

**PREVALENCE AND BARRIERS OF HIV STATUS DISCLOSURE
AMONG CHILDREN AGED 6-12 YEARS IN KASUNGU, MALAWI**

MSc. THESIS IN TRANSFORMATIVE COMMUNITY DEVELOPMENT

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DECLARATION

I, Mirriam Malijani Nkangala, declare that the research reported in this thesis, except where otherwise indicated, is my original work and has not been submitted for any degree or examination at any other university. I also declare that all sources of information used have been fully acknowledged through complete references.

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CERTIFICATE OF COMPLETION

The undersigned certify that this thesis represents the student's own work and effort and has been submitted with my approval.

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Major Supervisor

DEDICATION

To my husband, Innocent Nkangala, my children; Karren, Destinee and Lovemore as well as to my colleagues and friends.

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LIST OF ABBREVIATIONS AND ACRONYMS

AHI	Acute HIV Infection
AIDS	Acquired immunodeficiency syndrome
ALHIV	Adolescents living with HIV
ART	Antiretroviral therapy
ARV	Antiretroviral
CLHIV	Children living with HIV
DHA	Department of HIV/AIDS
DHO	District Health Office
DHSS	Director of Health and Social Services
DMO	District Medical Officer
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HAART	Highly active antiretroviral Therapy
HCWs	Healthcare workers
HIV	Human immunodeficiency syndrome
HMIS	Health Management Information Systems
HSSP III	Health Sector Strategic Plan III
KIIs	Key Informant Interviews

MOH	Ministry of Health
MZUNIREC	Mzuzu University Research Ethics Committee
NPC	National Planning Commission
PMTCT	Prevention of mother to child transmission
SDG	Sustainable Development Goals
SSA	Sub-Saharan Africa
UN	United Nations
UNAIDS	United Nations Programme on HIV and AIDS
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

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DEFINITION OF THE TERMS

Definition of disclosure: is defined as ‘a process, involving ongoing discussions about the disease as the child matures cognitively, socially, emotionally, and sexually’ (Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), 2018).

Pre-disclosure: The period under which the child has not yet been told about their HIV status (EGPAF, 2018).

Partial disclosure: it is the process of telling the child the truth gradually, but not the whole truth; usually the name of HIV is concealed (can be a step in the full disclosure process) (EGPAF, 2018).

Full disclosure: it is the process of providing full information and knowledge about HIV to the child (EGPAF, 2018).

Post-disclosure: it is the ‘period following disclosure, commonly described as early post disclosure (first three to six months) and late post-disclosure (over six months) periods (EGPAF, 2018).

Complete non-disclosure: it is the state of maintaining complete secrecy around the diagnoses; not telling the truth or not providing any information about the diagnosis (EGPAF, 2018).

Accidental disclosure: it is the state whereby the child is told about an HIV status without any preparation and disclosing to them by accident. It is usually done unintentionally when HIV diagnosis is being discussed among adults and a child overhears it (Shuaibu, 2024).

Deception: ascribing the child’s condition to a different disease (e.g., for not eating enough); frequently coupled with non-disclosure (EGPAF, 2018).

Prevalence: Merriam-Webster online dictionary (2017) defines prevalence as “the degree to which something is prevalent, *especially*: the percentage of a population that is affected with a particular disease at a given time”.

Barriers: ‘a natural formation or structure that prevents or hinders movement or action’ (Merriam-Webster online dictionary, 2017)

Disclosure ‘is the process of making facts or information known to the public. It refers to the act of revealing something that was previously secret or private’ (Merriam-Webster online dictionary, 2017).

Children: Children are defined as under age 10’ (EGPAF, 2018).

Health Care Workers: refers to ‘facility-based health care providers—such as doctors, psychologists, nurses—as well as social workers, community health workers (CHWs), and lay health workers.

ABSTRACT

Over the past years, the global community and individual countries have made progress in meeting the needs of adolescents living with HIV (ALHIV). This includes knowledge about their HIV status which needs to be age tailored and be gradually informed. Nevertheless, to date, researchers have focused on child and primary care giver experiences. Little is known about prevalence and barriers of HIV status disclosure among children aged 6 to 12 years old. The aim of this study was to assess the prevalence and the barriers of HIV status disclosure to children aged 6 to 12 years old in Kasungu, Malawi. A mixed method research approach and a transformative missed methods design were used in this study to explore the HIV status disclosure phenomenon and establish its gravity. A census sampling strategy was employed to include participants into the study. Survey questionnaire, in-depths key informant interview guide, and audio-recorder were used to collect data from all health care workers working in antiretroviral clinics who interacts with children in Kasungu, Malawi. Participants were interviewed to assess if they practice and their perspectives and the barriers encountered. Data were analyzed using descriptive and thematic analysis. The findings revealed that a small percentage (12%) of health care workers reported disclosure of HIV status to children. A significant proportion (72%) reported that they had never disclosed HIV status to children. The major barriers to disclosure were the age of the child, the fear of the consequences of disclosure, need for private space and the child's inability to maintain privacy regarding their diagnosis. The study further highlights the relevance for providing the appropriate training and mentorship on HIV status disclosure for health care workers among children and necessary resources.

Keywords: *HIV status, Practice, Disclosure, Barriers, Health care workers, Children, Malawi.*

CHAPTER 1: INTRODUCTION

1.0 Introduction

Human Immunodeficiency Virus (HIV) acquisition in children has been evidenced through studies to be mainly via childbirth and breastfeeding (Kalembo, et al., 2018). Prior to the advent of antiretroviral (ART) medications around 1990s HIV claimed a lot of lives among children before attaining their fifth birthday. In the aftermath, many children can make it into adolescent and adulthood. The ARVs brought new dawn to the affected families and the entire system of health professions globally. Nevertheless, their survival emerged with new concerns regarding their health and wellbeing in addition to risk of HIV transmission to others. An important aspect which remains a gatekeeper for engagement with continuum of care is disclosure of HIV status during childhood period (Hayfron-Benjamin, et al., 2018). In Sub-Saharan Africa (SSA) it is quite significant that the existing data has demonstrated low rates, as shown in section below, across many resource constraint countries despite the World Health Organization (WHO) recommendation to initiate age-appropriate disclosure as early as possible. Disclosure of HIV status to children has shown to have potential benefits as well undesirable outcome including enhanced linkage to medication, reduce the potential risk of HIV transmission during the adolescent period and on the other hand stigma and discrimination towards the family and the child's reduced coping skills to accommodate the diagnosis.

The study aims at investigating prevalence and barriers of Human Immunodeficiency Virus Status Disclosure among Children in Kasungu. Human Immunodeficiency Virus (HIV) continues to be a major global health challenge especially for adolescents (United Nations Programme on HIV and AIDS (UNAIDS), (2021). According to United Nations Children Fund (UNICEF) (2021) globally, it is estimated that 38 million people are living with HIV of whom 2 million are adolescents. Although new HIV infections have decreased, adolescents still represent a growing number of people living with HIV estimated at over 830 new infections

everyday globally (UNICEF, 2021). AIDS related deaths among HIV adolescents has increased by 50% compared to 32 % in adults from 2005 to 2012 (UNAIDS, 2016). Sub-Saharan Africa account for 83% to 88% of all children below 15 years living with HIV worldwide (Doat, et al., 2019; Gyamfie, et al., 2017). Inbaran, et al, (2022) estimates 1.7 million of the adolescents with HIV live in sub-Saharan Africa, where almost 92% of global AIDS related deaths occur (UNICEF, 2021).

In Malawi, the recent estimate by 2021 shows 58 000 children aged 0 to 14 were living with HIV, of those 42 484 (74%) were receiving antiretroviral therapy (ART), and there were about 3000 new infections in that pediatric population (UNAIDS, 2021). It is recommended by the World Health Organization (WHO) that children living with HIV should know their HIV status (Kalembo, et al., 2018). Despite the recommendation, disclosure remains a significant issue especially in Sub-Saharan Africa, a systematic review of this region showed the prevalence of HIV disclosure ranging from as low as 9% to 72% in 2019 (Doat, et al., 2019). The recent known prevalence of disclosure in some parts of Malawi is at 25% (Kalembo, et al., 2018) whereas Kasungu as a district is not known. Non-disclosure of HIV status is associated with a myriad of effects including the following; compromise in access to pediatric HIV treatment, care and support, adherence to treatment, increasing the risk of passing the infection to others through sexual contact, high depression rate among caregivers, accidental disclosure of HIV status to children, anger and resentment towards the caregiver, and poor health outcomes (Madiba and Diko, 2021; Doat, et al., 2019; Kalembo, et al., 2018; Gyamfie, et al., 2017). Disclosure of HIV status to children is very vital as it is associated with an increase in survival rate because it helps to revert the undesirable consequences of delayed or lack of disclosure (Doat, et al., 2019). Discussing HIV diagnosis with children remains complex, parents have the principle role, legally responsible, regarded to be in the best position to support their ward in terms of disclosing the HIV status, help them accept their condition, adhere to HIV

medication, and regain their self-esteem, however, they also have the right to decide to do so or not, if they consent to they also stand in position to decide when and who should do the disclosure (Doat, et al., 2019; Kalembo, et al., 2018). It is nonetheless noted that most parents refrain from doing so for fear of several issues such as parents' guilt, the impact on the child's emotional health, the child's capacity to understand and their emotional readiness to cope with the diagnosis (Mburu, et al., 2014; Kiwanuka, et al., 2014). Therefore, health care workers' role is essential despite being reluctant to do so for various reasons (Aderomilehin, et al., 2016; Sariah, et al., 2016).

1.1 Background of the study

1.1.1 HIV/AIDS global context and children's HIV positive status disclosure

Globally, a considerable number of children are positively living with HIV. Sub-Saharan Africa accounts for a greater proportion as opposed to the international community. Malawi is also struggling with the burden of HIV among children and adolescents. Over the past years, the global community and individual countries have made progress in meeting the needs of children and adolescents living with HIV (ALHIV). Notably, the introduction of Antiretroviral Therapy (ART) has shown remarkable strides in alleviating the impacts of HIV/AIDS pandemic (Hudelson & Cluver, 2015). This introduction of ART has also redefined the HIV epidemic from a deadly infectious disease to a chronic manageable disease making children live longer with HIV (Mukumbang et al, 2017; Mandawa 2022; Mutumba et al, 2016). Despite achieving significant milestones in the scale-up of life-saving ART-programs, uptake by children and adolescents living with HIV remains low (59%) (UNAIDS 2022; Wang et al., 2022; UNICEF, 2021). The remaining gap of children and adolescents living with HIV not linked to ART are a potential defeat to the ART program of ending HIV/AIDS by 2030. This population shall soon assume personal responsibility on issues of sexuality. Late medication initiation may be associated with treatment failure and in some instances have already indulged

in risky sexual behaviors and transmitting resistant strains due to partial HIV exposure to medicines in utero.

Mitigating the escalating incidence of HIV and reduce AIDS-related deaths, UNAIDS in 2014 set an ambitious 95-95-95 target which aimed at ending AIDS epidemic by 2030 by achieving 95% of all people living with HIV know their status; 95% of all diagnosed HIV positive be initiated on highly active antiretroviral Therapy (HAART); and 95% of all those on treatment be virally suppressed (UNAIDS, 2014). However, this target may not be met especially due to escalating number of ALHIV. During adolescence, they experience numerous physical, psychological and cognitive developmental changes which makes it a challenge to initiate and consistently adhere to ART and remaining engaged in care (Okonji, 2023; Sibhatu et al, 2009 as cited in Okonji 2023). Targeted efforts need to be developed and this can only be possible by establishing barriers including personal challenges in the local context through current research. This research helped to establish in part to expose the inner conflicts that all key players (child, health care worker, and parents or guardians) experience to refrain from the disclosure taking place. It also highlighted the skill set needed to deal with fears that health care worker and parents experience upon how the child would react after shared knowledge of their HIV status. It is an aspect that fosters health care worker/parent-child relationship when handled professionally.

Care and treatment for ALHIV has been associated with several factors that hamper complete roll out. Scholars have reported that forgetfulness, substance abuse, adverse effects of ART, perceived social support, and mental health issues which include depression and self-stigma as barriers to adherence and retention in treatment, care and support (Zelege, et al., 2025; Seunanden, et al., 2025). Hlophe et al, (2023) suggested that psychosocial risk factors such as orphan-hood, guardianship change, and lack of parental and social support lead to mental health

problems which consequently affect ART initiation and poor adherence. This psychosocial process disempowered parents and dread them of the disclosure of a positive HIV status to the child bearing in mind that it would disrupt the well-established relationship within the family. The need to maintain happiness within the family circle and more especially between the child and parents or guardian is an overarching reason that makes disclosure process a critical challenge. Furthermore, some biological parents in particular may not be flexible enough to disclose or consent for disclosure of an HIV status to the child for fear of indirect disclosure of their HIV status to the child and public if the child fails to keep the HIV status a secret. They also regard the parents as source of infection and mount a bitter confrontation against them. This study further aimed at finding plausible solutions to help parents with such situations on how to be mentally and psychologically prepared to handle such a conflict.

