PERSPECTIVES AND EXPERIENCES OF CAREGIVERS IN DISCLOSING HIV SEROSTATUS TO SCHOOL-AGE CHILDREN IN MARA REGION, TANZANIA

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By

Salehe Juma

A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree of Master of Public Health of

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CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled; **‘‘Perspectives and experiences of caregivers in disclosing HIV serostatus to school-age children in Mara region, Tanzania’’,** in (partial) fulfilment of the requirements for the degree of Master of Public Health of Muhimbili University of Health and Allied Sciences.

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(Co-Supervisor)

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Date

DECLARATION AND COPYRIGHT

I, **Salehe Juma**, declare that this **dissertation** is my original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.



Signature……. **Date**……..

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DEDICATION

I dedicate this dissertation to the cherished memory of my beloved mother, who has always been my inspirational beacon. Even though she is no longer with us (Rest in Eternal Peace), her love, strength, and unwavering support remain a constant source of inspiration for me. This work is a heartfelt tribute to her legacy and profound influence on my life.

ABSTRACT

Background: Human Immunodeficiency Virus (HIV) continues to be a significant public health, especially in sub-Saharan Africa, where approximately 2.9 million children were living with HIV in 2020. Antiretroviral therapy (ART) is the most effective way of managing HIV, including in children. Caregivers are responsible for administering medications, managing side effects, and ensuring adherence to treatment schedules. However, caregivers face various challenges, including disclosing HIV seropositive status to their children.

Objective: This study aimed to explore the perspectives and experiences of caregivers of school-age children attending ART clinics in the Mara Region in Tanzania regarding disclosing HIV seropositive status to children.

Methods: This was a descriptive phenomenological study exploring how caregivers of HIV-positive children experience the process of disclosing their child's status. The study used purposive sampling to select caregivers of school-aged children (ages 6-14) attending Shirati Mennonite Church of Tanzania Hospital's care and treatment clinics in Rorya District, Mara Region, Tanzania. They used an in-depth interview guide to gather data from these participants. Data collected from the in-depth interviews were transcribed verbatim and analyzed thematically to identify key themes related to the perceptions and experiences of caregivers in revealing HIV seropositive status to their children.

Findings: The findings revealed that the age at which caregivers choose to disclose serostatus to their children varies depending on their cognitive ability and self-awareness. The disclosure process was profoundly personal, and caregivers underwent emotional and spiritual preparations. Children's reactions post-disclosure were generally positive, though some experienced shock and distress. The decision to disclose was driven by the need to ensure the child's awareness of their HIV seropositive status and adhering to treatment. Some caregivers also felt that disclosing the status would help the children protect themselves and others as they approached adolescence. Reported challenges in the disclosure process included children's emotional distress and limited support from healthcare providers.

Conclusion: Caregivers' motives for disclosing HIV seropositive status to their children are driven by a balance of perceived risks and benefits. Caregivers' experiences in revealing a

child's HIV seropositive status are highly individualized, and they faced challenges in disclosing HIV seropositive status to children, emotional distress and limited support from healthcare providers. This individual uniqueness underscores the need for healthcare workers to provide tailored support to assist caregivers in navigating the complex emotional and practical aspects of HIV seropositive status disclosure to their children to leverage perceived enablers.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CLHIV	Children Living with HIV
CTC	Care and Treatment Centre
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
LMICs	Low- and Middle-Income Countries
MUHAS	Muhimbili University of Health and Allied Sciences
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
SPHSS	School of Public Health and Social Sciences
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

