

A health care worker elaborated on the importance of disclosure knowledge and how it improves the understanding of a child on taking medication.

“Disclosure training equips caregivers with knowledge about care of the child with HIV, this knowledge, the caregiver is able to transfer it to the child and with this improved understanding as to why he is taking medicines, the child takes medicines well and does not miss. Adherence to ARVs translates to good viral load.”[KII-INT-03]

Participants reported the need to disclose HIV status to the children.

“Lack of disclosure, when the child does not know why he is taking drugs, the child can decide to take a break in between taking drugs”[KII-CNT-01]

The Drug Side Effects

This theme informs of the extent to which adherence is affected by side effects of the drug among children living with HIV, most children experienced nausea, vomiting and abdominal pain as reported below;

“Yes, the commonness is side effects of the drugs. You find some drugs cause nausea, vomiting and abdominal discomfort. A child then refuses the drugs because the child will vomit when goes to school [KII-INT-01].

“There are some drugs that they take, some of the drugs have lots of side effects e.g lopinavir with side effects of nausea, abdominal pain and vomiting. Another thing also, the pill burden, some take a lot of pills, for those ones in second line, they take two in the morning and two in the evening and that really brings a lot of problems. [KII-INT-03]

“Lopinavir makes the child nauseated and the child feels like vomiting”[KII-INT-02]

Healthcare worker’s Attitude and Pattern of Dosage

A participant explained how the health care worker’s attitude can greatly affect adherence

“Healthcare workers attitude, like when the child comes late to the clinic, the healthcare worker gives the child drugs in annoyance and the child feels bad”[KII-INT-01]

Pill Burden

They also argued how pattern in the dosage made it difficult for children to adhere,

“Pill burdens especially those children on 2nd line, the pills are very big and many like 2 or 3. So the child feels the medicines are many to swallow in the morning and evening.”[KII-INT-01]

Environmental Factors

While the drugs are given for free, children from humble backgrounds are reported to have difficulty in adhering to the treatment;

“Poverty is a major issue that hinders coming to the clinic due to lack of fare [KII-CNT-03]

Change in Caregiver

Change in the care givers also posed risk especially to children who went to boarding schools

“Lack of stable caregivers e. g. today the child is with this caregiver, tomorrow another caregiver leading to adherence issue...”[KII-CNT-01]

Boarding Schools

“Scheduled hectic school calendar can hinder adherence in that when time reaches for the child to go and collect his drugs and is still held up in school... [KII-CNT-03]

Care givers also report difficulty in the children disclosing to the peers as indicated below;

“The child may find it difficult leaving the peers to go and take his medicines when they are playing and the time of taking medicines reaches. The child may fear that the peers might

know who he is. So I had to talk to the child to be brave with taking his medicine and he rectified”[KII-CNT-06]

4.6 Caregiver’s Perceptions on Pediatric HIV Status Disclosure in Homa Bay County

Caregiver’s views regarding pediatric HIV status disclosure are captured in figure 4.2 below

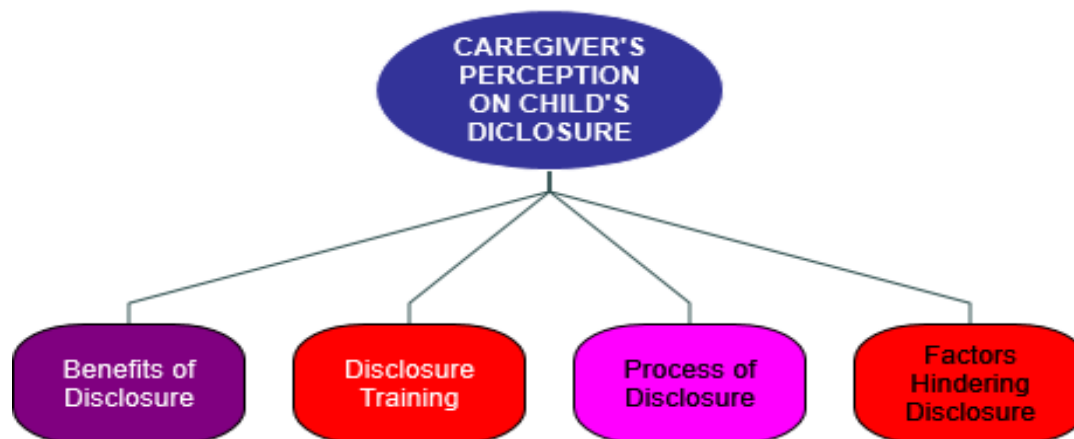


Figure 4.2: Theme and Sub-themes for Caregiver’s Perceptions on Child’s HIV Disclosure

Benefits of HIV status Disclosure

While disclosing a child HIV status is difficult, non-disclosure is likely to be associated with poor health outcome including increased risk of poor adherence and retention, and treatment failure hence the need to assess importance of disclosure among trained and untrained caregivers. Both trained and untrained caregivers reported benefits of disclosure. Care-givers reported several benefits of disclosure including improved adherence to antiretroviral treatment and an overall improvement in the child’s health status, improved communication between family members at home and improved behavior change.

Care-givers believed that the child would become more independent and responsible for their own health if they knew their HIV status, and that disclosure would help them to understand why they are taking treatment daily. A caregiver also narrated how disclosure had led to adherence and understanding of the treatment

“After disclosure the child just continues with taking the medicines well, he has never left because of the understanding of taking the medicines” [FGD-CNT-02].

Disclosure Training

“The challenge was, initially they didn’t realize the importance of caregiver’s training until they came to realize that they really needed caregivers on board. So the training of caregivers is important if started at an early age of child’s development. So I feel caregiver’s training is important if initiated early in the life of the peads..”[FGD-INT-01]

Care givers should be trained to ensure systematic steps into treatment adherence

“The caregivers are the ones to do disclosure to their children. Training makes caregivers understand the importance of disclosure hence disclose, after disclosure, then we don’t have problems with adherence which eventually leads to viral suppression. The training is good because it leads step by step into good adherence and then into viral suppression” [FGD-CNT-04]

A participant exhaustively explained how disclosure training inculcates knowledge among care givers. Disclosure is carried out in stages using suitable language that can be understood by children. Healthcare workers mentioned that the children were provided with general information in stages prior to the full disclosure.

“Disclosure training equips caregivers with knowledge about care of the child with HIV, this knowledge, the caregiver is able to transfer it to the child and with this improved understanding as to why he is taking medicines, the child takes medicines well and does not miss. Adherence to ARVs translates to good viral load.”[FGD-CNT-03]

4.7 Process of Disclosure by Caregivers

This theme explores the mode of disclosure used among trained and untrained caregivers as displayed in figure 4.3. Majority of the trained caregivers disclosed the HIV status to their children systematically and without difficulty compared to the untrained.

“I did disclosure in stages until the child fully understood his status. I started telling the child about red germs and green germs, I told him that if you swallow the medicines well, the red germs will reduce and the green germs will increase and you will be healthy (partial disclosure). As the days go by and with also the teachings we get from the clinic, I could answer his many questions. I did full disclosure in the clinic when the child was 8 years in the presence of a healthcare worker. The room was safe and private with enough seats. Then I explained to the child that he takes medicines every day to help him fight the red germs which are HIV virus so that he stays healthy”[FGD-INT-02].

One narrated how the disclosure was easy following the training.

“It was a bit easy following the disclosure training we had received. I was confident answering child’s questions because I had answers. What is very key is a child’s age and the ability to understand what a chronic disease is. I started telling the child about the germs in her body and how these germs can be affected if drugs given are not swallowed properly. The child was 7 years old”[FGD-INT-03]

Interviewees also reported how the disclosure training was helpful and had taught him stages of disclosure.

“... The disclosure training was very helpful since I could know how to answer the child whenever he asked questions. I informed the peer counselor early enough and on one of the clinic days, in the presence of a peer counselor, I managed to inform the child that the red germs he has been having are called HIV.”[FGD-INT-01]

Participants in the control group also reported their disclosure experiences;

“I disclosed when 10 years. I consulted with the clinician what to tell the child then the clinician told me what to do. Then I told the child that he was HIV positive”[FGD-CNT-05].

“So I sat him down and disclosed his status to him so as to understand why he has to take his medicines. The child felt so sad and was very much heartbroken. It forced me to explain the problem to the nurse who also talked to him and encouraged him to continue with the medicines.”[FGD-CNT-02]

“Teachings in the Psychosocial Support groups made my child to know his HIV status, so the child just confirmed with me”[FGD-CNT-04].