1.1.2 Disclosure of HIV status among Adolescents living with HIV (ALHIV)

Living with HIV among adolescents has been associated with the high levels of anxiety, isolation, depression and suicide (Wollet et al., 2017). A study from Eswatini found that adolescents experienced psychological distress which included unresolved grief, fear of stigmatized and discrimination, rejection, isolation and suicidal ideation (Nsibandze et al., 2021). Researchers have recommended that psychosocial support for ALHIV in addition to standard ART services would help them adapt and cope with the chronicity and stigma associated with HIV (Woollett et al, 2017; Mutumba et al, 2016). However, despite this recommendation, the psychosocial impact of HIV on ALHIV has been overlooked in sub-Saharan Africa (Gomo et al., 2017; Woollett et al, 2017; Mutumba et al, 2016). Despite this, the psychosocial care for ALHIV has proven to be meaningful. Elsewhere in Ghana, a study by Dake et al. (2023), found that social support from family and peers played a significant role in helping ALHIV to take up services and remain positively engaged in care. Though others have argued that ALHIV should be given a sense of independence and responsibility noted as

life-saving qualities in as far as adherence to life-long ART is concerned (Dadi, et al., 2024). Nabunya, et al. (2020) noted that complete independence and full personal responsibility of ART medication intake by the adolescents has been implicated in worse ART adherence outcome. Thence, it should be known that there is a need to balance between independence and responsibility for the adolescent and a sense of family support in ensuring continued medication intake without interruption.

WHO, developed guidelines in 2011 for HIV disclosure and counseling of adolescent living with HIV recommending disclosure of their status by 12 years (WHO, 2025)? According to Evangeli and Wroe (2017), disclosure of HIV status is helpful to adolescents as it enhances adherence to therapeutic support and promoting psychosocial support. However, disclosure has stirred contradiction among studies, some studies associate disclosure with negative psychological and mental health problems (Edun, et al., 2022). Despite the WHO 2011 guidelines recommendations, disclosure among children with HIV remains a big challenge, and many Children in sub-Saharan Africa are still unaware of their HIV status (Kalembo et al., 2019). A study from Malawi by Faidas et al., (2024) found that parents of children infected with HIV did not want to disclose the HIV status of children for fear of mental health problems in the child such as self-stigma. It should also be noted that once an individual's HIV status is shared it cannot be unshared. Hence, the interpersonal risks associated with HIV status awareness exhibit psychological distress especially anxiety which serves as an inhibitor of HIV disclosure. Worries that others may be aware of the individual's HIV status may be concerning to the extent of partial or no disclosure can take place. Instead, social ostracism may result. On the other hand, anxiety or stress may drive an individual to commit self-disclosure in the event that the PLWHIV is concerned that a third party would reveal to others.

1.1.3 Disclosure of parental HIV status

Disclosure of parental HIV status may be significant in the context of motivating child's acceptance of their positive HIV status and adhering to medication regimen. The advent of HAART transformed HIV into a manageable and chronic infection that human beings become accustomed to it, enjoy life, support their families and live longer to the extent of bearing children. These days due to public disclosure (individuals willingly revealing their positive HIV status through different media platforms) many are willing to play the part of peer support. Parental HIV positive disclosure is a critical part influencing encouragement and other benefits, though some parents are still engulfed in the fear of undesirable consequences. Studies have noted that disclosure of parental HIV status is associated with a number of positive outcomes on either side between children and parents. There was remarkable decline on levels of negative self-esteem and aggressiveness with heightened self-concept among children (Mugo, et al., 2023). On the other hand, there was improved adherence to clinic appointments, lower levels of parental anxiety and depression, and mutual emotional support among parents (Osingada, et al, 2016). Parental HIV positive disclosure is essential in promoting psychological and social well-being for both parties. It is evident from the studies above that family cohesion is likely to be promoted. Very few studies in low-resource settings have addressed the issues of parental disclosure of their HIV status to their children. In Uganda, a study by Osingada, et al. (2016) analyzed the impediments of parental HIV positive status disclosure qualitatively and found out that many biological parents were unable to initiate the disclosure process for fear of several reasons including disturbing the child's peace and happiness, disruption of the relationship between parents and child, let alone parental HIV positive status disclosure to a child. Parents and guardians play a vital role in the disclosure process of the child's HIV status and there is a need of strategizing our interventions to encourage parents or guardians who are positively

living with HIV to disclose their status. These needs research-based evidence from the local context to guide policy development and practice.

1.1.4 Malawi HIV context and disclosure

In Malawi, efforts to mitigate the impact of HIV have been employed. In 2014, Malawi adopted UNAIDS targets to achieve ending AIDS by 2030 (Sabapathy, et al., 2022). This ambitious target for Malawi showed that by the end of 2018, of the 1,064, 676 PLHIV, about 805, 232 were on ART representing 76% and 68% among adults and children respectively regarding ART coverage against 90% set target (Department of HIV- MOH, 2018). Despite this milestone achievement, ART treatment and care for ALHIV remain problematic in Malawi. An estimated 66,000 new HIV infections are occurring among adolescents aged 15-24years old yearly. Reports suggests that at least 300,000 children across the globe were newly infected with HIV in 2020, or one child every two minutes, according to a new UNICEF report 120,000 children died from AIDS-related causes during the same period relating to one child every five minutes (UNICEF, 2018). However, there is scarcity of data behind this escalating number including the psychosocial impact of living with HIV on adolescents. Similarly, there is lack of data on the disclosure of HIV to the adolescents in Malawi including Kasungu. Hence, we conducted a study to look at HIV status disclosure among children, the perspective of health care workers and the associated barriers to derive context specific data in Kasungu district.

1.2 Problem Statement

The prevalence of HIV status disclosure among children varies significantly across the global. The WHO recommends age-appropriate HIV status disclosure to children. Some health workers agree that it is important that children who are HIV positive should know their status as soon as possible (Madiba and Diko, 2021). Despite the large proportion of health professionals agreeing to the assertion and the WHO recommendation only 25 percent of

children who are HIV positive across Malawi had their HIV status disclosed to them (Kalembo, et al., 2018). The implications of low disclosure rate are linked to poor or non-adherence to medication. Poor adherence to the antiretroviral (ARV) regimen is seen as a setback to achieve the MOH program intervention of 95% viral suppression target among children in Malawi. Children who do not know their HIV status have difficulties adhering to treatment. They usually miss doses and clinic appointment dates. This is directly associated with poor adherence subsequently viral suppression is not achieved. The ART program in Kasungu experiences low rate of viral suppression (81%) and a considerable (1.5%) among children (MOH program data, 2025). Such problem requires identification of context specific root causes. In addition, there is failure to fully integrate the differentiated service delivery model (DSD) of teen clubs in Kasungu as participation in this MOH strategy of care is highly influenced by full disclosure among other criteria (Clinical Management of HIV in Children and Adults, 2022). Currently, there are 7 teen clubs instead of 12 needed to cover for the whole district. This gap has impact on the HIV cascade, from uptake of HIV testing (knowledge of status) to engagement in care and viral suppression coverage among children which are by far reaching the target.

Many studies have researched on health workers' perspective and barriers related to non-disclosure among children (Kirabira, et al., 2025; Yami, 2022). However, the level of health care workers' perspective and practices on disclosure of HIV status as well as quantitative information to characterize the level of HIV status disclosure to children is lacking specifically for Kasungu communities. Therefore, lack of data has implications on resource allocation. Resource provision to cover for HIV services for children is dependent on data availability which also enables evidence-based practice. In addition, the information on the barriers to HIV status disclosure to children living with HIV is lacking in Kasungu which disproportionately impact further on worse outcomes experienced by children living with HIV in the continuum

of care. This calls for a targeted research in-order to elucidate the specific community dynamics experienced by health care workers in the disclosure processes and channel more specific solutions to the revealed problems and foster growth to the enhancers through informing policy direction.

1.3 Main Objective

To examine the prevalence and the barriers of HIV status disclosure to children aged between 6 and 12 years diagnosed with HIV in Kasungu.

1.3.1 Specific Objectives

1. To determine the prevalence of HIV status disclosure among HIV infected children aged between 6 and 12 years in Kasungu.
2. To investigate the barriers among health care workers associated with disclosure of HIV status among children aged 6 to 12 years.
3. To understand healthcare workers' perspectives regarding the disclosure of HIV status to children aged between 6 and 12 years in Kasungu.
4. To assess healthcare workers' practices regarding the disclosure of HIV status to children aged between 6 and 12 years in Kasungu.

1.3.2 Research Questions

1. What is the prevalence of HIV status disclosure among HIV infected children aged between 6 and 12 years in Kasungu?
2. What are the barriers among health care workers associated with disclosure of HIV status among children aged 6 to 12 years?

3. In what ways do health workers practice HIV status disclosure to children aged between 6 and 12 years in Kasungu?
4. What are the views and attitudes of healthcare workers toward disclosing HIV status to children aged between 6 and 12 years in Kasungu?

1.4 Justification

This study is in line with the sustainable development goal (SDG) number three which aims at ‘ensuring healthy lives and promote well-being for all at all ages’ (United Nations, 2015). In relation to SDG3, the Malawi government’s health goal is ‘to improve the health status of all Malawians and increase client satisfaction and financial risk protection towards attainment of Universal Health Coverage’ (Health Sector Strategic Plan III (HSSP III) 2023-20230). In-order to achieve this, context specific health research as this one would be conducted in order to generate high-quality evidence required to inform the development of health and health care delivery system according to the seventh objective in HSSP III. Hence, it would form the basis for equitable resource distribution in form of infrastructure, medical supplies and working materials as well as health care workers which are crucial to accord all children living with HIV quality health and equal opportunities to access adequate health care services. The HSSP III strategy number 7.2 emphasizes achieving the development of evidence-based policies in health through intensified knowledge generation, which is then translated and shared for utilization. This research is based on that strategic plan. The research knowledge generated in this study was translated and shared in the results and discussion sections for public consumption at the local level, inform policy direction at the national level and support implementation of national health regulations and interventions towards children living with HIV. The Malawi vision 2063 agenda also acknowledges Human Capital Development among its key enablers. One possible way to achieve it, is through provision of quality health services

especially at the community level. Hence, this research has revealed the health need of children living with HIV in the communities of Kasungu and probes for full support and the requisite social services that will enable them to live and grow to their full potential (National Planning Commission (NPC), 2020). The study will also contribute to literature on disclosure of HIV status to children as there is not enough scholarly work on health care workers' practice of disclosure among children in ART program in Kasungu and the findings form a basis for further research on related aspects that are not addressed in this study.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

The World Health Organization (WHO) recommends age appropriate (between 6 through 12 years) HIV status disclosure to infected children bearing in mind their emotional, social and cognitive development (Kalembo, et al., 2018). Disclosure of HIV status to children diagnosed with HIV still remains complex for a caregiver despite the potential benefits connected with it and the nervousness that comes along with the process of disclosure (Appiah, et al., 2021). This is evidenced by the low prevalence rate of HIV status disclosure especially in limited resource settings (Alhassan, 2023). Several studies that researched on ‘persons best to disclose’ preferred disclosure by caregivers with support from health care workers (Aderomilehin, et al., 2016). This is in support with the WHO recommendation that parents seek support from, and share the disclosure process with, healthcare workers among other community leaders for enhanced health outcomes (Kalembo, et al., 2018). Disclosure, the process of gradually telling the child infected with HIV about their sero-status, is the gateway to treatment and care or continued adherence for better health outcomes.

Disclosure of HIV status to children infected with HIV is associated with a lot of benefits such as improved resilience, high chances of adhering to treatment, reduced likelihood of becoming depressed, and better engagement of a helping social network, (Ndambo, et al., 2022; Adam, et al., 2021; Dzansi, 2020). Despite the aforementioned benefits, disclosure has also the following consequences; stigma and discrimination being directed at the family, fears about the child’s ability to cope with the diagnosis, fearing blame, and negative judgment (Mengesha, 2023; Asrina, 2023). Non-disclosure of HIV infection impair treatment understanding consequently there is lack of ART medication adherence, which can lead to the development of drug-resistant strains, the potential for children to unknowingly transmit the virus to others

once they reach adolescence, and increased psychological and behavioral problems may occur (Fuente-Soro, et al., 2023).

HIV status disclosure is enhanced by the diagnosis of an Acute HIV Infection (AHI). Early diagnosis of HIV infection is linked to prompt engagement with preventive modalities in the period that is highly infectious (Hino, et al., 2018). The importance of early diagnosis cannot be overemphasized. It remains a channel for initiating health education on behavior change to facilitate safer sex practices. In addition, it provides linkage to the rehabilitation institution that provide supportive environment and nurture physical and social growth. Consequently, children experience good adherence to treatment and better outcome.