AIDS: Acquired Immune Deficiency Syndrome	A condition caused by HIV that can lead to severe immune system damage and potentially fatal infections (Centres for Disease Control and Prevention, accessed March 22, 2023, (https://www.cdc.gov/hiv/ basics/what-is-hiv-aids.html) Presence of AIDS: Confirmed diagnosis based on clinical criteria and laboratory tests for HIV and associated opportunistic infections. The diagnosed cases can be measured by the amount of virus particles in the blood (viral load) and the severity of immune system damage as measured by CD4 cell count.
Antiretroviral Therapy	A treatment that uses a combination of drugs to suppress the replication of HIV in the body (AIDS info, National Institutes of Health, accessed March 22, 2023, (https://aidsinfo.nih.gov/ understanding-HIV-AIDS/fact-sheets/21/58/antiretroviral-therapy--art--for-HIV). Patients are identified as using ART by medical records. Measurement is done by examining the types of drugs administered and adherence and viral suppression rates.
Care and Treatment Centre	A health facility that provides HIV care and treatment services (UNAIDS, accessed March 22, 2023, https://www. unaids.org/en/resources/ press centre/ feature stories/2016/ April/20160405_treatment_centers). Facilities are identified by a unique CTC ID number (In Tanzania, a 14-digit identification number is specific to region, district, facility, and patient). The number of patients receiving care, the range of services provided, and health outcomes are some of the measures of service provisions.
Caregivers	Individuals who provide care and support to children living with HIV. This includes parents, legal guardians, family members, or other individuals primarily responsible for the child's physical,

	emotional, and psychological well-being. (WHO Guideline on HIV disclosure counselling for children up to 12 years of age)
HAART: Highly Active Antiretroviral Therapy	A combination of antiretroviral drugs used to suppress the replication of HIV in the body and reduce the risk of AIDS-related illnesses (AIDS info, National Institutes of Health, accessed March 22, 2023, https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21/59/highly-active-antiretroviral-therapy--haart). Patients are identified as receiving HAART by medical records both paper and electronic version. Monitoring is done by looking at the types of drugs used, patient adherence, and health outcomes such as viral load suppression and CD4 counts.
Human Immunodeficiency Virus	A virus that attacks the immune system and can lead to AIDS. HIV seropositive status is confirmed by laboratory tests looking at the presence of viral particles and the presence of HIV-specific immunological markers in the human body. Incidence, prevalence, and suppression rates are measured at population and individual levels, respectively (World Health Organization, accessed March 22, 2023, https://www.who.int/news-room/fact-sheets/detail/hiv-aids).
In-depth Interviews	A qualitative research method involves a detailed and comprehensive exploration of a participant's experiences, beliefs, attitudes, and perspectives on a topic or phenomenon. (Rubin HJ, Rubin IS., 2012.). Participants are selected based on pre-set criteria relevant to the research question. Emerging themes are used to conclude.
Low- and Middle-Income Countries	Countries with relatively low levels of income per capita Countries are categorised by the World Bank based on income levels. Economic indicators such as GDP per capita and population demographics are used as criteria for categorization. (World Bank.

	Accessed March 22, 2023 (https://data.world bank.org/income-level/low-and-middle-income).
Prevention of Mother-to-Child Transmission	A strategy to reduce the risk of mother-to-child transmission of HIV (UNAIDS. Accessed March 22, 2023. Programs and strategies identified as implementing PMTCT. Rates of mother-to-child transmission, the number of pregnant women receiving PMTCT services, and health outcomes for mothers and infants are often used to measure programmatic interventions. (https://www.unaids.org/en/resources/topics/prevention-of-mother-to-child-transmission).
School Age Children	Children who are between the ages of 6 and 12 years. This period typically encompasses the years children attend primary or elementary school. During this time, children experience significant cognitive, social, and emotional development as they progress through their early education. (WHO, 2011**).** In the context of this study, the age range has been expanded to include children between 6 and 14 years old.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Introduction

This chapter covers the general background, a literature review of the research topic, and its conceptual genesis. It also details issues related to the research problem and this investigation's primary and specific objective. Lastly, this chapter highlights the utility of research findings.

1.2 Background

According to UNAIDS data, globally, 39 million people were living with HIV by the end of 2022, of which children below 14 years of age accounted for 1.7 million (1). Children around the globe are disproportionately impacted by the HIV/AIDS epidemic, ranging from the acquisition of vertical infection to inequalities in accessing proven interventions to mitigate this public health crisis (1). Despite progress in reducing mother-to-child transmission (MTCT) of HIV, around 120,000 children contracted the virus in 2022(2). MTCT remains the primary way children under 15 acquire HIV, with the highest prevalence in sub-Saharan Africa. The introduction of antiretroviral therapy (ART) has enabled children born with HIV to live into adolescence and adulthood and, therefore, need to inform them of their health.