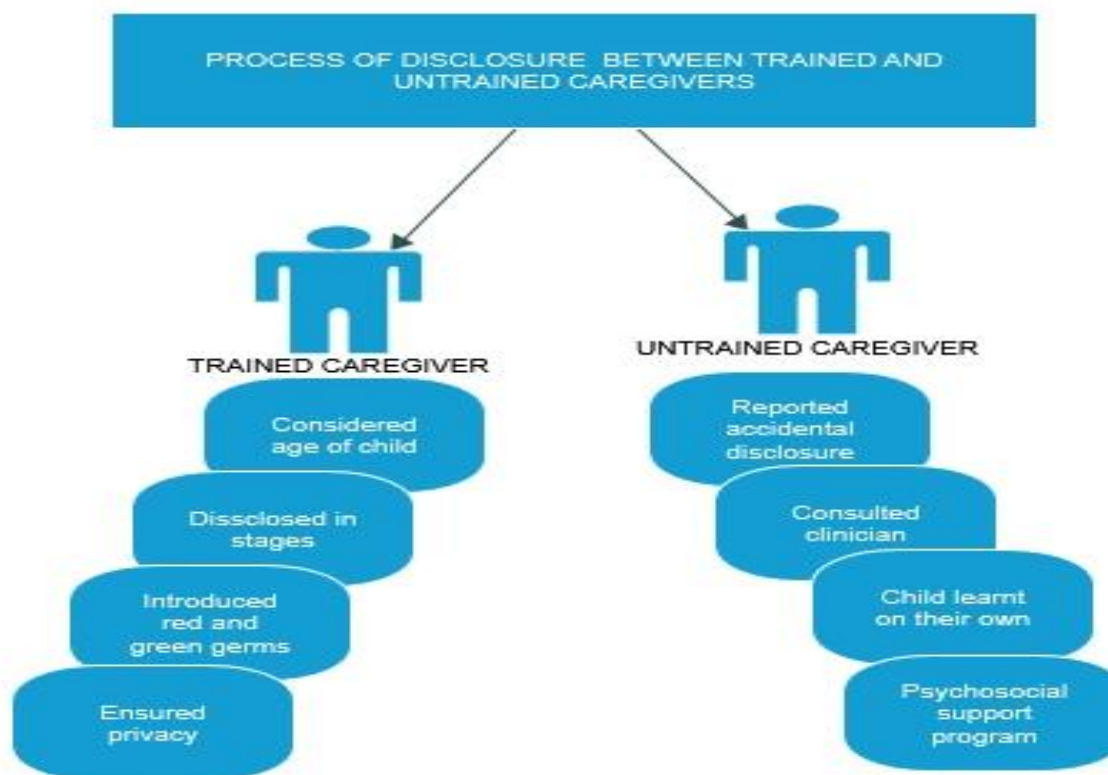


Figure 4.3: Process of Disclosure between Trained and Untrained Caregivers

4.8 Factors Hindering Disclosure

Most untrained caregivers 323(75%) felt that disclosure was complex and difficult and were concerned that they did not have the necessary skills to disclose and so requested counselors and clinicians to disclose to their children their HIV status on their behalf. Almost all trained caregivers (98%) disclosed to their children their HIV status. Figure 4.4 shows reasons that they gave as cited in both FGD and KIIs.



Figure 4.4: Factors Hindering HIV status Disclosure

Inadequate Disclosure Knowledge

“Knowledge, HCW lacking knowledge on disclosure and just telling the caregiver to go and disclose” [FGD-INT-01]

This is similar to the caregiver’s response who perceived lack of knowledge as a factor hindering disclosure.

“Yes, number one factor, in case a parent doesn’t have knowledge on HIV, then the parents become worried about how he can tell the child and how he can start disclosing the child’s HIV status. Orphans who are left with step mothers or uncles as caregivers who are HIV negative sometimes it is a challenge for them to start disclosing to such like children stats.” [FGD-INT-03].

Young Age of the Child

Majority of the participants reported age as a barrier to status disclosure because the child may not understand.

“0-5 years, don’t have understanding since they are still very playful. It’s the caregivers duty to help them with taking medicines”[FGD-INT-04]

“Young children lack understanding and confidentiality. My child knew accidentally that he is HIV positive. From that point on, I had to talk to the child. We as parents, also fear embarrassment that we can get from children when we tell them their HIV status”[FGD-CNT-05]

“It is hard to disclose to the child because sometimes the child may not understand the person disclosing to him. I gave birth to my child not knowing my status. I learnt about my status when I had herpes; I got tested and turned HIV positive. They also tested my child at 2 years and the child also turned HIV positive”[FGD-CNT-03]

Disability among Children

Despite having care givers, disclosure may be difficult to the mentally disabled children.

“Children who are mentally challenged e.g. epileptic, cerebral palsy, making communication for disclosure difficult. There are children who are deaf but because you don’t understand the sign language, disclosure becomes difficult” [FGD-INT-05]

“Another one is that if the child has a low IQ, it hinders the child’s understanding of the disclosure process. The discussant added that the language barriers between the caregiver, the healthcare worker and the child can also hinder disclosure”[FGD-INT-02]

Culture and Religion

“..Some religions do not appreciate things to do with hospital and you cannot discuss this with the child and this delays disclosure. Another thing is culture, for example when a caregiver tells the child that children are found from the supermarket, so when the child asks how he got the HIV, the caregivers is not in a position to explain”[FGD-INT-04]

“Yes there are those who believe that they shouldn’t mix the drugs, a belief can hinder disclosure...and also, cultural beliefs that we should not talk about sex to young children, can hinder disclosure.”[FGD-INT-06]

Fear amongst Caregivers

This care-giver who was looking after her son described her concerns and why she did not want him to learn about his HIV status:

“What if he stops taking medication? What if he judges me of being immoral...that has been my fear all along”[FGD-CNT-03]

CHAPTER FIVE

DISCUSSION

5.1 Introduction

In this interventional study, that broadly assessed the effect of HIV disclosure training on ART adherence by HIV positive children in Homa Bay County. The study was anchored on the Health Belief model that informs that “self-efficacy” (the ability of one to execute an action after training due to improved skills), consequently strengthening an individual’s response towards a particular health behavior change (i.e. ART adherence). In light of this, the study conducted a disclosure training intervention for caregivers on disclosure process as a way of achieving self-efficacy to Pediatric HIV status disclosure and subsequently achieves ART adherence. The intervention group caregivers were trained on pediatric HIV disclosure process while control group caregivers were not trained. After the disclosure training, both group caregivers performed HIV status disclosures to their children and both mid-line and end-line antiretroviral therapy (ART) adherence for the children in both groups were compared with baseline ART adherence.

5.2 Comparing ART adherence before and after training caregivers on the disclosure process

Three different adherence measurements were used in this study; Pill count that determines consistency with which the pills were swallowed, keeping clinic appointment through pharmacy refill records and viral load measurements. i). Pill counts: adherence rate based on pill counts of >95% is good adherence. Patients are asked to bring all their pills with them to follow-up visits. Calculate how many pills should be remaining based on the previous prescription date and amount prescribed, and compare to how many pills are actually remaining. Excess pills are assumed to be missed doses, ii). Pharmacy refill records: Compare drug pick-up date with expected date of pick-up (based on number of pills dispensed at last visit). If drug pick-up date is later than expected, it is assumed the patient is missing doses equivalent to the number of days late, iii). Viral Load: Viral load of below <1000/ml was a confirmation of adequate adherence.

Regarding the patterns by which both groups kept their clinic appointments for drug refills, the study established that the risk of not keeping clinic appointments were 10 times and 24 times higher after 6 months and 12 months in the control group compared to the intervention group respectively. Keeping clinic appointment for drug refill determines the adherence level

of an individual. The Kenyan ART guideline (NASCO, 2022) recommends every service delivery point that is providing ARVs for patients (whether ART, PEP, or PrEP) to have a functional system for identifying patients who miss clinic appointments and for taking action within 24 hours of a missed appointment. In the local context, keeping clinic appointment is ascertained through pharmacy refill records. In this study, the control group finding falls short of the recommended adherence rate of above >95%, while the intervention group achieved the good adherence rate of above >95%. This finding implies that a high proportion of HIV patients in the control group stand the risk of progressing to AIDS due to sub-optimal adherence to ART. Sub-optimal adherence to ART, lead to the development and transmission of drug-resistant viruses which cannot be treated with first line (lower cost) medicines. According to Boerma and colleagues study (Boerma et al., 2016) on sub-optimal viral suppression rates among HIV-infected children in Low- and Middle-Income Countries, achieving optimal adherence (viral suppression) in children on ART is challenging for various reasons: lack of HIV status disclosure, variability in children's weight, variability in antiretroviral pharmacokinetics, poor palatability of drugs or dependence on caregivers who are frequently ill themselves for medication adherence. Similar to our study findings, keeping clinic appointments and consistency in taking ART have been associated with ART adherence in many studies (Haberer et al., 2017; Hayfron-Benjamin et al., 2018; Madiba & Diko, 2021; Masaba et al., 2023; Rodger et al., 2019). Additionally, disclosure training had significant effect ($p < 0.05$) on ART adherence of children. Children whose care givers were trained (intervention group) were nine times ($OR = 9.145$) likely to have good adherence to ART (suppressed viral load). In terms of relative risk (RR), the control group had a comparatively higher risk of viral non-suppression than the intervention group. Most studies (Chen et al., 2022; Fonseca et al., 2020; Raghupathi & Raghupathi, 2020; Zajacova & Lawrence, 2018) have shown positive relationship between level of education and health outcomes. Wandude et al. study (Wadunde et al., 2018), also found a relationship between HIV disclosure skills and ART adherence. In their study in Eastern Europe Guta and colleagues (Guta et al., 2020) informed that children with HIV and ART adherence literacy were significantly associated with ART adherence compared to their counterparts with no literacy.