Disclosure of HIV status is an important strategy in reducing onward transmission of HIV and further acquiring the resistant associated HIV due to reduced risky sexual behavior during the teenage exploratory period soon after graduating from childhood. Disclosure of HIV status to children is a significant landmark associated with remarkable risk reduction. However, disclosure process, despite its significance, has encountered downfalls in reaching total coverage. A study in Malawi by Kalembo, et al., (2018) has demonstrated how those barriers emanate from all concerned players; health care workers, caregivers and the child being the central point themselves. Sections below have demonstrated the magnitude of disclosure process from the known literature and explicitly exhibited the barriers underpinning disclosure process.

2.1 The prevalence of human immuno-deficiency virus status disclosure among human immuno-deficiency virus infected children.

The prevalence of HIV status disclosure among children varies significantly in different contexts across the global community. The level of HIV status disclosure among children infected with HIV is still lagging despite the WHO recommendation to disclose at the

appropriate age 6 through 12 (Magobo, et al., 2025). This shows there is reduced robustness of data on disclosure among children living with HIV across the continents. A review of literature has noted inconsistencies of data at the global level. Globally, it is estimated that approximately 3.3 million children below 15 years of age are living with HIV and 88% (3 million) of them live in Sub-Saharan Africa (Gyamfie, et al., 2017). For example, in Asia estimates indicate that the prevalence of disclosure was 42% among 6 to 19 years old (Sornillo, et al., 2023). Whereas, in coastal Karnataka, India 58% of children had their HIV status disclosed (Kodyalamoole, et al., 2021). These differing rates indicate the need for context specific data that will help channeling resources more appropriately. Also, there is a need to scale up the interventions on research at the global perspective to generate more data that may reveal the patterns of factors that facilitates non-disclosure.

In the sub-Saharan regions of Africa, the rate of HIV status disclosure remains relatively low. Studies conducted among resource limited settings show that many HIV-infected children are not aware of their HIV status. A Systematic Review on disclosure of HIV Status to Children in this region found a wide gap of the prevalence on disclosure ranging between 9% and 72% (Doat, et al., 2019). Opposed to the systematic review findings and global data, the literature in this region has demonstrated a small gap among the findings. Data review shows rates of HIV status disclosure being consistently low among children in Sub-Saharan Africa (Kenya, Ghana, Ethiopia, Tanzania) indicating 36.6%, 33.5%, 31.2%, 42 % subsequently (Ngeno, et al., 2019; Amankwah-Poku, 2021; Belay, et al., 2022; Msoka, 2025). In Malawi, 58 000 children aged 0 to 14 were living with HIV by 2021, of those 42 484 (74%) were receiving antiretroviral therapy (ART), and there were about 3000 new infections in that pediatric population (UNAIDS, 2021). A study by Kalembo, et al. (2018) showed that 25% of HIV positive children knew their HIV status. This consistency indicates the prevailing issues leading to non-disclosure in the region. Further studies need to focus on the pervasive factors that have

led to low disclosure rates in individual contexts. Efforts to increase the prevalence of HIV status disclosure should focus on developing context-specific interventions that guide and encourage health care workers to help disclose HIV status to children.

2.2 Healthcare workers' perspectives and practices regarding the disclosure of human immuno-deficiency virus status to children.

Disclosure of HIV status to children has gradually evolved from what would be referred to as a taboo to a necessity for proper care and support among CLHIV. Since the knowledge of modes of HIV transmission among children became apparent around 1980's literature has it that many children could not make it before five years of age (Mohammed, et al., 2024). The introduction of antiretroviral therapy (ART) among exposed babies and other ages has made the condition a preventable and manageable chronic condition (WHO, 2017). Despite this notable stride support and care among children still remains a challenge as many health workers find it hard to tell children of their HIV status and facilitate adherence to treatment (Kalembo, et al., 2018). The growth in childhood carries with it an increase in curiosity to understand the reason of taking daily pills, their health status and the potential risks associated with sexual activity in the adolescence and a very penitent question is the proper age at which children should be disclosed of their HIV diagnosis (Ankunda, et al., 2016). Despite disclosure being a WHO recommendation, non-disclosure still remains a challenge and its notable consequences have been discussed (Toromo, et al., 2022). Literature has it that healthcare workers are key and stand in the best position in the disclosure process due to their ability to offer biopsychosocial support (Lukyamuzi, et al., 2023). However, studies have shown that many healthcare workers have poor perspective towards primary caregivers willing to disclose HIV status to their children (Kirabira, et al., 2025), the main contributing factors include reduced empathy, lack of professionalism, rudeness and uncaring behavior which led to lack of involvement among some healthcare workers (Wachira, et al, cited in Kalembo, et al., 2018).

Whereas the practice of disclosure among some healthcare workers encountered the following challenges lack of standardized disclosure policies and materials, lack of trainings and skills, poor cooperation from primary care givers and inadequate time (Madiba and Diko (2021).

The HIV diagnosis disclosure which involves the process of telling the child of the highly transmissible, stigmatized, and potentially life-threatening condition that he or she is living with is an apparent psychosocial challenge that studies have demonstrated above. Psychologically it is associated with fear that both parents and health care workers harbor that disclosure would bring distress on the child. The sense of knowing that the infection was contracted from the parents may create mistrust and poor social interaction in some children towards their caregivers. However, different sources demonstrated positive impacts of disclosure including promotion of trust, improved social interaction with caregivers, medication adherence, strengthened connection with support services and improved overall health outcome (Msoka, et al., 2025; Alhassan, 2023; Mkandawire, 2022; John and Chipwaza, 2022; Izudi, 2021). This study has presented specific findings at the local context in Kasungu by looking at the experiences health care workers encountered after disclosure.

2.3 The barriers among health care workers associated with disclosure of human immuno-deficiency virus status among children

The persistent lower rates of children's HIV status disclosure among the international communities call for collaborative approach between health care workers and guardians. However, there are established impediments on either side hampering the disclosure rate from escalating. The authors of recent sub-Saharan African studies have revealed that many health workers are reluctant to disclose the child's HIV status because of lack of professionalism and empathy by health workers, unwillingness of parents to disclose, a lack of training, inadequate knowledge and skills, and a lack of disclosure materials (Adeniyi, et al., 2021; Ismail, et al.,

202). In addition, other barriers emanate from guardians' perspective including younger age was thought to be unfit, the expected psychological effect on the child, knowledge on how disclosure can be done, a child's inability to keep their HIV status secret, fear of stigmatization, and level of education were found to be associated with non-disclosure (Mphego, et al., 2023; Tessema, et al., 2023; Tesfahunegn, et al., 2023; Doat, et al., 2019). It has been noted from both literature and the findings in this study that disclosure of an HIV status to a child is not easy. Disclosing the diagnosis of HIV to a child is emotionally stressful and controversial among both health care workers and parents or guardians.

Non-disclosure of HIV status is an issue that needs collaborative efforts among health care workers, families and researchers to deal with. Disclosure of HIV to children is generally important as they gain understanding of the need for ART and may facilitate medication adherence through creating a trusting relationship between children and parents or guardians. This trusting relationship should be supportive to adherence rather than leaving the child with complete responsibility. Children who independently take medication, no supervision and reminding, have been linked to poor adherence despite full knowledge of their status, and ART benefits (Moyo, et al., 2025; Villiera, et al., 2022). Therefore, an inherent element that associates disclosure and non-adherence is leaving the child to take full responsibility of personal medication intake in either age group. This behavior needed thorough assessment and develop targeted solutions to mitigate its effect on disclosure. This study is the first of its kind aimed at providing insight on the rate of disclosure and its correlates from the local context in Kasungu. It explored financial, human, material and infrastructure barriers linked to disclosure of HIV status among children. It stands in the best position to enlighten policy makers in developing recommendations regarding the conditions and proper timing for disclosure.

2.4 Theoretical framework

2.4.1 Theoretical Background

The theoretical foundation of this study is based on the theory of family systems theory by Dr. Murray Bowen. It was developed as a framework for understanding the emotional dynamics within families. Is an ‘approach to understand human functioning that focuses on interactions between people in a family and between the family and the context(s) in which that family is embedded’ It depicts that families are a network and interdependent systems, where the emotions, behaviors and relationships of each member influence the whole unit (Friedman and Allen, no date, 2012).

2.4.2 Family Systems Theory

This study explored and utilized the Family Systems Theory to explain influence of key players of a family and health care worker in the disclosure process of HIV status. This theory ‘views the family as an interconnected system where each member's behavior affects the whole family. It has been adopted for use in this study to explain how family dynamics, communication patterns, and relationships influence the process of HIV disclosure to children. Family Systems Theory provides a valuable framework for understanding how family dynamics, the patterns of communications, and relationships shape the process of HIV disclosure to children living with HIV (Cohen, 2023). Family dynamics vary between families in a community. The dynamics of any family plays a significant role in disclosure of HIV. The structure and the roles of a family has profound influence on disclosure. Families with strong bonds and supportive relationships are more likely to approach disclosure collaboratively, ensuring the child feels safe and free. Health care workers can easily work through a collaborative and supportive families to get through the disclosure process successfully or with minimal negative reactions. On the other hand, families with conflict and rigid hierarchies struggles with open dialogue, may delay or complicate the disclosure process. The health care worker finds it hard

to initiate the disclosure process in such a complicated environment. Communication patterns plays another important role in disclosure process. Open and honest communication is very essential for effective disclosure. Families that foster disclosure where emotions and concerns can be freely expressed are better equipped to navigate the sensitive topic of HIV. Health care workers further equips the caregivers with skills on handling the minimal negative reactions the child may express. If the families are open to discuss issues of HIV provides a very good platform for the health care workers to initiate the disclosure process. Whereas, families with avoidance patterns of behavior or secrecy may find it very challenging to disclose, potentially leading to confusion and mistrust in children living with HIV. Lack of open and honest dialogue between caregiver and child complicates the process of disclosure and effect psychological stress upon the child. Children may learn not to trust on anyone at all including the health care worker. Also, relationships are very crucial in disclosure process. The quality of relationships between members within a family plays a pivotal role. A strong parent-child bond built on trust and empathy can help the health care worker to facilitate a smoother disclosure process easily. On the contrary, the involvement of health care worker and the caregiver with a poor bond or weak relationship with the child can hinder disclosure, depending on their attitude and understanding of HIV. Applying the Family Systems Theory, health care workers may evaluate these factors and tailor their approach to support families in disclosing HIV status in a way that minimizes emotional distress and fosters understanding to the child and the concerned family as a whole. The theory helps to assess and interrupt the patterns of repeating behavioral exchanges which are an integral part of problem behavior. Interrupting the problem perpetuating patterns normalizes the problem behavior and problem is solved (Johnson and Ray, 2016).

2.5 Non-disclosure of human immuno-deficiency status to children

Non-disclosure of HIV status to children can significantly impact their adherence to ART treatment. It is hard for children to understand the importance of consistently taking medication so long they are unaware of their HIV status; this leads to poor adherence. Negative outcomes emerge as a result of lack of knowledge of HIV status. These include; lack of understanding. It is difficult for children to comprehend the need of taking medication regularly if they are not informed about their HIV status. Hence, they are prone to missing doses. HIV status un-disclosure to children is also linked to psychological impacts of confusion and mistrust. As children grow, they begin asking questions as to why they are taking the medications. They sense something is wrong but are not given the full picture. This consequently leads to anxiety and stress and resulting in inconsistent treatment adherence. Keeping the HIV status secret perpetuates the stigma and shame associated with the disease. The environment of secrecy discourages open communication about health and treatment which makes it hard for children to adhere to treatment. Children who are void of knowledge of their HIV status lack support found in crucial resources such as support groups and education programs that emphasize on the importance of medication adherence (Amankwah-Poku, et al., (2021). ART treatment adherence and overall health outcomes for children living with HIV can be improved through open communication and providing age-appropriate information.

2.6 Reduced health care worker participation

Reduced health worker participation can act as a mediator variable between non-disclosure of positive HIV status to children and poor adherence to ART treatment. The relationship between two variables and the outcome unfolds in following way. First, non-disclosure of HIV status to children creates a barrier for open dialogue and understanding about the importance of medication adherence. Mistrust and confusion follow lack of disclosure and it becomes uneasy for health workers to effectively engage with the child (Kalembo, et al., 2018). The reduced

health worker participation limits their role in providing education, support, comprehensive care, and fail build trust and rapport as the child is unaware of their status. Health care worker participation is further compromised with lack of necessary training and tools to navigate the complexities of non-disclosure (Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) (2018). This leads to poor guidance and lack of encouragement by health care worker consequently there is lack of understanding of the importance of adhering to medication regimen. Therefore, they tend to miss doses and become inconsistent in taking medication and ultimately poor adherence to treatment.

2.7 Sub-optimal counselling sessions

Sub-optimal counselling sessions emerges due to inability of HCW to provide comprehensive and tailored advice when the child is not aware of their HIV status. In this case the child fails to receive necessary information and support to help adhere to the medication regimen. Effective counseling session are vital for supporting children and their caregivers. Nevertheless, non-disclosure can limit the effectiveness of the counselling sessions (Nakaye, et al., 2023). Non-attendance or reduced clinic attendance can be perpetuated by non-disclosure of child's HIV status. Parents may avoid attending the clinic regularly for fear that the child may learn about their HIV status (Dear, et al., 2022). This missed appointments limit the HCW opportunities to monitor the child's health, emphasize the benefits of adherence, and provide necessary interventions (Kumwenda, et al., 2024).