In the 12 months end-line follow up, the viral load levels of children in the intervention group (90.1%) achieved the UNAIDS 90% target of viral suppression, control group children (70.1%) did not achieve the UNAIDS 90% target of viral load suppression, denoting some

level of non-adherence to ART. Successful ART not only improves the health, lifespan and wellbeing of the person living with HIV and receiving treatment, but there is a growing scientific consensus that effective ART, leading to viral suppression, also means that onward transmission of HIV is eliminated (Rodger et al., 2019). This consensus in the scientific community builds on results from large multi-national research studies (Rodger et al., 2019) which involved both heterosexual and homosexual couples in which one partner was HIV-positive. These studies followed the couples over time and found no transmission from virally suppressed HIV-positive persons to their HIV-negative partner. Study results indicate that an undetectable viral load practically eliminates the risk of someone transmitting HIV once viral suppression has been achieved and maintained and so contributes to achieving an AIDS free generation which is the 2030 Sustainable Development Goal.

5.3 Effect of HIV disclosure training on HIV disclosure process by caregivers of HIV positive children

The study also investigated the effect of HIV disclosure training on HIV disclosure process by caregivers of HIV positive children. The study found that training caregivers on HIV disclosure process significantly improves caregiver's knowledge on the disclosure process. Consistent with the Health belief model (Green et al., 2020) that informs that self-efficacy culminates into behavior change, the trained caregivers were 2 times (2.369) likely to disclose children's HIV status. Only 23% of control caregivers managed to disclose to their children their HIV status against the 98% intervention disclosures, and that most (75%) control disclosures were done by healthcare workers upon request by the caregivers who felt incompetent and inadequate to conduct the disclosures to their children due to lack of disclosure skills. Similar to many studies (Bulali et al., 2018b; Galea et al., 2018; Guta et al., 2020; Melis Berhe et al., 2020; Mphego et al., 2023), that inform that caregivers of HIV positive children, should be empowered with practical skills in-order to recognize opportunities to initiate the disclosure process early. Madiba's study (Madiba, 2019) also found the same, i.e. lack of disclosure skills by caregivers delayed disclosure to Children with Perinatal HIV in resource limited setting.

Disclosure skills have also been cited in a number of studies (Bulali et al., 2018a; Dessie et al., 2019; Madiba & Diko, 2021) to facilitate HIV status disclosure, although no study was found training caregivers in the disclosure process as the current study. In their study on Disclosure of human immunodeficiency virus status to children: Pattern followed by parents

and caregivers, other studies (Dlamini & Matlakala, 2020) found out that caregivers of HIV positive children, should be empowered with practical skills in-order to recognise opportunities to initiate the disclosure process. In another study (Haberer et al., 2017), improving antiretroviral therapy adherence in resource-limited settings revealed that 20 children who had full HIV disclosure literacy had optimized ART adherence than those with partial HIV disclosure. From the focus group discussions (FGD), caregivers further confirmed that disclosure training is important as it equips caregivers with the necessary skills that make them disclose children's HIV status. In a previous study, (Galea et al., 2018) they reported that HIV status disclosure process would evolve when children were able to ask questions about their sicknesses, with detailed questioning about their HIV status facilitated by the knowledge they acquire through health education at the support groups. Regarding the disclosure experiences between trained and untrained group caregivers, the current study revealed that trained caregivers were able to tackle child's disclosure in stages unlike the untrained caregivers. The trained caregivers were also able to disclose to their children status with ease, unlike the untrained caregivers, some of whom, consulted with the healthcare workers on what to tell the children during the disclosure process due to lack of knowledge on the disclosure process.

Another study (Dlamini&Matlakala, 2020) on Patterns of Disclosure of HIV status to infected Children in Sub-Saharan African setting with 259 caregivers not trained on HIV Disclosure process, revealed low rate of pediatric HIV disclosure of 15% partial disclosure with no full disclosure done. It further informed that 50% of the caregivers provided no information to their children about their health while 33% provided information that deflected attention from HIV. Other investigations (Doat et al., 2019a) on disclosure of HIV status to children in Sub-Saharan Africa in Ethiopia, South Africa, Ghana, Kenya, Cote d'Ivoire, Burundi, Cameroon, Democratic Republic of Congo, Uganda, Burkina Faso and Zambia, also revealed a disclosure prevalence rate of between 9% -72% depending on the literacy level of persons conducting the disclosure on HIV disclosure process. Another study (Hayfron-Benjamin et al., 2018), on HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central region of Ghana, identified the strongest factor for non-disclosure as lack of knowledge on the disclosure process, which were cited in a number of expressions among children's primary caregivers as follows; "I do not know what and how to tell", "I do not know how child will react and how to handle any negative reaction", "I do not know the exact age at which to tell the child.", and "I do not know how to

explain sex to child if asked how he/she got infected. Similarly, Madiha and Diko (Madiba & Diko, 2021) found that healthcare workers were reluctant to disclose to HIV positive children their status due to lack of disclosure skills and training and so lacked confidence to tell children their status.

A study conducted in South Africa at Chris Hani Baragwanath Hospital (Joyce et al., 2022), established that primary caregivers of children with HIV did not disclose HIV status to their children, despite the fact that these children often asked questions about their illnesses. The reasons that they gave for not disclosing included fear of stigma, lack of knowledge and skills on disclosure process, and emotional unpreparedness. They also felt uncomfortable discussing HIV illness with children. In other similar studies (Aderomilehin et al., 2016; Bortich, 2016; Butler et al., 2019; Doat et al., 2019a) and (Finnegan et al., 2019), common barriers to disclosure included insufficient disclosure knowledge, fear of rejection or loss of respect, negative emotional reactions from their children, and inadvertent disclosure to others by them (children). Additionally, in their study on factors associated with HIV Status disclosure and its effect on treatment adherence and quality of life among Children 6–17 years on antiretroviral therapy in Tanzania, a previous study (Bulali et al., 2018a), highlighted that limited skills by both parents/guardians and healthcare workers on how to handle the disclosure processes and the uncertainties in the aftermath of disclosure and caring for a child growing up aware of being HIV infected could complicate the situation. In their study on “How do you start? And how will they react? Disclosing to young people with perinatally acquired HIV in Uganda”, other studies (Namukwaya et al., 2017) concluded that there was need to actively engage and equip parents and caregivers’ of young children living with HIV with adequate knowledge, information and skills which would prepare them to initiate and facilitate discussions around disclosure of HIV.

5.4 Socio-demographic factors associated with ART adherence

This study also investigated socio-demographic factors associated with ART adherence. The study found significant relationships with age of the caregiver, education level of the household head and knowledge of care givers on the disclosure process to be associated with ART adherence. From FGD and KIIs, knowledge of HIV disclosure, drug side effect, healthcare worker’s attitude, dosage patterns and environmental factors were reported to be associated with ART adherence.

5.4.1 Age

This study found a significant correlation with age and ART adherence. Studies have found that with the exception of the most elderly, adherence increases with age. In two studies associated with ART adherence, sub-optimal adherence showed a positive correlation with being younger (Tanser et al., 2019; Wadunde et al., 2018). Contrarily, the clinicians (KII) at the comprehensive care centers study sites reported that ART adherence in children decreases with increasing age. They informed that as the children reach adolescents, their ART adherence diminishes as displayed in most non-suppressed viral loads. Most adolescents feel well in their bodies and so stop taking their medicines. It is also coupled with stigma issue which is rampant in the adolescents.

5.4.2 Level of Education and HIV Disclosure Knowledge

This study found the highest level of education (tertiary) of the household head to be significantly associated with ART adherence. A lower level of general education and poorer literacy may impact negatively on some patient's ability to adhere, while a higher level of education has a positive impact (Dorcélus et al., 2021). Most studies (Chen et al., 2022; Fonseca et al., 2020; Raghupathi & Raghupathi, 2020; Zajacova & Lawrence, 2018) have also shown positive relationship between level of education and health outcomes. Additionally, in this study, children of trained caregivers displayed a better adherence to ART than of untrained caregivers. Disclosure skills have also been cited in a number of studies (Bulali et al., 2018a; Dessie et al., 2019; Madiba & Diko, 2021) to facilitate ART adherence. These studies (Bulali et al., 2018b; Galea et al., 2018; Guta et al., 2020; Melis Berhe et al., 2020; Mphego et al., 2023), also found that training caregivers on HIV status disclosure significantly improves caregiver's knowledge on the disclosure process, culminating into ART adherence. In their study on disclosure knowledge and health related outcomes among children living with HIV and their caregivers, (Amankwah-Poku et al., 2021), the authors found that disclosure knowledge was significantly related to medication adherence. In his study on Factors affecting adherence to antiretroviral therapy among children and adolescents living with HIV in the Mbita Sub-County Hospital, Homa Bay- Kenya, other studies (Tanyi et al., 2021) found a positive relationship between education level and ART adherence.

5.5 Study Limitation

The study suffered from lost to follow ups given a lengthy period of follow up periods. Some participants transferred to other stations convenient to them while others died. However, given that the study's design considered these variables during the initial phases, such limitations did not affect the overall conclusion of the study. The current study also highlights the fact that future longitudinal HIV disclosure studies should acquire enough funding for the research projects. In addition, foreseeable and unforeseeable risks to the study should be costed and included into the study budget.

CHAPTER SIX

SUMMARY, CONCLUSION, RECOMMENDATION AND SUGGESTIONS FOR FURTHER STUDIES

6.1 Summary of Study Results

Major findings of this study are summarized in this section according to the study objectives.

6.2 Compare the ART Adherence of Children before and after Training of Caregivers on Disclosure Process in Homa Bay County

Viral Load

Disclosure training had significant effect on ART adherence of children. Children whose care givers were trained (intervention group) were nine times (OR=9.145) likely to have good adherence to ART (suppressed viral load) with respect to HIV disclosure training for caregivers. Additionally, in terms of relative risk (RR), the control group had a comparatively higher risk of viral non-suppression than the intervention group (6 months: RR = 1.96, 95% CI = 1.536 – 2.583; end line: RR = 3.028, CI = 2.194 – 4.180).

Keeping Clinic Appointments

The risk of not keeping clinic appointments were 10 times and 24 times higher after 6 months and 12 months in the control group compared to the intervention group (6 months: RR = 9.737, 95% CL = 4.525-20.953; end line: RR = 24.227, 95% CI = 3.292-178.276).

Consistency in Taking ARVs

Consistent taking of anti-retroviral drugs of >95% is recommended by National Syndemic Disease Control Council (NSDCC) as good adherence. Consistency in taking ARVs improved overtime in both control and Intervention group. However, Intervention group (95.6%) improvement achieved NSDCC recommendation of good adherence rate of above >95% at end-line, control (70.0%) did not.

6.3 Effect of HIV Disclosure Training on Knowledge of HIV Disclosure Process of Caregivers of HIV Positive Children in Homa Bay County

The study established that trained care givers on HIV disclosure were 1.486 times likely to have good knowledge on appropriate time to disclose to a child his/her own HIV status OR=1.486; 1.225-1.801) at 95% confidence interval, understanding what is involved in child reassurance before a disclosure OR=4.972; 3.860-6.405) and knowledge on what is needed to be prepared for a pediatric disclosure session OR=18.545 with lower bound as 12.076 and

upper bound as 28.480. However, at 95% confidence interval, training of care givers on HIV Status Disclosure did not increase the odds of understanding on who should be present during a pediatric disclosure session, understanding severity of illness or abnormal behavior, the age at which a child should be disclosed to their own HIV status and the level of understanding on who should disclose to a child his or her own HIV status. This is evidenced by odds ratio (OR) below 1.0 and negative beta coefficients (B). This therefore implies that training of care givers on HIV disclosure process helps in improving knowledge on appropriate time to disclose to a child their own HIV status, what is involved in child reassurance before a disclosure and knowledge on what is needed to be prepared for a pediatric disclosure session.

6.4 Socio-demographic Factors Associated with ART Adherence for HIV Positive Children in Homa Bay County

All socio-demographic factors showed no significant relationship except age of the caregiver ($p=0.04$) and level of education of the household head $p=0.035$. However, the level of knowledge of care givers on the disclosure process was significantly ($P<0.05$) associated with ART adherence. In addition to socio-demographic factors, other socio-demographic factors associated with ART adherence were revealed in the FGDs and KIIs to include; disclosure knowledge and age of both caregiver and child.

6.5 Conclusion

6.5.1 Compare the ART Adherence of Children before and after Training of Caregivers on Disclosure Process in Homa Bay County

This study concludes that HIV disclosure training for caregivers of HIV positive children increases disclosure, and subsequently increases ART adherence in children 6-10 years.

6.5.2 Effect of Pediatric HIV Disclosure Training on Knowledge of HIV Disclosure Process by Caregivers of HIV Positive Children in Homa Bay County

The study concludes that training care givers on HIV disclosure process improves caregiver's knowledge on HIV disclosure aspects, increases disclosure, and subsequently improves ART adherence in children 6-10 years.

6.5.3 Socio-demographic Factors Associated with ART Adherence of HIV Positive Children after Disclosure Training of Caregivers in Homa Bay County

The study concludes that age of the caregiver ($p=0.041$), level of education of the household head ($p=0.035$) and the level of knowledge of care givers on the disclosure process ($P=0.049$)

are significantly associated with ART adherence. Additionally, disclosure knowledge and age of both caregiver and child are also associated with ART adherence from focus group discussion and Key Informant interviews.

6.6 Recommendations

6.6.1 Compare the ART Adherence of Children before and after Training of Caregivers on Disclosure Process in Homa Bay County

The study recommends that all children in the age bracket of 6-10 years to be disclosed to their own HIV status by their caregivers in order to increase their level of adherence to ART. This recommendation is based on the findings that children whose caregivers were trained (intervention group) were nine times more likely to have suppressed viral load. This will reduce cases whereby the children refuse to take drugs without knowing the purpose of the drugs in their lives.

6.6.2 Effect of Pediatric HIV Disclosure Training on Knowledge of HIV Disclosure Process by Caregivers of HIV Positive Children in Homa Bay County

The study also recommends caregivers of HIV positive children to be trained on various HIV status disclosure aspects such as the appropriate time to disclose child's own HIV status, what is involved in child reassurance before a disclosure session, what needs to be prepared for a pediatric disclosure session and who should be involved during pediatric disclosure. This recommendation is based on the finding that trained were two times (OR=2.369) likely to disclose children's HIV status. Additionally, trained caregivers, disclosed to more children their HIV status than untrained caregivers.

6.6.3 Socio-demographic Factors Associated with ART Adherence for HIV Positive Children in Homa Bay County

The study recommends disclosure training for caregivers of HIV positive children since disclosure training significantly facilitated ART adherence.

6.7 Suggestion for Further Studies

The current study conducted a longitudinal study in which caregivers were followed up for a period of one year. The study suggests a further longitudinal study with longer follow up period to a certain a sustained ART adherence by HIV positive children. The study also suggests a study on children's socio-demographic factors associated with ART adherence in adolescents and later in adulthood. The study also suggests a study on characteristics of children that influence their knowledge on HIV status disclosure.