2.8 Poor adherence to medication

Poor adherence to treatment is an outcome variable that arises as a result of a strong relationship between non-disclosure of HIV status to children, reduced health care worker participation and sub-optimal counseling session as well as non-attendance or reduced clinic attendance (Nhlongolwane and Shonisani, 2023). Sub-optimal counseling session and non-attendance or

reduced clinic attendance lead to inadequate support and health education for the child and parent or caregiver. Instead, they lack proper guidance and encouragement from the health care worker consequently children lack proper understanding the importance of taking medication regularly and adhering to treatment regimen.

2.9 Conclusion

The World Health Organization (WHO) recommends age appropriate and gradual disclosure of HIV status to children. Disclosure of HIV status has a myriad of benefits including easy compliance to treatment and care and better health outcomes. On the other hand, non-disclosure of HIV infection impairs treatment understanding consequently there is lack of ART medication adherence. Despite the WHO recommendation, the process of disclosure meets a lot of resistance. Hence, the rates of disclosure in many parts across all regions are consistently low. Literature has it that healthcare workers are key and stand in the best position in the disclosure process. However, studies have shown that many healthcare workers have poor perspective towards primary caregivers willing to disclose HIV status to their children and lack of professionalism. Whereas the practice of disclosure by some healthcare workers encountered the following challenges lack of standardized tools and trainings, poor cooperation from caregivers. This study has used a Family Systems Theory to explain the influence of family dynamics, communication patterns, and family relationship in relation to the health care worker to facilitate HIV status disclosure. The theory highlights the understanding that non-disclosure of HIV status to children is a significant predictor of poor adherence to medication. Addressing this issue requires consideration of several children's dimension such as age, psychological readiness and the support systems in place. Non-disclosure of HIV status to children can further compromise health care worker participation and further impact negatively on adherence to treatment regimen. To deal with this requires a multifaceted approach, such as training of health care workers on disclosure practices, making available standardized tools for

disclosure, and create a conducive environment that fosters open communication and between health care worker, children and parents. It should also be known that non-disclosure of HIV status to children leads to sub-optimal counselling sessions and reduced clinic attendance consequently poor adherence to medication.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

Research methodology refer to a set of approaches that define what and how data is collected based on the broad assumptions of a study (Creswell, 2014), whereas, Flick (2015) describes research methodology as a set of procedures and techniques that are used to create and collect information or evidence for the research project.

This chapter describes the research methods and techniques used related to the research under investigation. The chapter discusses research paradigm, research approaches, research designs, target population, sampling method, sample size, data collection instruments and data collection procedures, data analysis, validity and reliability, ethical consideration and dissemination of study results.

3.1 Study Site

The study was conducted in 35 ART clinics in Kasungu District among ART providers. This site was considered due to the availability of data for children living with HIV in order to explore prevalence and factors related to disclosure among health care workers to generate context-specific data to inform programmatic designs on interventions and strategies. Ease of access, availability of logistical resources and access to key informants were also put into consideration. The study site has one district hospital and about 35 health facilities that provide biological and psychological care to all age groups. The main district hospital has one designated ART clinic and 34 of the health facilities in the peripherals offer ART services (Figure 1).

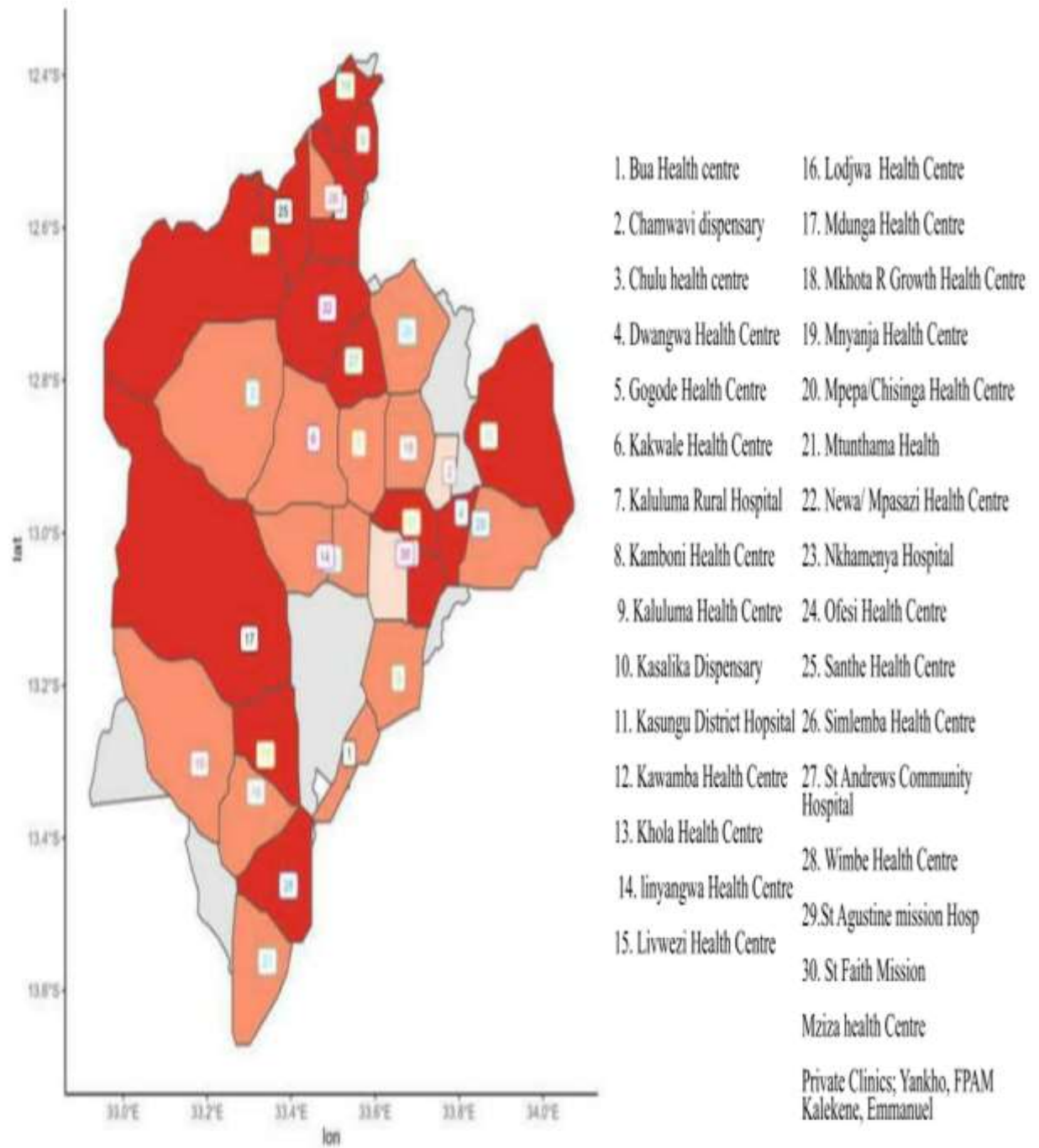


Figure 1: Study area map

3.2 Target Population

The target population for this study were individuals who directly interact with children accessing ART and other health services. These were clinicians and nurses. These have different professional background but related to health such as medicine, nursing and counselling. Subjects were selected from ART clinics at Kasungu District Hospital and from the health facilities that offer ART services as a representative upon which judgment and inferences about the whole were made (LoBiondo-Wood and Haber, 2014). The district health system has a population size of 103 staff members designated to work in ART clinics beside counsellors employed by partner organization (Partners in Hope) (Kasungu DHO HMIS database 2021-2022). According to De Vos et al. (2015), population refers to individuals in the universe who possess specific characteristics or set of entities that represent all measurement of interest to the researcher. Neuman (2011) stated that, when defining the population, the researcher must specify the unit being sampled, the geographical location and temporal boundaries of the situation.

Table 1: Population distribution (Kasungu DHO HMIS database 2021-2022)

S/N	HEALTH CENTRE	OCCUPATION						TOTAL
		NURSES		CLINICIANS		COUNSELORS		
		M	F	M	F	M	F	
1	Bua	0	2	3	0	0	0	5
2	Chamwabvi	0	1	0	1	0	0	2
3	Chulu	1	1	2	0	0	0	4
4	Kasungu DHO	1	4	3	0	0	1	9
5	FPAM	1	0	1	0	0	0	2
6	Kalikene	0	1	1	0	0	0	2
7	Yankho	0	0	1	0	0	0	1
8	Dwangwa	0	1	0	1	0	0	2
9	Gogode	0	1	1	0	0	0	2
10	Mnyanja	0	1	1	0	0	0	2
11	Kaluluma	1	1	2	0	0	0	4
12	Nkhamenya	0	3	3	0	0	0	6
13	Lodjwa	0	1	1	0	0	0	2
14	Kakwale	0	1	1	0	0	0	2
15	Mpepa	0	1	1	0	0	0	2
16	Ofesi	0	1	1	0	0	0	2
17	Kasalika	0	1	0	1	0	0	2
18	ST Andrews	0	5	4	0	0	0	9
19	Wimbe	0	1	1	0	0	0	2
20	Mtunthama	0	2	2	0	0	0	4
21	Simulemba	1	0	1	0	0	0	2
22	Faith St	0	1	1	0	0	0	2
23	Augustine St	0	2	1	0	0	0	3
24	Mdunga	0	1	1	0	0	0	2
25	Kapelula	0	1	1	0	0	0	2
26	Kawamba	0	2	0	1	0	0	3
27	Kamboni	0	2	1	0	0	0	3
28	Khola	0	2	1	0	0	0	3
29	Mkhota	0	1	1	0	0	0	2
30	Santhe	0	2	1	0	0	0	3
31	Kamuzu Acadamy	1	2	1	0	0	0	3
32	Linyangwa	0	1	1	0	0	0	2
33	Emmanuel PVT	0	0	1	0	0	0	1
34	Livwezi	0	1	1	0	0	0	2
35	Newa	0	2	0	0	0	0	2
	TOTAL	6	49	43	4	0	1	103

A total of 103 health care workers comprising of clinicians and nurses were evenly distributed in primary health facilities and secondary level of care across Kasungu District. Ideally, peripheral health facilities are supposed to have at least one clinician and one nurse manning the health centre. Clinicians are medical practitioners whose primary purpose is patient assessment, diagnosing and prescribing treatment for various illnesses. Those in primary level of care primarily hold medical certificates and diplomas with few holding health related degrees. Whereas those at secondary level of care primarily hold diplomas and degrees. Nurses are health professions whose primary purpose is to make an assessment, provide basic patient care and give prescribed treatment by a medical practitioner. They possess certificates, diplomas and degrees as well. Few nurses possess certificates with many of them possessing diplomas and few with degrees (Kasungu HMIS data base, 2024). The data provided in the table above is for those who directly interact with children living with HIV in those designated health facilities at the primary and secondary level of care. The statistics shows that among clinicians there is 4 female clinicians against 43 their male counterparts. On the other hand, the number female nurses (50) are much high compared to the number of male nurses (6). This shows gender imbalance in the medical and nursing professions despite both the national and international call for equity in enrollment of individuals in the training institutions of medical and nursing practitioners. There are a few exceptions where the health facility is manned by a nurse only in the event that the clinician has gone for further studies and the district management is organizing a replacement, such was the case with Newa health facility.

3.3 Research Approach

A research approach is the framework or overall strategy, processes or technique utilised in the collection of data for analysis in order to uncover new information or create better understanding of the topic (Kumar, 2014). There are three types of research approaches namely qualitative, quantitative and mixed methods (Creswell, 2014). Qualitative research methods collect and work with non-numerical data and seek to interpret meaning from the data to understand social phenomena (Creswell & Creswell, 2009). On the other hand, quantitative research approach uses descriptive statistics and allows the researcher to summarise large quantitative of data using graphs and number values and percentages (Creswell, 2014). Lastly, mixed method research is a procedure for collecting, analysing and integrating quantitative and qualitative data in the research process in a single study for the purpose of gaining a better understanding of the research problem (Teddlie & Tashakkori, 2009). The current study adopted mixed methods approach. The use of mixed methods approach in studies help to combine the strong points of the qualitative and quantitative methods into one study (Kumar, 2014)

It is advantageous to use a mixed method approach in order to gain a better and thorough understanding of the subject. In this study initially a structured questionnaire was used to capture the quantitative information. The qualitative aspect of the study occurred within the same period and involved the key informants composed mainly of healthcare workers involved in the provision of care to infected children and their families. The interviews were conducted by the principal investigator and one assistant who was recruited and trained by the researcher. The interviews were conducted at the hospital premises for the healthcare workers.