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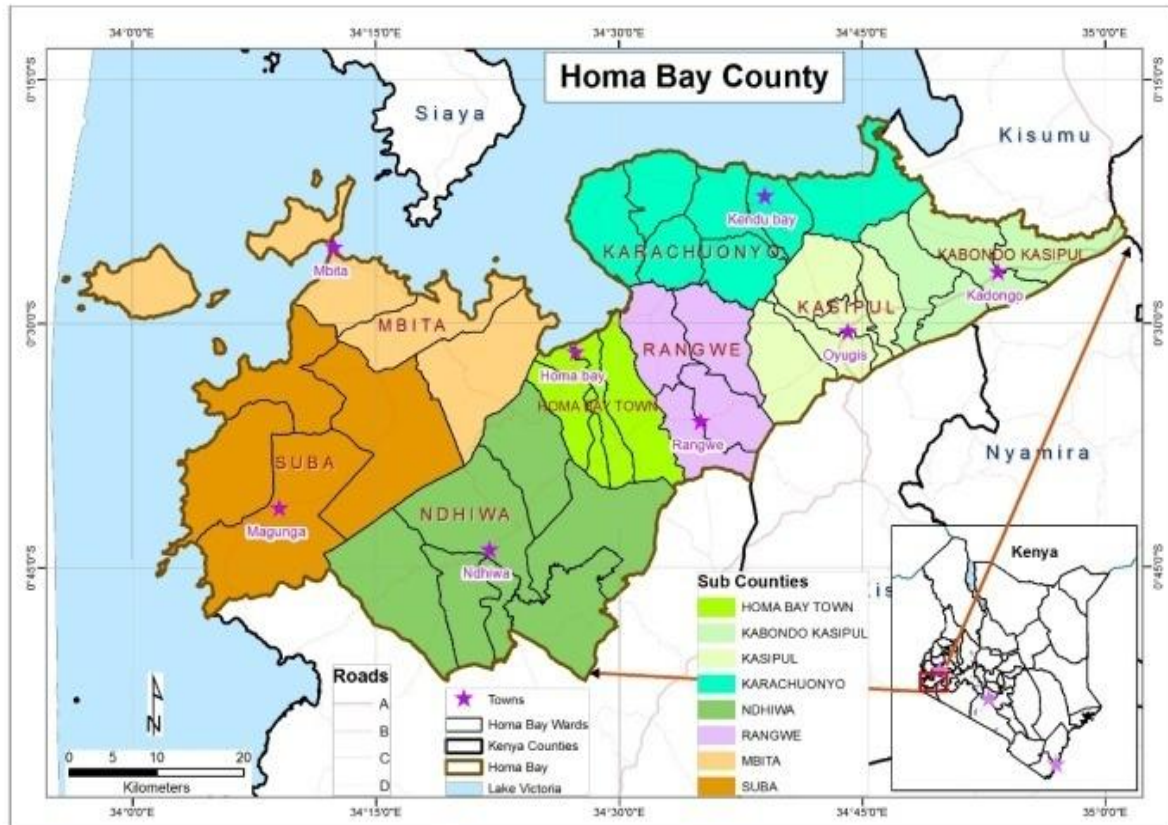
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APPENDICES

Appendix 1: Map of the Study Area



		3. Primary complete	3
		4. Secondary incomplete	4
		5. Secondary complete	5
		6. Tertiary	6
		98. Others (Specify)	98
104.	What is highest education level of HHH?	1. None	1
		2. Primary incomplete	2
		3. Primary complete	3
		4. Secondary incomplete	4
		5. Secondary complete	5
		6. Tertiary	6
		98. Others (Specify)	98
105.	Marital Status	1. Single, Never married	1
		2. Married	2
		3. Divorced	3
		4. Separated	4
		5. Widowed	5
		98. Others (<i>please specify</i>):	
106.	What is the occupation of household head	1. Peasant farmer	1
		2. Pastoral/cattle keeper	2
		3. Trader	3
		4. Formal employment	4
		98. Others (<i>Please specify</i>):	98
107	What is the average yearly HH income		
108.	How many have been consistently staying in this household for the last three months	1. 1 – 2	1
		2. 3 – 5	2
		3. 6 and above	3
109.	What is the age of <i>child on ART</i> in complete years.....?		
110	Gender (<i>NAME of child on ART</i>)?	1. Male	1
		2. Female	2

SECTION 2: KNOWLEDGE OF CAREGIVERS ON THE DISCLOSURE GUIDELINES OF A CHILD'S OWN HIV STATUS

201. What is HIV pediatric status disclosure?

1. Inform a child about their own HIV status - **disclosure** ()
2. Giving information about what is happening in the body without naming the disease - **partial disclosure** ()
3. Declaring the name of the virus and the disease = giving more detailed information - **Full Disclosure** ()
4. I don't know ()

(mentioning any of 1, 2 or 3 is knowledgeable = 1; failing to mention any of 1, 2, 3 is Not knowledgeable = 0)

202. When is it appropriate to disclose to a child their own HIV status? What to consider;

- 1. Developmental stage of child ()
- 2. Emotional maturity of child ()
- 3. Family dynamics ()
- 4. Readiness of caretaker ()
- 5. At reassurance of the child ()
- 6. Clinical state of child ()
- 7. I don't know ()

(Knowledge: mentioning of ≥ 3 is knowledgeable = 1; failing or mentioning <3 is Not knowledgeable = 0)

203 (a). What is it that is involved in child reassurance before a disclosure session may start?

- 1. Greetings ()
- 2. Introductions ()
- 3. Explanations of the procedures ()
- 4. Explanation of scope of confidentiality ()
- 5. I don't know ()
- 98. Others specify ()

(Knowledge: mentioning of ≥ 3 is knowledgeable = 1; failing or mentioning <3 is Not knowledgeable = 0)

203 (b). What do you need to prepare for a pediatric disclosure session?

- 1. Child friendly counseling environment (*no sharp objects or anything that can cause harm/distraction*) ()
- 2. Drinking water ()
- 3. Clean cup for drinking, ()
- 4. 2 Seats ()
- 98.Others specify:.....

(Knowledge: mentioning of ≥ 4 is knowledgeable = 1; failing or mentioning <4 is Not knowledgeable = 0)

204. Who should be present during a pediatric disclosure session?

- 1. Caregiver ()
- 2. Child ()
- 3. Health service provider ()
- 4. I don't know ()
- 5. Others specify:.....

(Knowledge: mentioning of 1, 2, and 3 options is knowledgeable = 1; failing or mentioning <3 is Not knowledgeable = 0)

205. Is(NAME of child) free from:

- 1. Severe physical illness ()
- 2. Trauma ()
- 3. Psychological illness ()
- 4. Psychiatric illness ()

*(Refer to past medical history, present medical history and client's actual presentation).
(Any signs of illness or abnormal behaviour e.g. lack of eye contact with the interviewer;
restlessness; feeling of pain; violent, general fear).*

206. At what age of the child should their own HIV status be disclosed?

- 1. <5 ()
- 2. 6 - 9 years ()
- 3. 10 - 12 years ()
- 4. 14 - 17 years ()
- 5. I don't know ()

(Mention of options 2 and 3 are knowledgeable, mention of other ages ≤ 5 and option 4 is not knowledgeable).

207. Has(NAME of child) reached the right age to know their own HIV status?

- 1. Yes ()
- 2. No ()
- 3. I don't know ()

208. In your opinion who should disclose to (NAME of child) his/her own HIV status?

- 1. Caregiver at home ()
- 2. Health care worker at HIV testing health facility ()
- 3. Caregivers and health care worker ()
- 4. I don't know ()

(Mentioning options 1-3 is knowledgeable, option 4 not knowledgeable)

SECTION 3: DISCLOSURE EFFECT: ADHERENCE TO ART BY HIV POSITIVE CHILDREN IN HOMA BAY COUNTY

301. Does(NAME of child) keep her/his appointment dates?

- 1. Yes ()
- 2. No ()

302. When was the last time(NAME of child) picked her ARVs?

- 1. Today ()
- 2. Last week ()
- 3. Last 2 weeks ()
- 4. Last month ()
- 5. I don't know ()

303. Does.....(NAME of child) always take his/her ARVs?

- 1. Consistently as indicated in the ARV card ()
- 2. Consistently from the clinic as directed by physician ()
- 3. Consistently from the house under my supervision ()
- 4. I'm not sure if s/he consistently take ARVs ()
- 5. S/he does not consistently take ARVs ()

304. What was the baseline CD4 count of patient number according to your records

before being started on ART?.....

305. What was the CD4 Count of patient Number six months after starting ART?.....

306. What is the current CD4 count of patient numberaccording to your records after starting ART? (Skip if it is a first time patient)?.....

307. What was the Viral Load of patient Number three months to the study?.....

308a. What is the current viral load of patient numberaccording to your records, 6 months after HIV status disclosure?.....(1. <1000copies/ml= Adhered, 2. >1000copies/ml = Failing adherence).

308b. What is the current viral load of patient numberaccording to your records, 12 months after HIV status disclosure?.....(1. <1000copies/ml= Adhered, 2. >1000copies/ml = Failing adherence).

THE END (Thank the participant for accepting to participate in the interview)

PENJO MAR: DUOKO MIYUDO KALUWORE GI KAKA NYITHINDO MA JOHIGNI 6-10 MANIGI AYAKI MUONYO YATH MAR AYAKI BANG' KA OSENYISGI CHALGI E MIGAWO MAR HOMA BAY, EI KENYA.

TARIK MAR PENJO.....NUMBA BUK MAR JATUO.....

NYING JAPENJ PENJO.....