3.4 Research Design

A transformative mixed methods design was used in this study under the mixed method approach. This transformative mixed methods design was used to explore the HIV status disclosure phenomenon and establish its gravity. In addition, it helped to explore the perspectives and experiences of the respondents in relation to the practice of HIV disclosure process. It was an ideal design as it helped to respond to the complex research questions and yielded responses with adequate depth and width which sets a better platform for result generalization and implications to the whole population. It further, brought a comprehensive understanding of the research phenomenon and a greater certainty of the study findings as the results provided a complete picture and a holistic view (Sharma, et al., 2023). Hence, the study results form a basis for guiding best practices and policy direction in dealing with children with HIV positive test result.

3.5 Sampling strategies

Sampling is the process of selecting a few elements from a bigger group which become the basis for estimating the prevalence of an unknown piece of information, situation or outcome regarding the bigger group (Kumar, 2014). According to Creswell (2014), sampling techniques is an art of applying methods of selecting representatives of the population that can participate in a study. There are basically two categories of sampling method which include probability and non-probability. Probability sampling is a method in which participants are selected by chance or randomly from the known population (Creswell, 2014). Examples of probability sampling techniques are simple random, systematic, stratified and cluster. In contrast, non-probability sampling is a method which is used to select participants from unknown population (Creswell, 2014). Examples of non-probability sampling techniques include purposive sampling, convenience sampling, quota sampling, judgmental sampling and snowball.

Israel (2013) recommends that the whole population should be included in the study if the study population is 200 or less. Therefore, the researcher employed census method to select all staff from targeted sites to purposively participate in the study. Census method of data collection refers to systematically collecting information by covering every individual or item within a specific population or universe, it may also be defined as an operation which produces an official count of a country's population, right down to the lowest level of the geographical detail, at regular intervals (United Nations, 2024)). The method was used to collect data through questionnaires and in-depth interviews of all participants who were present during data collection period. Information was collected from all individuals of the defined population. Data analysis followed data collection to identify patterns, trends and relationships. The results are reported for possible generalization and inform decision-making processes. The method was selected and applied to comprehensively assess and get accurate data from a small population defined to avoid excluding significant participant and without margin of error if sampling methods were used. The relevance of this method supersedes sampling methods as it aims to provide complete and detailed picture of the entire group. It provides comprehensive and highly accurate results which is appropriate for planning and policy-making for resource allocation, development of infrastructure and delivery of public services (United Nations, 2024)). Census data is also useful for comparing population over time to observe changes and trends. It is also important for understanding demographic dynamics such as age distribution, levels of education, population growth and economic activity (Easy Sociology, 2024).

3.6 Data collection instruments

Data collection is essential to any research endeavor because it helps the researcher knowing the unknown things for the benefit of humanity through research process (Kumar, 2014). Basically, in choosing instruments for collecting data, the research approach is crucial because it determines what type of instruments should be used. As already noted, this study used mixed method approach, where both quantitative and qualitative methods data were employed. Therefore, the study used questionnaires and interview guides to collect data from the participants.

3.6.1 Survey questionnaire

A survey questionnaire was employed to capture primary quantitative data. This data collection instrument was used to achieve the first objective; to determine the prevalence of HIV status disclosure among HIV infected children aged between 6 and 12 years in Kasungu. In addition, it also assessed the study objects demographic characteristics such as age distribution, education levels, professional background among others. The quantitative aspect of the study involved face-to-face administration of semi-structured questionnaires to respondents comprising health workers which include clinicians and nurses working in ART clinics. A structured questionnaire was used to record socio-demographic characteristics such as age, sex and educational level and questions probing more on the elements that measured HIV status disclosure. The researcher ensured that participants of the semi-structured interviews understand the purpose of this study and were assured that their responses were treated with confidentiality. Further to this, an in-depths key informant interview guide was also used to capture the qualitative aspect of the study in-order to achieve the two objectives which were: to assess healthcare workers' perspectives and practices regarding the disclosure of HIV status to children aged between 6 and 12 years in Kasungu and to explore the barriers among health

care workers associated with disclosure of HIV status among children aged 6 to 12 years. The key informant interview (KII) is well described below.

3.6.2 Sample size

The sample frame for the survey was the population targeted by the study (Table 2). Therefore, the researcher determined the sample size by selecting all 103 staff, as distributed in Table 2, to participate in the study. However, the actual sample size that participated in the interview was 84. Eighty-four participants responded through the questionnaire survey interview as these were present at the period allocated for data collection. 19 health care workers could not participate due to their absence during the period of the survey for various reasons. Some had left for studies, others for workshops and sicknesses. These reasons made them unfit to take part in the interview during the period under study. Hence, the researcher could not manage to access all the targeted staff because of their unavailability during and within the data collection period. Time and resource constraints did not allow revisit of places where one participant could not be found or was highly committed to other equally important engagements making it not feasible to conduct an interview. However, the interviewed staff comprised more than 30% of the targeted total population, which was statistically acceptable.

3.7 Key Informants Interviews (KIIs) Guide

This study involved conducting in-depth interviews using a key informant interview guide with clinicians, nurses and a counsellor who were regarded as key informants for the study. This data collection tool was used to achieve the last two objectives; to assess healthcare workers' perspectives and practices regarding the disclosure of HIV status to children aged between 6 and 12 years in Kasungu and to explore the barriers among health care workers associated with disclosure of HIV status among children aged 6 to 12 years., The interviewer used the audio-recorder and the in-depths interview guide which guided the researcher to probe appropriate

questions and not deviating from the topic under study. Open ended questions were used to probe more on perspectives, practices and barriers regarding HIV status disclosure. Field notes were collected and clarification was requested where there was need to do so. Audio records and field notes served as raw data that was later consolidated after transcription of the audios into texts. The data collection process was rigorous and participant-centered. Prior to conducting the interviews, the researcher briefed relevant stakeholders (Table 3). Participants received information sheets outlining the study's ethical considerations, and individual in-depth interviews were conducted in a private setting with audio recording, following participants' consent. The in-depths interview utilized open-ended questions to gather detailed information, allowing for probing and exploration of disclosure-related aspects, such as their practice and perspective, the presence of guidelines and prior training on disclosure and any barriers encountered (Kalembo, et al., 2018; Gyamfie, et al., 2017). Field notes were taken during each interview, capturing the voice notes and insights De Vos et al. (2015). Saturation was reached after nine interviews. The interviews lasted for about 30 to 40 minutes' maximum. Interviewers were prudent and fluent in both local and English languages which made the interview easier to conduct as both the researcher and the research assistant have bachelor's degree as their highest qualifications. They have also participated in qualitative data collection through focus group discussions. In addition, their day-to-day work involves clerking clients' health history which is largely qualitative in nature. No cultural influence skewed the participant's responses as both parties shared common cultural values. The respondents were primarily asked in English however, they were free to respond in the local language which is commonly spoken (Chichewa) and with their consent, the audio recordings were made which were transcribed into verbatim and translated into English from which analysis was made after thorough reviews.

This qualitative approach purposively selected those individuals who possessed specialized knowledge and expertise on the subject matter as key informants. These beside possessing certificates, diplomas and degrees in the field of medicine, nursing and counselling had also undergone special on job training regarding disclosure. Hence, they possess special knowledge, insights, and perspectives about the topic under study. Their day-to-day interaction with children living with HIV makes them ideal persons as primary source of information and that their input was considered valuable. These privileged witnesses were chosen based on their daily experiences, expertise and direct involvement with the topic under investigation.

Table 2: List of Key Informants

#	Key Informants	Number of Key Informants Interviews (KIIs)
1	Clinicians	4
2	Nurses	4
3	Counsellor	1
	Total	9

3.8 Reliability and Validity of Data Collection Tools

The tools used in this study were valid as they were appropriately aligned to address the research purposes. They were also suitable as the participants could also be reached easily with them and interviewed within a considerable period of time. They did not demand any finance expenditure from the participants. They were also ethically right as they were designed to protect the rights and privacy of the participants. In addition, they were reliable tools as they could yield consistent results to participants when repeated during pretest. The questionnaire

and the interview guide were pre-tested to see if it captures the intended responses. The tools measured what was intended during pretest assuring of its accuracy. Validity in research denotes how the researcher checks for accuracy, trustworthiness, authenticity and credibility of the findings (Creswell & Creswell, 2018). On the other hand, reliability deals with the consistency, dependability and replicability of the results obtained from a piece of research (Creswell, 2014). Kumar (2014) further explains that, reliability is to provide similar results when used repeatedly under similar conditions. Mixed method research is considered to be valid and reliable because of its use of several techniques of collecting data (Creswell, 2014). Furthermore, Creswell (2014) provides a number of strategies for achieving both validity and reliability.

In this study, the researcher further achieved validity through triangulation of data collected through questionnaires and interviews and through expert members who were the supervisors and then went for ethical review with MZUNIREC where reviewers further added value to the instruments. According to Creswell (2014), the procedure of having an independent investigator to check on various aspects of the project enhances the overall validity of a qualitative aspects of any study. In ensuring the reliability of a questionnaire and interview guide, the researcher used appropriate sampling methods, a standardized questionnaire and interview guide, or the tools based on established theories or findings of previous studies (Middleton, 2020). The researcher therefore designed the questionnaire and interview guide based on findings from prior studies to align the themes in the questionnaire with consistent trends within the topic of study.

3.9 Data analysis

Hennink et al. (2011) define data analysis as a process of systematically applying statistical or logical techniques to describe, illustrate, condense, recap and evaluate data for the purpose of making conclusions which includes accepting or rejecting hypothesis in research. Qualitative data is transcribed and major themes identified to form qualitative findings of the study. In addition, qualitative data can be analysed using other software such as NVivo and Gioia. Quantitative data is analyzed using a computer which uses software such as Statistical Package for Social Sciences (SPSS) to produce charts, graphs and tables which help the researcher to interpret the findings of the study.

In this study, quantitative data analysis was performed using SPSS version 20.0 to generate frequencies and percentages, facilitating the examination of respondents' demographics and the prevalence of HIV status disclosure among HIV-infected children aged 6-12 years. This analysis enabled the determination of key disclosure-related factors, including participation in disclosure training, the optimal stage for disclosure, and the most suitable person to disclose HIV status to children, thereby providing valuable insights into the disclosure practices and trends among the study population.

Information pertaining to health workers' perception and barriers to disclosure was transcribed and analyzed using content analysis. This involved developing a codebook by establishing specific categories, broader codes, and codes, followed by reviewing the codes, creating themes, and interpreting the data to describe, compare, categorize, and conceptualize (Mumburi, L. P., et al., 2014; Kiwanuka, J., et al., 2014). Both researchers collaborated to identify categories, develop a codebook, and tabulate categories using Microsoft Word. Broader codes and subsequent codes were identified, compared, and discussed to reach consensus, ensuring a rigorous analysis process.

To ensure that the data was thoroughly examined to uncover meaningful insights into the perspectives of respondents regarding disclosure of HIV status and the disclosure process, the researcher therefore employed a systematic approach in analyzing themes. The thematic analysis followed a six-step process outlined by Naeem, et al. (2023)). Therefore, according to Naeem, et al. (2023) the researcher analyzed data in the following ways;

- **Familiarizing with the data:** The researcher listened several times the recorded interviews before transcribing and later read the transcripts several times in order to understand the collected data while paying attention to patterns and occurrences and to verify that it was a true representation of what participants meant.
- **Generating initial codes:** during this step, the researcher manually used pen markers of different colors to group the identified statements, words and information relating to particular codes in the transcript to meaningfully organize data. Colors of markers were utilized to group similar words and statements so as to develop themes from them.
- **Searching for themes among codes:** after the grouping of data and codes generated, the researcher selected text within each data set according to the designated colors and group each meaning by describing to solicit themes and subthemes.
- **Review of themes:** the researcher critically checked across the codes and categories to look on how the themes support the collected data. Whole data set was read several times and the themes that were initially found but lacked supportive data were ignored.
- **Defining and naming themes:** The researcher continued to interpret categories in order to determine the real meaning of the text. At the end of the analysis, the themes

were cross-checked with the interview transcripts to check the validity of the data (Zulu et al., 2014).

- **Write up:** after making a consensus of the themes confirmed by the supervisor, a final report was written.

3.10 Ethical Considerations

Ethical consideration was a necessary approach in dealing with research subjects in this study. It formulated the appropriate conduct of the researcher who safeguarded those affected by the research. Creswell (2018) argues that anyone involved in social science research is supposed to be aware of the general agreements shared by researchers about what is proper and improper in conducting research. Ethics assures approval to conduct a study, risks, rights and dignity and confidentiality of participants (Creswell, 2014). The researcher got ethical clearance from the Mzuzu University Research Ethics Committee (MZUNIREC). Similarly, permission was sought from the Director of Health and Social Services (DHSS) of KDH through the District Medical Officer (DMO). Nothing endangered the life of the participants. An informed consent was sought, in which clear information about the purpose of the study was provided and there was an understanding of the study and voluntariness to participate by study subjects and had the right to consent to or refuse (LoBiondo-Wood and Haber, 2014). Participants were free not to answer some questions if they so wish without giving reasons and they also had the right to withdraw in the course of the study, participants freely read through the consent form and asked questions whenever necessary for further explanation. Privacy and confidentiality regarding participants and their information were observed and continued even after the study period. Codes were used for names on the questionnaire for anonymity and interviews were carried out in a closet. The consent forms and questionnaires were kept in a private room to maintain confidentiality.