<u>WECHE MAG NONRO:</u>		
Amosi. Nyinga en _____ to atiyogi _____ ne Rosemary Obado mar Maseno University e migawo mar ngima jopiny gi dongruok margi. Watimononro e weche mar ngima nyithindo. Kendo diber ahinya ka idonjo e nonroni. Duoko ma ibiro miyowa kuom donjoni e nonroni biro konyo ahinya migawo mar puonj ruok kendo mar pango yore mamiyo ngima dhi maber. Penjo mawa ok nyal kawo nyirri moloyo dakika 25 kidwoko. Kendo agoyo ero kamano kuom Kawo thuoloni mondo idonj e nonroni. Wabiro kano weche moa kuomi maber kendo ok wabi nyiso nga'to ang'ata.		
Donjo e nonro en yiero mari, kendo inyalo yiero mondo iduok penjo kata ooyo. Kata kamano, wageno kendo bermondo idonji e nonroni nikech ler mar riekko ma ibiro chiwo biro konyo mang'eny.		
Sani, inyalo bedo gipenjo e wach nonro mawa timoni?		
Iyie donjo e nonro?	Yes <input type="checkbox"/>	ooyo <input type="checkbox"/>
.....
Nyingi	Seyi	Tarik
<input type="text"/>		
Lweti ma thoon		
Nying ja neno	Seyi	Tarik
.....
Nying japenj penjo	Seyi	Tarik
.....
Saa ma penjo ochakorego	Nyiiir.....	

Namba	Penjo		Kal
MOKUONGO: NGIMANI NI KAKA IDAK			
101.	Hiki en adi sani?.....		
102.	Dichuo koso dhako	1. Dichuo	1
		2. Dhako	2
103.	Sombi nade?	1. Ok asomo	1
		2. Ok atieko praimari	2
		3. Atieko praimari	3
		4. Ok atieko sekondari	4
		5. Atieko sekundari	5
		6. Achopo ekolej	6
		98. Mamoko (Wachi)	98
104.	Sombi nade, (wuo not)?	1. Ok a somo	1
		2. Ok atieko praimari	2
		3. Atieko praimari	3
		4. Ok atieko sekondari	4
		5. Atieko sekundari	5
		6. Achopo ekolej	6
		98. Mamoko (Wachi)	98
105.	In nade kuom kend?	1. Poka nyombo	1
		2. Okenda/Akendo	2
		3. Waweyore	3
		4. Wapogore	4
		5. Chiega/chuora notho	5
		98. Mamoko (<i>wachi</i>):	
106.	Wuon ot tiyo tich mane?	1. Japur	1
		2. Japith chiaye	2
		3. Ja ohala	3
		4. Ondik tich	4
		98. Mamoko (<i>wachi</i>):	98
107.	Iyudo pesa adi ehiga?		
108.	Idak gi jiadi e dweche adekmokalo?	1. 1 – 2	1
		2. 3 – 5	2
		3. 6 kata mo kalo	3
109.	Hik nyathi manie nonro gin adi?		
110.	Nyathino en wuoyi koso nyako?	1. wuoi	1
		2. nyako	2

MARARIYO 2: NG'EYO MA JORIT NYITHINDO NI GO KUOM NYISO NYITHINDO MANIGI AYAKI CHALGI

201. Nyiso nyathi manigi ayaki chalne en ang'o?

1. Nyiso nyathi ni engi ayaki ()
2. Nyiso nyathi gima dhi nyime e dende maok inyise ni en gi ayaki -iluongoni

Nyiso nyathi chalne matin ()

3. Nyiso nyathi ayanga ni engi ayaki = Nyise weche matut koluware gi tuono

Nyiso nyathi chalne duto ()

4. Ok ang'eyo ()

(Wacho 1, 2, 3 nyiso rieko = 1; Kia wacho 1, 2, 3 Ok nyis rieko = 0)

202. Kara ng'o ma inyalo wacho ne nyathi ni en gi ayaki?

1. Kaka nyathi dongo ()
2. Pach nyathi kaka dongo ()

3. Dongruok mar anyuola ()
4. Ikuok mar jarit nyathi ()
5. Ikuok mar nyathi ()
6. Ngima nyathi samaonge midekre ()
7. Akia ()

(Ng'eyo :duoko maromo kata mokalo 3 en ng'eyo = 1; Kia, kata duoko matin ne adek ok en ng'eyo = 0)

203 (a) Ang'oma oromo tim kapok onyis nyathi chalne?

1. Mos ()
2. Ng'er ruok ()
3. Nyiso chenro ()
4. Nyiso kaka weche mowachi ibiro rito ma ok nyisji ()
5. Akia ()
98. Gimamoko (wachi)

(Ng'eyo: duoko maromo kata mokalo adek en ng'eyo = 1; Kia, kata duoko matin ne adek ok en ng'eyo = 0)

203 (b) Ang'o monego ibedgo e seche ma inyiso nyathi chalne?

1. Od hocho (ma onge gi gik mabith kata manyalo hinyo nyathi) ()
2. Pi modho ()
3. Okombe maler mar modho ()
4. Kombe ariyo ()
98. Gimamoko (wachi):.....

(Ng'eyo: duoko maromo kata mokalo 4 en ng'eyo = 1; Kia, kata duoko matin ne 4 ok en ng'eyo = 0)

204. Ng'ama oromo bedie e seche ma inyiso nyathi chalne?

1. Jarit nyathi ()
2. Nyathi ()
3. Ja thieth ()
4. Akia ()
5. Gimamoko:.....

(Ng'eyo: Duoko 1, 2, kata 3 kuom duoko mochiw en ng'eyo = 1; Kia, kata duoko matin ne 3 ok en ng'eyo = 0)

205. Be Nyathini (Nyinge) nigi chandruok gi?

1. Tuo matek/ahinya ()
2. Kwiri mar chandruok ()
3. Tuo mar paro ()
4. Tuo mar neko ()

(Par bende touché machon, gima sani kod kaka nyathi chal sani).

(Ranyisi moro amora kaka luoro ng'iyoy wang'ji, tam ruok bet mos, winjo rem kod luoro moro amora).

206. Bang' higni adi eka nyathi ma nigi ayaki inyiso chalne mar tuo?

1. Matin ne higni 5 ()
2. Higni 6 - 9 ()
3. Higni 10 - 13 ()
4. Higni 14 - 17 ()
5. Akia ()

(Duoko mar 2 gi 3 nyiso ng'eyo, Duoko ma chien ne higni 5 ok nyis ng'eyo).

207. Bende nyathini oseromo higni ma inyisego chalne??

1. Eee ()
2. Ooyo ()
3. Akia ()

208. Epachi, ng'ama onego nyis nyathi chalne?

1. Jarit nyathi edala ()
2. Jathieth mar ayaki ()
3. Jarit nyathi kod Jathieth ()
4. Akia ()

MAR ADEK 3: DUOKO MIYUDO BANG' NYISO NYATHI MANIGI TUO MAR AYAKI CHALNE: KAKA NYITHINDO MANIGI TUO MAR AYAKI MUONYO YADH AYAKI E E MIGAO MAR HOMABEI

301. Bende nyathi matuoni orito sechene mar thieth?

1. Eee ()
2. Ooyo ()

302. En odie chien'g mane ma nyathi matuoni ne oomo yedhene kar thieth?

1. Kawuono ()
2. Juma mokalo ()
3. Jumbe ariyo mokalo ()
4. Dwe a chiel mokadho ()
5. Akia ()

303. Nyathi manyinge iwachono bende muonyo yadhe kaka owinjore?

1. Pile kaka opange ()
2. Pile koa kuom Jothieth ()
3. Pile koa kuom jaritne ()
4. Ok ang'eyo kaka omuonyo yath ()
5. Ok omuony yath pile kaka owinjore ()

304. Kane pok ichako muonyo yath mar ayaki, ra gen'g mar dendi (CD4 count) ne chalnade?.....

305. Rageng' mar dende (numba jatuo) chal nade sani bang' kane ose chako muonyo yath?

306. Rageng' mar dend nyathi sani chalnade dweche apar gi ariyo bang' donjo enonro?

307 Kute mag ayaki mar jatuo ni ne rom nade dueche adek kane pok odonjo enonro?.....

308a. Chakre odonj enonro nyaka dweche auchil bang' ng'eyo chalne kute mag ayaki rom nade kuom jatuo ni?

1. Tin ne rapim moromo 1000= omuonyo yath maber, 2. Ng'eny ne 1000 = Ok omuony yath maber). ()

308b. Chakre odonj enonro nyaka dweche apar giariyo bang' ng'eyo chalnae kute mag ayaki rom nade kuom ja tuoni?

1. Tin ne rapim moromo 1000= omuonyo yath maber, 2. Ng'eny ne 1000 = Ok omuony yath maber). ()

Giko mar penjo (Go erokamo ne jarit nyathi kuom yie duoko penjowa)

Appendix 3: FGD Interview Guide

FGD Interview Guide:

1. Do all our children living with HIV Aids know their status? If no why?
2. What makes it difficult to tell them their HIV status? What can we do about these challenges?
3. How did you disclose the HIV status to your child? How do you compare adherence and viral load after disclosure? Explain
4. Do you think all the children are taking or being given drug as prescribed in the hospital i.e. the right dose and on time?
5. What made it difficult for the children to take drugs as prescribed after disclosure?
6. What do you think can be done to increase adherence to medication and viral load suppression?

Appendix 4: Key Informant Interview Guide

Key Informant Interview Guide: Homa Bay County HIV and AIDS control Unit

1. Generally, how is the viral load status among children living with HIV in Homa Bay County
2. How do you compare the viral load among children who know their HIV status and those who don't know
3. Could you say there is a relationship between viral load and adherence to treatment?
4. How does disclosure training for care givers contribute to viral load status and adherence to treatment?
5. Are there some factors that hinder disclosure of HIV status to the children? What are these factors? How do these factors hinder disclosure of HIV status?
6. Are there factors that make it difficult for the children to adhere to the HIV treatment?
 - b) What are these factors?
 - c) How do they hinder adherence?
 - d) What is currently being done about them?
 - e) What can be done about them?

-END-

Appendix 5: CDC Disclosure guideline

Task 1: Assess the child for disclosure eligibility

Goal: to establish eligibility of the child

Duration: 45-60minutes

Requirements: Child friendly counseling room, bottle of drinking water, clean cup for drinking, 3 seats (counselor, child and caregiver), child, caregiver, a clock and time.

Process:

(a) Is the child between **6** and **10** years: (**yes/No**)?

- **If yes**, proceed to the next step.
- **If no**, defer disclosure until the child meets the age criteria but continue with caregiver education on what disclosure is and its benefits.

(b) Is the child and caregiver knowledgeable on the benefits of disclosure (**Yes/No**)

- **If yes**, assess the scope of understanding on (what disclosure is, benefits of disclosure and barriers to disclosure).
 - Benefits of disclosure to the child (enhances adherence, increases cooperation from the child, promotes communication, enhances risk reduction, promotes positive living among the pediatrics).
- **If no**,
 - Educate on disclosure – its definition and benefits.
 - Explore possible barriers from the caregiver (if there are barriers then discuss each with mechanism of overcoming them).
 - Re-assess during the next clinic visit (preferably after one month).
 - **If the answer is yes during re-assessment**, then proceed to the next task.
 - **If no**,
 - Then explore for alternative support and if available involve him or her in the disclosure process during the subsequent visits.
 - During the next visit, explore the willingness of the secondary caregiver to be involved in the process.
 - If they are willing assess knowledge: if adequate proceed,
 - if knowledge is inadequate, then take through step **a** and **b** of task 1 and re-assess appropriately during the next visit

Task 1 Caution: *only proceed to task 2 when all the steps in task 1 have been successfully completed.*

Task 2: Assess the child and caregiver for readiness

Goal: to establish readiness of the child and caregiver for disclosure

Duration: 45-60minutes

Requirements: Child friendly counseling room, bottle of drinking water, clean cup for drinking, 3 seats (counselor, child and caregiver), child, caregiver, a clock and time

Process:

- (a) Is child or caregiver free from severe physical illness, trauma, psychological illness or psychiatric illness? (**Yes/No**). (Refer to past medical history, present medical history and client's actual presentation).
- **If No**, proceed to the next step (b).
 - **If yes:**
 - i. Explore and refer appropriately for management and re-assess during the next visit. Only proceed to the next step when the client and the caregiver have been stabilized.
- (b) Does the child have consistent family, peer support or social support (**Yes/No**)
- **If yes**, proceed to the next step (c).
 - **If no**, re-evaluate support structure and strengthen or attach to alternative support mechanism (peer educator, CHV, support group, church, etc).
 - i. Follow up on those attached to alternative support mechanism every visit.
 - ii. Re-assess the effectiveness of the linkage during the subsequent visit:
 1. If effective proceed to the next step.
 2. If not, mobilize alternative support but only proceed when there is some level of psychosocial support available to the child which is essential in case of post-disclosure crisis.
- (c) Does the child demonstrate interest in the environment and playing activities? (**Yes/No**)
- **If yes**, proceed to the next step (d).
 - **If no:**
 - i. Assess the development stages of the child (psychomotor stages, age, milestones and age appropriate task performance) then refer appropriately.
 - ii. Only proceed to the next step if the child is stable emotionally & socially, and likely to benefit from the process as established by assessment of development stages during subsequent visits.
- (d) Is the child functionally engaged in school activities? (Consistent school attendance, interacts well with the school community, able to freely discuss school activities, etc).
- **If yes**, proceed to the next step (e).
 - **If no:**
 - i. Explore for possible reasons and provide appropriate linkages.
 - ii. Explore psychosocial support mechanism available within the school and link the child to that.
 - iii. Only proceed when the child is ready (reasonably coping with school dynamics – compare the current activities performance with the previous best)
- (e) Is the caregiver ready to disclose to the child that the child is HIV positive? (**Yes/No**)
- **If yes**, proceed to the next step.
 - **If no:**
 - i. Explore the barriers (fears, challenges, ignorance, negative attitudes, stigma, religion etc).

- ii. Support the caregiver to develop strategies of overcoming the barriers.
- iii. Support the caregiver to develop barriers' mitigation action plan.
- iv. Support the caregiver to implement the action plan.
- v. Review for progress during the subsequent clinic visits and;
 - 1. *If caregiver ready* to disclose, proceed to the next step (f).
 - 2. *If not ready*, repeat the empowerment cycle until some reasonable level of readiness is established then proceed to the next step.

(f) Have you assessed what the caregiver has communicated to the child?

- Has the care giver discussed anything regarding the child's HIV status (yes/No)?
 - i. **If yes**, assess how much, build on the foundation and then proceed to the next step (task 3).
 - ii. **If no**,
 - 1. Support the caregiver to initiate the discussion with the child in a language the child can understand as soon as possible.
 - a. Assist caregiver to rehearse direct face-face communications with the child using role plays or empty chair techniques.
 - b. Educate on use of discussion starters like brief story or picture codes.
 - c. And only proceed to task 3 when the caregiver is ready to execute.

Note: In case the caregiver is willing but needs help with the task, the health worker can execute the disclosure in the presence of the caregiver (assisted disclosure) but jointly answer the questions from the child with the caregiver.

Task 2 Caution: Only proceed to task 3 when all the steps of task 2 have been successfully completed.

Task 3: Execute disclosure

Goal: to make the child aware of his or her HIV status.

Duration: 45-60 minutes.

Requirements: Child friendly counseling room, bottle of drinking water, clean cup for drinking, 3 seats (counselor, child and caregiver), child, caregiver, a clock and time

Process:

Disclosure transaction done by the caregiver and supported by Health worker. Can be done by Health Worker if care giver is willing but unable and has invited help.

- a) Has the caregiver and the child been reassured as part of disclosure process execution? (*Reassurance includes:* greetings, introductions, explanations of the procedures, explanation of scope of confidentiality, etc).
 - **If yes**, proceed to the next step (b).