3.11 Conclusion

This study highlighted the use of mixed method by allowing the use of quantitative and qualitative insights. The selection of health care workers ensured a comprehensive understanding of the topic under study. Valid and reliable tools which were questionnaire survey and in-depths key informant interview guide facilitated by an audio recorder and field notes were used to capture both quantitative and qualitative data in an ethical manner. The information was later processes, cleaned and analyzed using SPSS and thematic analysis. Ethical consideration was also put into effect where in consent form participants was obtained, their rights and privacy were maintained and the information kept confidential. The study results are necessary to inform policy direction but difficult to generalize due to cultural differences which varies across the regions.

CHAPTER FOUR: RESULTS

4.0 Introduction

This chapter presents summaries and interprets the quantitative and qualitative data that were collected using the questionnaires and interview guide respectively. As discussed in Chapter three, the researcher collected quantitative data through questionnaires and qualitative data through interview guide in a face-to-face interview. Data extracted from the interviews is presented in verbatim and analysed based on related content and themes.

4.1 Demographic Characteristics

This study achieved 82% ($84/103 \times 100$) response rate against 18% ($19/103 \times 100$) non-response rate. The results in Table 1 shows that 60% of the respondents were female health care workers and 40 % were male health care workers. The table below has further delineated population distribution by age, marital status, professional qualification and work experience.

Table 3: Demographic characteristics

Variable		Frequency	Percentage
Gender	Male	34	40
	Female	50	60
Age	20-30	44	52
	31-40	21	25
	41-50	19	23
Marital status	Single	23	27
	Married	33	39
	Divorced	15	18
	Widow/widower	13	16
Professional qualification	Certificate	50	59
	Diploma	20	24
	Degree	14	17
Work experience	Less than 5 years	35	41.6
	5-10 years	24	28.6
	More than 10 years	25	29.8

4.2 Prevalence of HIV Status Disclosure Among HIV Infected Children

4.2.1 Disclosure training

The results in Table 2 shows that 40% of the health care workers attended a training on disclosure while 60% did not attend the training. This indicate that less than half of the participants are less skilled and knowledgeable about disclosure. This influences motivation of disclosure to children with HIV. Untrained professionals are less likely to engage in disclosure process. This contributes to increased numbers of un disclosure among children living with HIV.

Table 4: Disclosure training

HIV status disclosure training	Frequency	Percent
No	50	60.0
Yes	34	40.0
Total	84	100.0

4.2.2 Disclosure to children

The results show that the majority (88%) of healthcare workers chose not to disclose HIV status to children, with only 12% reporting that they had done so, as illustrated in Figure 2.

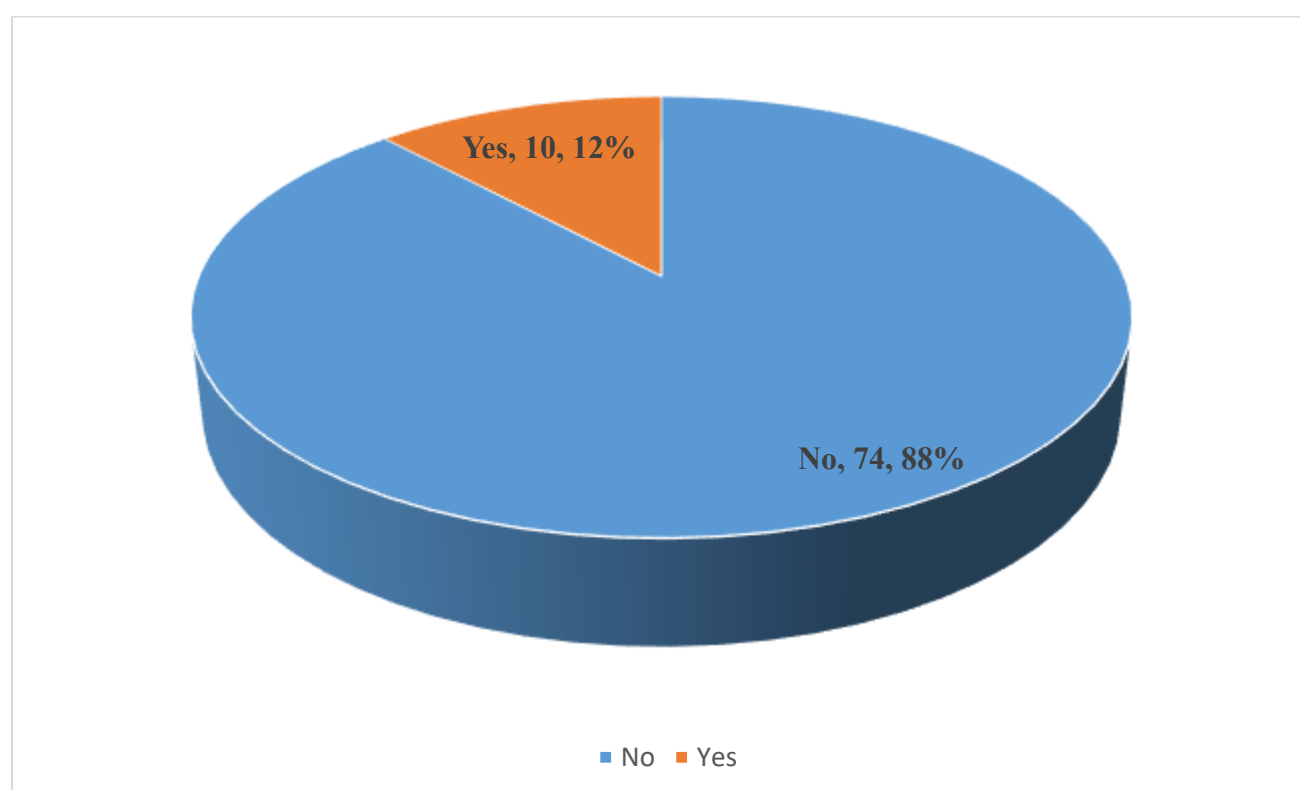


Figure 2: HIV disclosure to children

4.2.3 Appropriate persons to disclose HIV status

The study revealed that 51% of respondents identified healthcare providers as the appropriate group to disclose a child's HIV status. In contrast, 25% believed that parents or caregivers should handle this disclosure, while 24% felt that both parents/caregivers and healthcare providers should be informed of the child's HIV status (Table 3).

Table 5: Appropriate persons to disclose HIV status

Appropriate persons to disclose HIV status	Frequency	Percentage
Parents/Care giver	21	25
Health care providers	43	51
Both	20	24
Total	84	100

A 34-year-old male nurse narrated that, “I believe that health workers play a crucial role in helping parents disclose sensitive information to their children. Many parents hesitate because they fear how to approach the topic and worry about their child’s perception. Health workers possess the skills necessary to guide parents on how to communicate these issues effectively. Often, parents lack the knowledge or confidence to discuss these matters, and health workers can provide them with strategies for disclosure. Additionally, health care professionals are well-equipped to manage the emotional reactions that may arise during these conversations.”

A 41-year-old male clinical associate said that,

“I suppose the parents should lead the disclosure because the child can understand better with the kind and regards the reason why that has happened. I think the parents should be able to do that...because they usually rely on parents in everything they do because the health workers are just there to make sure that the process is done accordingly and where the gaps are they should be able to come in. The parents are the one that are supposed to initiate the disclosure process. If they have come to the hospital and we want to start disclosure, we do not disclose if the parents have not consented. So, at times we need to get consent from the parents or the guardian then at times also they are also available in making sure we do that so that the child can get the actual information they are supposed to get”

4.3 Healthcare Workers Perspectives and Practices Regarding Disclosure

4.3.1 Health care workers’ perception on Age

The perception of many healthcare workers revolved around imparting age-appropriate information to children about their HIV status. Seventy-four health workers had not disclosed HIV status to the children. Non-disclosure of HIV status to children was noted among 55 of the health workers who cited fear that the child would tell others about his diagnosis as a reason for refraining. Additionally, 30 out of 84 healthcare workers believed the children whom they interacted with were too young to know their status. Lastly, 12 healthcare workers chose not to disclose because they thought that if they knew their status, the children would be worried, scared or think that they were dying. Overall, the healthcare workers agreed that children should be told their HIV status.

4.3.1.1 Child awareness to their HIV status.

Healthcare workers’ general conception was that children who are infected with HIV have the right to know their HIV status. Knowledge or HIV status awareness dispels the wonder of

taking medication blindly, prompts lifestyle modification and seeking medical care. It is the right of children to acquire knowledge of their health.

A 39-year-old trained medical assistant narrated, *“it’s the children’s right to know their status....”*

“For these children, we begin their treatment at a young age. As they grow, they tend to wonder why they are taking medication. So, they need to know their status, hence this knowledge about themselves will prompt seeking medical treatment,” lamented one key informant.

4.3.2 Benefits of disclosure

4.3.2.1 Adherence to medication

The majority of survey participants believed that unveiling the diagnosis would motivate HIV-infected youngsters to take their daily drugs. They believed that this would have a good impact on medication adherence.

A 42-year-old female nurse ART provider (KII Jun 01) elucidated, *“It is important for children to learn their HIV status as early as possible. Understanding their HIV status enhances their adherence to medication, which is crucial for achieving viral suppression. Delaying the disclosure of this information can sometimes lead to poor adherence because children may think that their caregivers are intentionally hiding it from them. This misunderstanding can negatively impact their overall care and treatment.”*

Also, A 35-year-old female nurse said,

‘it’s very important, it helps to bring an insight and know how to live in-order to prevent transmission, prompt disclosure facilitates acceptance, and adherence.’ (KII Jun 03)

4.3.2.2 Responsible adolescent sexual behaviour

Another key benefit of disclosure was related to adolescent sexual behaviour. Because adolescence is often regarded as a period of experimentation in sexual and other areas, the majority of respondents said that irresponsible sexual behaviour by infected adolescents at this age could have serious effects on viral transmission. Most respondents agreed that making infected teenagers aware of their HIV status was a crucial approach of coping with this.

A 29-year-old male nurse (KII Jun 05) highlighted that *“when the child understands their status, it will be important for them to know their lifestyle by engaging in prevention measures such as dual protection using condoms and abstinence.”*

“Is their safety in terms of, when they are growing, they indulge into sexual relationships, they would want to start sexual activity hence they may transmit to others and also helps them to understand their HIV status and how to live responsibly.” A 41-year-old male medical assistant narrated, (KII Jun 06).

In addition, the study participants emphasized the importance of educating adolescents about maintaining their health, preventing reinfection, and safeguarding others from infections during their teenage years, particularly when engaging in romantic relationships.

4.3.2.3 Empowering children to take responsibility for their own health

Children who receive adequate HIV information are more likely to adhere to medication and actively manage their condition, including reminding parents of allergies, medication timing, and reviews. This viewpoint was demonstrated by one worker, who noted that one other thing is to provide people with knowledge and empower them to take control of their own health. This will lead to the youngster managing their own health condition.

“Once the children are empowered to take responsibility for their own health, such as attending drug reviews and collecting their medications alone. This will also relieve care givers of the need to leave their work every time the youngster is scheduled for a check-up or review”, said A 34-year-old male nurse, (KII Jun 07).

4.3.3 Disclosure as a shared responsibility

The feedback from participants highlighted that both health care workers and caregivers play important roles in the disclosure process. It was clear that caregivers often need support from health care workers during this process.

“I believe that both parents and healthcare workers play a crucial role in supporting children with HIV. If a child is only informed about their condition by a healthcare worker, there are often questions they may have that go unanswered. Children might not always feel comfortable asking these questions, and instead, they might blame their parents for their situation. Therefore, it’s important to recognize that healthcare personnel alone cannot provide the full context of how a child contracted HIV. In addition, Children tend to trust their parents more than medical personnel since they spend most of their time with them. If parents foster this trust, it will be easier for children to understand the information shared and adhere to their medication, which can lead to better health outcomes. Additionally, when parents take their medication consistently, children are likely to emulate this positive behavior,” said A 49-year-old male clinical officer, (KII Jun 08).

4.3.4 The Importance of Counselling and Education

The study further unearthed that health care workers can provide counselling and instruction to caregivers to help them disclose to their children. Health care personnel can educate caregivers on when and how to disclose to children. This teaching should be repeated as often

as possible to assist them understand the importance of informing the child about his or her condition as narrated by two health workers:

A 29-year-old male nurse (KII Jun 05) said *"I believe we should improve our counselling sessions with both parents and children." We should offer them with sufficient information."*

"I believe health care workers should provide ongoing counselling to both caregivers and children, in addition to pre- and post-testing. By constantly advising the caregivers, it will make more caregivers aware of the need to disclose." Said a 35-year-old female counsellor, (KII Jun 09).