- **If no,**
 - Reassure both the child and caregiver then proceed to the next step (b).
- b) Has the comfort of the child and caregiver been assessed? (Both have seats, distance between seats is reasonable for face-face discussion, enough ventilation, child friendly space, lighting, no tension, etc).(Yes/No)
- **If yes,** proceed to the next step (c).
 - **If no,** make the child and the caregiver comfortable using the threshold describe above then proceed to next step (c)
- c) Has the safety of both been assessed? (Conduciveness of environment, location of the room-not upstairs with open windows, no portable equipment that can be used to execute violence, etc)? (Yes/No)
- **If yes,** proceed to the next stage.
 - **If no,**
 - Ensure safety in the room before proceeding in order to minimize risk of harm both to the child, caregiver and to the Health worker in case on post disclosure violent reaction then proceed to the next step (d)
- d) Has the child knowledge been assessed? (basic HIV/AIDS information, knowledge of what disclosure is, benefits of disclosure, etc) (Yes/No)
- **If yes,** proceed to the next step (e).
 - **If no,**
 - Educate and re-enforce the basic messages on disclosure (definition and benefits) and proceed to the next step (e).
- e) Has the caregiver been invited to disclose using the simplest language that the child can understand? (Simple language include child's mother tongue, avoidance of medical jargons) (Yes/No)
- **If yes,** proceed and give the caregiver time to disclose to the child the child's HIV Status and answer any arising questions: sensitively, clearly and patiently then proceed to next step (f)
 - **If no,** then invite the caregiver to execute disclosure after which proceed to next step (f).
- f) Have you observed the immediate reactions of both the child and caregivers and addressed concerns or negative reactions? (Reactions could manifest in sitting angle, fidgeting, confused language, silence, violence, crying, shouting, raising the voice tone, etc) (Yes/No)
- **If yes,** proceed to the next step (g)
 - **If no** observe the response of both (caregiver and the child) to the message and the process, take note of abnormalities and address them then proceed to the next step (g).
- g) Have you invited questions from the child? (Yes/No)

- **If yes**, listen to the questions and concerns then respond appropriately before proceeding to the next step (h).
 - **If no**, deliberately offer an opportunity to the child to air questions and concerns then proceed to the next step (h).
- h) Have you revisited/reviewed the benefits of disclosure? (**Yes/No**)
- **If yes**, proceed to the next step (i).
 - **If no**, revisit the disclosure benefits and then proceed to the next step (i).
- i) Have you explained care options available? (Septrin only, ARVs plus Septrin, etc) (**Yes/No**)
- **If yes**, answer any concern appropriately then proceed to the next step (j).
 - **If no**, explain the options and the rationale according to the understanding of the child then proceed to the next step (j).
- j) Have you concluded the session with reassurance to both child and caregiver? (Reassurance means giving hope on the options, sharing case studies, open invitation to seek help, etc) (**Yes/No**)
- If yes, then close the session and thank both the child and caregiver for their availability and cooperation.
 - If no, do as above and discuss the expectations during the next visit.

Task 3 Caution: *Only proceed to task 4 when all the steps of task 3 have been successfully completed.*

Task 4: Post disclosure assessment

Goal: early detection and prompt management of post disclosure complications.

Duration: 45-60 minutes.

Requirements: Child friendly counseling room, bottle of drinking water, clean cup for drinking, 3 seats (counselor, child and caregiver), child, caregiver, a clock and time

Process:

- Have you assessed the child for functional school engagement?
 - **If yes**, proceed to the next step (b).
 - **If no**, then assess for functional school engagement, investigate and address any changes appropriately then re-assess during the subsequent visit. When ok proceed to the next step (b)
- Have you assessed for availability of family, social, peer relationship and support after disclosure?
 - **If yes**, address the gaps or concerns then proceed to the next step (c).
 - **If no** then assess appropriately and address the gaps or concerns then proceed to the next step (c) when ready.
- Have your assessed the child's interest and engagement in children's activities like playing?
 - **If yes**, address the gaps or concerns then proceed to the next step (d)
 - **If no**, then assess appropriately and address the gaps or concerns then proceed to the next step when ready (d)
- Have you assessed the child for moodiness and negative behaviors? (isolation, violence, pathological tantrums, rebellion, etc)

- **If yes**, address the difficulties or concerns then proceed to the next step (e).
- **If no**, assess appropriately and address the gaps or concerns then proceed to the next step (e) when ready.
- Have you referred the child and caregiver appropriately for psychiatric and other psychosomatic complications developed post disclosure, if any?
 - **If no condition or indication**, end the session (reassurance, appreciation and open invitation in case of need)
 - **If there is a condition or indication**,
 - Refer appropriately
 - Follow up during the next visit and if still persistent then refer again for specialized management and continue follow up.
 - Keep monitoring the child for any relapse of the challenges or difficulties that were treated or any other new developments before final termination of the disclosure cascade when the child and caregiver are both psychologically and emotionally stable.

Task 4 caution: *strive to terminate the process formally (in a meeting). No part of this process should be left hanging. This will enable you to do the final assessment when the process is through.*

Pediatric Disclosure Checklist

Name Facility _____ Name of the child _____

DOB _____ Sex _____ Caregiver's name _____ CCC No _____

Task 1. Assess the child for disclosure eligibility	Date task 1 executed:		Facilitator's name:
Child has met the age criteria (between 6 and 10 years)	Yes	No	
Child and caregiver knowledgeable on the benefits of disclosure (Yes/No)	Yes	No.	
Caregiver willing to disclose to the child	Yes	No.	
Task 1 Comments:			
2. Assess the child and caregiver for readiness	Date task 2 executed:		Facilitator's name:
Child or caregiver free from severe physical illness, trauma, psychological illness or psychiatric illness?	Yes	No.	
Child have consistent family, peer support or social support	Yes	No.	
Child demonstrates interest in the environment and playing	Yes	No.	
Assess what the child already knows about the medicines and illness and address needs and concerns	Yes	No	
Assess functional school engagement by the child (consistent attendance, interacts well with the school community, able to freely discuss school activities	Yes	No.	

Is the caregiver ready to disclose to the child?	Yes	No.	
Assess what the caregiver has communicated to the child-	Yes	No.	
Task 2 Comments:			
3. Execute disclosure: done guided by caregiver and supported by Health care worker in the clinic	Date task 3 executed:		Facilitator's name:
Reassure both caregiver and child and assess their comfort and safety	Yes	No.	
Invite caregiver to disclose using the simplest language the child can understand	Yes	No.	
Observe immediate reactions of both child and caregivers and address concerns or negative reactions	Yes	No.	
Invite questions from the child and revisit benefits of disclosure	Yes	No.	
Explain care options available to the child and caregiver	Yes	No.	
Conclude session with reassurance to both child and caregiver	Yes	No.	
Task 3 Comments:			

Appendix 6: MUERC Approval



MASENO UNIVERSITY ETHICS REVIEW COMMITTEE

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

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

FROM: Secretary - MUERC

DATE: 5th May, 2017

TO: Rosemary Obado Opiyo
PG/PhD/PH/0074/2014
Department of Public Health
School of Public Health and Community Development
Maseno University
P. O. Box, Private Bag, Maseno, Kenya

REF: MSU/DRPI/MUERC/00386/17

RE: Effects of Paediatric HIV Status Disclosure to ART Adherence by Positive Children Aged 6-10 Years in Homa Bay County, Kenya. Proposal Reference Number MSU/DRPI/MUERC/00386/17

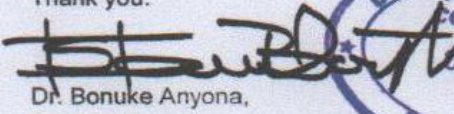
This is to inform you that the Maseno University Ethics Review Committee (MUERC) determined that the ethics issues raised at the initial review were adequately addressed in the revised proposal. Consequently, the study is granted approval for implementation effective this 5th day of May, 2017 for a period of one (1) year.

Please note that authorization to conduct this study will automatically expire on 4th May, 2018. If you plan to continue with the study beyond this date, please submit an application for continuation approval to the MUERC Secretariat by 5th April, 2018.

Approval for continuation of the study will be subject to successful submission of an annual progress report that is to reach the MUERC Secretariat by 5th April, 2018.

Please note that any unanticipated problems resulting from the conduct of this study must be reported to MUERC. You are required to submit any proposed changes to this study to MUERC for review and approval prior to initiation. Please advise MUERC when the study is completed or discontinued.

Thank you.


Dr. Bonuke Anyona,
Secretary,
Maseno University Ethics Review Committee



Cc: Chairman,
Maseno University Ethics Review Committee.

MASENO UNIVERSITY IS ISO 9001:2008 CERTIFIED



Ministry of Health Approval

MINISTRY OF HEALTH

Telegrams: "MOH" Homa Bay

MINISTRY OF HEALTH

TELEPHONE: 21039
When replying please quote
homabaychc@gmail.com



HOMA BAY COUNTY
P.O. BOX 52
HOMA-BAY

REF: MOH/HB/CTY/RA/VOL.2/006

9th May,2017

Rosemary Obado Opiyo
Maseno University

Dear Sir/Madam,

RE: AUTHORITY TO CONDUCT A STUDY IN HOMA BAY

Following your request to conduct a study entitled "**Effect of paediatric HIV Status Disclosure to ART Adherence by HIV Positive Children Aged 6-10 years**" in Homa Bay County. You are hereby authorized to conduct the study in the County for the duration permitted by the Maseno University Ethical Review Committee (ERC) starting from 10th May,2017

You will be expected to observe all the study ethics, norms and regulations and work closely with the Sub County Management Team during the study period for the purpose of continuity and sustainability. You are also expected to communicate your findings to the County Directors' Office at the end of the study.

Dr. Vincent Waringa
Deputy Director of Health Services
HOMA BAY COUNTY