4.4 Barriers to Disclosure

Participants discussed what they considered to be critical components among the barriers to disclosure. Although healthcare workers had a strong desire to disclose information, they faced numerous challenges from various aspects of their practice. During the analysis, four main sub-themes emerged regarding the barriers to disclosure: the age of the child, the fear of the consequences of disclosure, need for private space and the child's inability to maintain privacy regarding their diagnosis.

4.4.1 Age of child

One significant obstacle to disclosure was the child's age. Children under the age of 13 were viewed by the majority of health workers as immature and unable to comprehend their disease. At one of the hospital's HIV Testing and Counselling units, a qualified counsellor and medical professional stated that *"some of the children are under aged, especially those under 13 years old."* Similarly, another qualified counsellor and medical professional from another hospital's HIV Counselling and Testing unit noted that many children are deemed too young to understand their illness.

A 41-year-old male participant (KII Jun 02) elucidated that *“barriers often arise when a child enters without a parent or guardian. In such cases, consent becomes an issue. However, if we are dealing with someone who has just been diagnosed as an adult and can give consent on their own, then there is no barrier in terms of age. For minors, we must obtain consent from a guardian; without it, this absence of consent is considered a barrier.”*

4.4.2 Fear of the consequences of disclosure

Disclosure is often hindered by the fear of unintended repercussions. Disclosure may have negative repercussions for mother-child relationships, children's emotional and psychological well-being, and mothers' feeling of being accountable for their children contracting the illness. Some study participants stated that:

“Others are likewise afraid about what would happen after the disclosure. They worry that the disclosure could have negative consequences. Informing the child about the illness and how the infection occurred because they are unsure of what will happen, they fear that the child would stop taking their medication or perhaps distance themselves from the parents. Some people might even start thinking about suicide.” A 29-year-old male participant (KII Jun 05).

A 35-year-old female participant further articulated that, *“Another child started misusing alcohol, smoking cannabis soon after knowing his HIV status and was considering himself as one already dead, he was pessimistic of the future, and another was threatening to commit suicide, in addition level of understanding of the child may very low to comprehend the nature of the disease and all that goes with it.”*

4.4.3 Need for private space

The study revealed that, due to the busy nature of hospitals, health workers often struggle to spend one-on-one time with children to discuss their HIV status. This difficulty acts as a barrier to effective communication. Therefore, there is a need for a quiet environment that facilitates the disclosure process.

A 35-year-old female nurse (KII Jun 01) stated that, *“there is a need for additional space for ART and another area for disclosure.”*

“One of the most common barriers we encounter is related to space. Often, we need to disclose sensitive information in busy hospital settings, which can be quite challenging. It is essential to have a quiet environment that allows for better understanding and communication” said A 49-year-old male clinical officer.

4.4.4 Inability to get child to keep his diagnosis to him/herself

The stigma surrounding HIV, along with children's tendency to be "open talkers," makes it difficult to inform them about their HIV-positive status. Participants in the study expressed concerns that children might accidentally or intentionally reveal their status to their friends during conversations. They were worried about the potential repercussions of such disclosures.

A 49-year-old male clinical officer (KII Jun 08) lamented that, *“Since children often talk a lot, sharing the diagnosis can be challenging. They may share it with others, which could result in the mother and other family members' status becoming public, potentially leading to stigmatization.”*

“parents wouldn't want the status of the child to be known to other children for fear of stigma and discrimination, so they know if they disclose to us may be at one point or the other the information may end up falling in others (fear of breach of confidentiality), so

they would prefer that the child keep the secret and manage themselves.” A 39-year-old male nurse (KII Jun 04).

4.5 Conclusion

This study revealed 12% rate of HIV status disclosure among children living with HIV in Kasungu district by health care workers. The results are consistent with low data demonstrated by several literatures in various contexts and regions across the global. Demographic data showed that many of health care workers were female (60%). Generally, females as mothers have a concealing behavior to what may be deemed as distressing to the child's mind. Therefore, the rate of disclosure may be affected by such behavior. This study has also revealed that health care workers (51%) are in the best place to do disclosure as opposed to caregivers (25%) or in conjunction with caregivers (24%). Several factors have emerged including health care workers being well equipped professionally. It was also noted that children have the right to know their HIV status and health care workers are mandated to do so in the disclosure process. Disclosure has a myriad of benefits including improved medication adherence, responsible adolescent sexual behavior and good health outcome. The study also discussed the barriers that health care workers encounter during their practice such as fear of the consequences of disclosure among others. Therefore, this study recommends policy support and targeted interventions to improve rates of children's HIV status disclosure and health outcome.

CHAPTER FIVE: DISCUSSION

5.0 Introduction

This chapter discusses findings of the study and then compares them to the existing literature from previous studies. Each section of the chapter has been thoroughly discussed in the context of the need of the study and synthesizes the study findings into meaningful interpretations.

5.1 Prevalence of HIV Status Disclosure Among HIV-Infected Children

5.1.1 Disclosure Training

The study found that only 40% of healthcare workers attended training on HIV status disclosure, while a concerning 60% had not received any formal training. This lack of professional training among healthcare providers is alarming, as it directly impacts their ability to communicate sensitive information effectively. Previous studies, such as those conducted by Madiba (2016), emphasize that inadequate training contributes to delayed disclosure, causing significant emotional distress for both the child and their caregivers. Proper training provides healthcare workers with the necessary skills, knowledge, and confidence to navigate complex discussions about HIV disclosure, ensuring that children are informed in a supportive and developmentally appropriate manner.

5.1.2 Disclosure to Children

Despite global advocacy for early HIV disclosure, this study revealed that 12% of healthcare workers had disclosed HIV status to children under their care. The reluctance to disclose may stem from multiple factors, including fear of the child's psychological reaction, social stigma, and a lack of standardized guidelines on the appropriate age for disclosure. This finding aligns with previous research indicating that caregivers and healthcare professionals often delay disclosure due to fear that the child will suffer emotional trauma or resentment towards caregivers (Buckley, et al., 2022). However, research suggests that timely disclosure improves

treatment adherence, psychological resilience, and overall well-being (Paintsil, et al., 2020). Encouraging structured disclosure practices could enhance trust between children and caregivers while promoting long-term adherence to antiretroviral therapy (ART).

5.1.3 Appropriate Persons to Disclose HIV Status

The study found that 51% of respondents believed healthcare providers should disclose HIV status to children, while 25% thought it should be done by parents or caregivers. This discrepancy highlights the debate on the appropriate party responsible for disclosure. Research by Sumbi, et al. (2021) suggests that while healthcare workers have the medical expertise to explain HIV and its implications, caregivers provide the emotional support necessary for children to process such sensitive information. Therefore, a collaborative approach where both parties work together in a structured, supportive manner can facilitate a more positive disclosure experience. This dual approach ensures that children receive accurate medical information from professionals while also receiving reassurance and emotional guidance from their caregivers.

5.2 Healthcare Workers' Perspectives and Practices Regarding Disclosure

5.2.1 Health Care Workers' Perception of Age

Most healthcare workers believe that HIV disclosure should be age-appropriate and that young children may not fully comprehend the significance of their diagnosis. Many refrained from disclosure due to concerns that children might share their status with others, inadvertently exposing themselves to stigma. Research by WHO (2025) supports the notion that gradual disclosure beginning with partial information at a young age and progressing to full disclosure by adolescence ensures that children have sufficient time to process the information. An age-appropriate approach allows children to gradually develop coping mechanisms, leading to better psychological adaptation (Kaseka, et al., 2024).

5.2.1.1 Child Awareness of HIV Status

Findings suggest that knowledge of one's HIV status empowers children to take an active role in their healthcare, improving medication adherence and prompting them to adopt healthier lifestyles. Similarly, research by Faidas, et al. (2024) indicates that children who are aware of their status exhibit better adherence to treatment, reduced anxiety, and an improved sense of self-efficacy. When children are kept in the dark about their diagnosis, they may experience confusion and frustration, which could lead to non-adherence to ART. Therefore, disclosure must be handled sensitively but not indefinitely postponed, as early awareness fosters long-term health management and a sense of personal responsibility.

5.2.2 Benefits of Disclosure

5.2.2.1 Adherence to Medication

The study highlighted that disclosure positively impacts medication adherence, as children who understand their diagnosis are more likely to comply with their treatment regimens. This aligns with research by Amankwah-Poku, et al., (2021), which found that children who knew their status demonstrated significantly higher adherence levels compared to those unaware. When children are given clear explanations about why they must take their medication, they become more motivated to follow treatment protocols, leading to better viral suppression and overall health outcomes (Phiri, et al., 2025). Thus, proactive disclosure strategies should be encouraged to reinforce treatment adherence.

5.2.2.2 Responsible Adolescent Sexual Behavior

Findings indicated that disclosure helps adolescents adopt responsible sexual behaviors, reducing the risk of HIV transmission. Given that adolescence is often characterized by experimentation, HIV-positive teenagers must understand the importance of safe sexual practices. Bhattacharya et al. (2018) emphasize that informed adolescents are more likely to

engage in safer sexual behaviors, including the use of condoms and open discussions with partners about their status. Empowering adolescents with knowledge can reduce transmission risks and promote responsible decision-making regarding relationships and sexual activity.

5.2.2.3 Empowering Children to Take Responsibility for Their Health

Empowered children tend to manage their condition more effectively, ensuring adherence to treatment and consistent follow-up care. This finding aligns with research by Ashaba, et al., (2024), which emphasizes that HIV disclosure fosters self-management, reduces dependency on caregivers, and builds resilience. By involving children in their healthcare journey, they develop confidence in managing their condition, resulting in better health outcomes.

5.2.3 Disclosure as a Shared Responsibility

The study revealed that both healthcare workers and caregivers play vital roles in disclosure, suggesting that a shared approach yields the best results. This aligns with the work of Attigah, et al. (2025), which underscores the necessity of caregiver involvement in disclosure to ensure that the process is continuous and emotionally supportive. Healthcare professionals must work closely with caregivers to create a conducive disclosure environment.

5.2.4 Importance of Counselling and Education

Healthcare workers emphasized the need for continuous counselling and education for both caregivers and children. This finding is consistent with research by Kennedy et al. (2015), which suggests that structured counselling interventions enhance the effectiveness of disclosure processes. Proper education ensures that caregivers are well-equipped to handle disclosure sensitively and that children are given the necessary psychological support.

5.3 Barriers to Disclosure

5.3.1 Age of the Child

One of the most significant barriers to disclosure identified in this study was the child's age. Many healthcare workers hesitate to disclose HIV status to children under the age of 13, believing that younger children lack the cognitive ability to understand their diagnosis fully. This aligns with findings from previous research, which suggest that younger children may struggle to grasp the long-term implications of living with HIV (Kimera, et al., 2019). However, studies recommend that a gradual and age-appropriate disclosure strategy can help children process the information over time, reducing anxiety and enhancing treatment adherence (Msoka, et al., 2025). Nevertheless, it is appropriate for children to know their status. Delayed disclosure has also its repercussions which are even worse in certain circumstances where substance misuse and psychological distress often follow. Therefore, starting disclosure process as early as possible in a gradual manner and help the child with psychological readiness is necessary.

5.3.2 Fear of the Consequences of Disclosure

Fear of negative consequences emerged as another major barrier to disclosure. Many caregivers and healthcare workers expressed concerns that children might react emotionally, leading to psychological distress, non-adherence to medication, or even suicidal thoughts. This finding is supported by Mumburi, et al. (2019), who argue that fear of unintended repercussions discourages disclosure. Caregivers also worry about being blamed for transmitting the virus, which adds to their reluctance to disclose the child's status. However, research suggests that well-structured counseling programs can help mitigate these fears by preparing both caregivers and children for disclosure in a controlled and supportive environment (Toromo, et al., 2022).

5.3.3 Need for Private Space

The study found that healthcare workers struggled to find private and confidential spaces within hospitals to conduct disclosure conversations. Given the busy and often overcrowded nature of healthcare facilities, discussions about HIV status frequently lack privacy, making it challenging for healthcare workers to communicate effectively. This finding is consistent with research by Nguyen et al. (2024), who highlight the importance of private settings in facilitating open and honest conversations about HIV status. Establishing designated counselling spaces within healthcare facilities could improve the disclosure process and create a more supportive environment for both children and caregivers.

5.3.4 Children's Inability to Maintain Privacy

Another significant barrier identified was children's tendency to disclose their HIV status to peers, either intentionally or accidentally. Given the stigma surrounding HIV, healthcare workers and caregivers worried that children might face discrimination or bullying if their status became known. This aligns with the findings of Moodley et al. (2016), which highlight that stigma remains one of the biggest challenges to pediatric HIV disclosure. Educating children on the importance of discretion while providing them with emotional support can help reduce these risks and encourage responsible communication about their diagnosis.

5.4 Conclusion

The study found a notable tendency among healthcare workers to conceal the HIV status of children, emphasizing the critical role a child's age plays in the decision to disclose. It uncovered a range of obstacles that hinder transparency, including the delicate age of the child, fears about the potential repercussions of disclosure, and the pressing need for a private and confidential setting. The discussion delved deeply into these findings, illuminating the vital need for targeted training, systematic approaches to disclosure, and the cultivation of a

nurturing environment. By tackling the barriers identified in this research through thoughtful policy interventions and expanded studies, we can refine the disclosure process, enhance treatment adherence, and ultimately foster improved health outcomes for children living with HIV.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.0 Introduction

This study has achieved its aim of exploring the prevalence of HIV status disclosure among children and identified the barriers associated with the hindrance of this process. The importance of this topic cannot be over emphasized. It is crucial to understand the disclosure patterns and barriers which contribute to better health outcomes for children living with HIV, improve adherence to medication, and reduce stigma and discrimination.

6.1 Conclusions

The study focused on health care workers who ever interacted with children who were both aware and unaware of their HIV status. It has a strength in the sense that it included both health care workers who ever disclosed and those who never disclosed yet both parties showed consistency in their response to the questions. Hence, it can be concluded that health care workers are the major facilitators of disclosure. Disclosure of HIV status among children is associated with improved public health outcomes in several ways. Initially, there is an overall enhanced treatment adherence. This is based on the health care workers' understanding of the barriers to disclosure thereby helping them to better design strategies that can facilitate disclosing HIV status to children. This leads to improved adherence to antiretroviral therapy (ART) among children and better long-term health outcomes. Next, findings will inform the development of targeted intervention programs that addresses specific needs of children living with HIV and their families, ensuring that disclosure happens in a safe and supportive manner. In addition, disclosure reduces stigma and psychological impact. Identifying stigma serves as a platform for the need of community education programs to minimize stigma and discrimination towards children living with HIV and their families. Specialized counselling can also help children cope with the diagnosis and potential psychological distress post-disclosure. Further to that, findings have revealed the need to strengthen disclosure skills among health care

workers through capacity building and provision of disclosure guidelines to facilitate effective disclosure. There is also a need encourage further peer support groups such as teen clubs for children to share experiences and solutions.

6.2 Recommendations

The researcher recommends;

1. The development of evidence-based disclosure guidelines for health care workers to support appropriate standardized age, gradual and culturally sensitive disclosure of HIV status among children.
2. Training of health care workers and equipping parents or guardians with skills on how to handle negative reactions emanating from disclosure of HIV status to the child.
3. Infrastructure creation to support private disclosure of the child's HIV status and supporting the child psychologically to keep the diagnosis confidential
4. Informing policy direction, policy makers are urged to integrate findings into national HIV/AIDS programs, making disclosure process a structured part of care for children living with HIV.

6.3 Study limitations

The results from the quantitative sample size for this study may not be generalized over the larger population. The experiences of participants in rural setting may not represent those in urban setting or different cultural contexts. Data is also subject to self-reporting bias as it relies on information from health care workers, which can be influenced by social desirability and memory recall. Disclosure of HIV status is a sensitive issue despite the consent approval form participants they may refrain from giving full details of the experience hence minor distortion

of the context can happen. Also, barriers to disclosure varies widely across cultures and regions, which makes it hard to draw universal conclusion. This type of study is unable to establish causality or changes over time as it captures data at a single point in time.

6.4 Areas for further study

Further study is needed;

- To explore the long-term effects of disclosure on children's health and social well-being.
- The barriers identified varies across regions, culture and societal norms, emphasizing the need for context specific research to tailor interventions effectively.
- Parental HIV positive status disclosure to similar affected household children

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APPENDICES

Appendix 1: Methodology matrix

Variable	Method of data collection	Method of analysis
Disclosure status Age of the child Age of child at first diagnosis with HIV Child on antiretroviral medication Child currently in School Level of education of child Age at disclosure for children who have been told	structured questionnaires	Descriptive statistics means, frequencies, percentages.
Involvement Practice	In depth interviews (One-on-one interviews)	Thematic analysis
Age group of healthcare workers	structured questionnaires	Descriptive statistics means,

Position within the hospital Professional qualification Number of years worked in the hospital Opinion about telling a child his/her HIV status Preferred age of disclosure Face barrier in telling the child his/her HIV status Barriers to the disclosure of status to child; ● Fear of psychological harm to child ● Child may be too young to understand ● Child will not be able to keep the diagnosis	● In depth interview	frequencies, percentages and standard deviation Thematic analysis (Gyamfie, et al., 2017)
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Appendix 2: Data Collections Tools

Part A. Structured Questionnaire

Questions probing Socio-demographic characteristics of health care workers

Please may I know your gender?

May I know your marital status?.....

How old are you?.....

What is your highest professional qualification?.....

How long have you been working in the health
system?.....

Have you ever received training on disclosure
process?.....

Part B. In-depths Key Informant Interview Guide.

Questions Probing more on healthcare workers' perspectives, practices and barriers on disclosure.

Should children be told about their HIV
status?.....

What is the preferred age of the child during
disclosure?.....

What is the right time for disclosure?.....

Who is the appropriate person to disclose?.....

Have you ever disclosed a positive HIV test result to a
child?.....

What was the level of education of a child at
disclosure?.....

Is it appropriate to disclose a positive test result to the child?
.....

What are the barriers encountered that hinders the disclosure process?
.....

Is there disclosure guidelines available at this
facility?.....

Appendix 3: Mzunirec research ethics letter



MZUZU UNIVERSITY

DIRECTORATE OF RESEARCH

Mzuzu University
Private Bag 201
Luwinga
Mzuzu 2
MALAWI
TEL: 01 320 722
FAX: 01 320 648

MZUZU UNIVERSITY RESEARCH ETHICS COMMITTEE (MZUNIREC)

Ref No: MZUNIREC/DOR/23/100

11/03/2025

Mirriam Nkangala,
Mzuzu University,
P/Bag 201, Luwinga,
Mzuzu 2.

Email: tmalijani@yahoo.com

Dear Mirriam,

**RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR
PROTOCOL REF NO. MZUNIREC/DOR/23/100: PREVALENCE AND
BARRIERS OF HUMAN IMMUNO DEFICIENCY VIRUS STATUS DISCLOSURE
AMONG CHILDREN IN KASUNGU.**

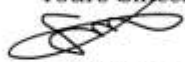
Having satisfied all the relevant ethical and regulatory requirements, I am pleased to inform you that the above referred research protocol has officially been approved. You are now permitted to proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this approval. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the Mzuzu University Research Ethics Committee (MZUNIREC) in a format that is available at the Secretariat. Once the study is finalised, you are required to furnish the Committee with a final report of the study.

The Committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms.

Wishing you a successful implementation of your study.

Yours Sincerely,



Faith Mwangonde
Ethics Administrator
FOR: MZUNIREC CHAIRPERSON



Mzuzu University Research Ethics Committee
Directorate of Research
Mzuzu University
P/Bag 201
Luwinga
Mzuzu 2

Appendix 4: Support letter from ministry of health, Kasungu district hospital

Telephone: +265 253 400
Fax: +265 253 630

All Communications should be addressed to:

The District Health Officer



In reply please quote No.
Ref. No. KDH/PF/435
MINISTRY OF HEALTH
KASUNGU DISTRICT HOSPITAL
P. O. BOX 19,
KASUNGU

29th June, 2023

The Chairperson
Mzuzu University
Faculty of Health Sciences,
Research Ethics and Administration Committee
P/Bag 201,
Luwinga
Mzuzu 2

Dear Chairperson,

LETTER OF SUPPORT FOR PROTOCOL TITLED "PREVALENCE AND BARRIERS OF HUMAN IMMUNODEFICIENCY VIRUS STATUS DISCLOSURE AMONG CHILDREN IN KASUNGU MALAWI".

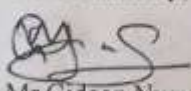
Reference is made to the aforementioned protocol submitted for approval by your committee.

The aim of this study is to determine the prevalence of HIV status disclosure to children aged between 6 and 12 years diagnosed with HIV in Kasungu. As a district we are so excited to be part of this study bearing in mind that HIV status disclosure to infected children is one of our challenges.

This letter therefore serves to endorse the conduct of this survey in Kasungu to generate information that will fill gaps as well as offer recommendations for better service delivery and also recommendations for further HIV related studies.

Sir, may you please assist her accordingly.

Yours faithfully,



Mr Gideon Nyasulu



Chairperson of Kasungu District Health Research Coordinating Committee

Appendix 5: Informed consent form (english)



Mzuzu University Research Ethics Committee (MZUNIREC)

Informed Consent Form for Research in Transformative Community Development

Introduction

I am **Mirriam Malijani Nkangala** from the Department of Agri-Sciences in the Faculty of Environmental Sciences at Mzuzu University proposing to do research on ***Prevalence and Barriers of Immunodeficiency Virus Status Disclosure among Children in Kasungu***. This consent form may contain words that may be hard to understand. Please do not hesitate to ask as we go through the information and I will take time to explain. If you have questions later, feel free to ask any of the researchers.

Purpose of the research

This research aims to determine the level and the barriers of HIV status disclosure among health workers to children aged between 6 and 12 years diagnosed with HIV in Kasungu.

Type of Research Intervention

This research will involve health worker participation in answering the interview questions as an individual.

Participant Selection

You are being invited to take part in this research because of your capacity as a health worker and ART provider.

Voluntary Participation

Your participation in this research is entirely voluntary. The participant has a choice whether to participate or not or withdraw at any point whenever they feel like doing so. If you choose not to participate nothing will change. You may skip any question and move on to the next question if you feel like doing so.

Duration

The research takes place from the month of November 2022 to August 2023.

Risks

You do not have to answer any question or take part in the discussion/interview/survey if you feel the question(s) are too personal or if talking about them brings discomfort.

Reimbursements

The research does not provide any incentive to the participants.

Sharing the Results

The knowledge acquired from this research will be shared with the participants and the involved community before it is made widely available to the public. Then, the results will be published so that other interested parties may learn from the research.

Who to Contact

If you have any questions, do not hesitate to ask them now or later. If you wish to ask questions later, you may contact: Associate Professor Mavuto Tembo (supervisor), Mzuzu University, Private Bag 201, Luwingu, Mzuzu 2. Phone: 0997376822, Email: tembo.m@mzuni.ac.mw; or you can contact Dr Ulemu msiska (program coordinator), Department of Agri-Sciences, Mzuzu University, Private Bag 201, Luwingu, Mzuzu 2. Phone: 0994 95 40 25 Email: ulemumsiska2004@yahoo.com

This proposal has been reviewed and approved by Mzuzu University Research Ethics Committee (MZUNIREC) which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find out more about the Committee, contact Mr. Gift Mbwele, Mzuzu University Research Ethics (MZUNIREC) Administrator, Mzuzu University, P/Bag 201, Luwingu, Mzuzu 2. Phone: 0999404008/0888641486

Is there any question?

Part II: Certificate of Consent

*I have been invited to participate in research about **Prevalence and Barriers of Human Immunodeficiency Virus Status Disclosure among Children in Kasungu.***

I have read the foregoing information. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have clearly read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the research project. I confirm the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been responded rightly and to the best of my knowledge. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

Appendix 6: Permission to carry out the study

Miriam Malijani

Nkangala

Mzuzu University

Private Bag 201

Luwinga

Mzuzu 2

13th April, 2023

The Chairman

The District Health Research Coordinating Committee Chair

Kasungu District Health Research Committee

Kasungu District Hospital

Post office Box 19.

Dear Sir,

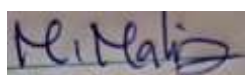
Re; Seeking Permission to Conduct the Study on ‘Prevalence and Barriers of Human Immunodeficiency Virus Status Disclosure among Children in Kasungu’.

I am writing to seek permission from the office of Kasungu District Health Research Committee to conduct a study titled '*Prevalence and Barriers of Human Immunodeficiency Virus Status Disclosure among Children in Kasungu*'.

I have been a Masters student at Mzuzu University since early 2022 studying Master of Science in Transformative Community Development. It is a program which looks at cross-cutting issues in all government sectors to spur development. In the researcher's view development in Malawi has been staggering with most people being underserved especially in the health sector. HIV remains one of the global burdens especially in sub-Saharan Africa impacting on our development. Hence, the researcher aims at conducting a study titled '*Prevalence and Barriers of Human Immunodeficiency Virus Status Disclosure among Children in Kasungu*' in all health facilities offering ART services in Kasungu District in order to curb aggravating factors of disease progression. All hospital protocols regarding participants' rights and freedom will be adhered to.

I hope the proposal will meet the merits required for acceptance by the district research health committee. Should there be any need required do not hesitate to contact me on the above contact details.

Yours faithfully,

A handwritten signature in blue ink, appearing to read 'Miriam Malijani', is shown within a rectangular box.

Miriam Malijani Nkangala (Senior Clinical Officer (SCO)).