In the context of children living with HIV, disclosure of HIV seropositive status involves informing a child about their HIV status, typically carried out by parents, caregivers, or healthcare providers. Disclosure is considered complete when a child is fully informed of their seropositive status, including the use of terms such as HIV, AIDS, or any specific local terminology related to HIV/AIDS during discussions about their health (3). In this study, disclosure of HIV seropositive status to children refers to school-age children (6-14 years) gaining knowledge of their HIV seropositive status (4). The Tanzania Child Act of 2009 defines a child as any male or female under 18 years. However, this study focuses specifically on children aged 6 to 14 years.

The WHO recommends disclosing HIV seropositive status to older children who attend school to enhance medication adherence and ensure they continue receiving medical care (3). However, any adaptation of this recommendation must be tailored to the country's specific context. Further, the WHO advises that to improve the quality of long-term care for this vulnerable group, school-age children should be informed of their HIV seropositive status. Younger children should be gradually educated about their condition in a manner that suits their cognitive and emotional development. This incremental approach should prepare them for eventual full disclosure (3).

The psychological and health benefits of disclosing HIV seropositive status to children, which includes influence on treatment outcomes within this age range, have been well-documented (5). Deciding to disclose a child's HIV seropositive status can be a complex and challenging process. Parents or caregivers might worry that the child will encounter stigma and discrimination or not fully grasp the information. Nonetheless, it is generally advised that children are informed about their HIV seropositive status in an age-appropriate manner to help them understand their health condition and actively participate in managing their health (4).

Caregivers frequently struggle with the decision of if or when to inform a child about their HIV-positive diagnosis, contributing to low rates of disclosure. The decision is complex and does not come quickly, as there is no universal consensus on the optimal timing and choices regarding the processes involved. The World Health Organization (WHO) has recommended a specialized training package for healthcare providers who manage CLHIV to equip them with the skills needed to support disclosure (3).

The rate of disclosure of HIV diagnosis to infected children varies widely throughout the world. This variation in disclosure rates may be associated with the geographical and age range of study populations. Globally, the disclosure rate ranges from 9% to 72% (5,6).

Findings from Low and Middle-Income Countries (LMICs) show that HIV diagnosis disclosure to children ranges from 0–69% (7). In Sub-Saharan Africa, HIV seropositive status disclosure practices are influenced by various factors, including stigma, discrimination, and emotional concerns. Many caregivers do not disclose their children's

HIV seropositive status, and disclosure rates vary significantly across the region. For instance, a study among caregivers of children aged 0-14 years, with a mean age of 6.8 years in Kenya, reported a disclosure rate of just 1.6% (8). Other studies in Ethiopia reported 3.9% to 45.6% (9–12). A quantitative survey in Uganda among caregivers of children aged 5-18 reported a 43.1% disclosure rate (6). A study in Tanzania (13) reported a disclosure rate of 22% using an age band of 5-14 years, which is consistent with a similar study in Ghana (14).

Given the wide variation in HIV status disclosure rates globally, establishing clear guidelines for disclosure is crucial for ensuring effective care and treatment. The Tanzania National Guideline for the Management of HIV/AIDS emphasizes the importance of disclosing HIV seropositive status to children as a crucial part of their care. This practice promotes greater engagement in treatment and helps mitigate the stigma and discrimination associated with HIV. It is recommended that all people living with HIV (PLHIV) who are enrolled in HIV care receive disclosure counselling and be supported through the process of assisted disclosure.

Early and beneficial disclosure can enhance treatment adherence and is considered advantageous. Conversely, non-disclosure can hinder adherence, making it crucial to identify and address barriers to support caregivers and clients in adhering to antiretroviral regimens (15).

1.3 Problem statement

Early disclosure of HIV seropositive status is considered a significant predictor of adherence and, consequently, achieving viral suppression. The WHO advises disclosing an HIV seropositive status to older children who have reached school age or beyond. This practice encourages medication adherence and ensures ongoing medical care for these children (3,16).

Despite the available evidence and recommendations, disclosure rates remain below optimal in Tanzania (13,17) and other countries (8–12). Non-disclosure of HIV seropositive status to children is associated with various issues, including limited access and adherence to ART (18) and poor health decisions, such as engaging in risky behaviours (17,19). A study was conducted in Dar es Salaam to explore healthcare providers' perspectives on disclosing HIV

seropositive status to infected children, indirectly capturing caregivers' perspectives through healthcare providers (17). One limitation noted in this study was its inability to directly assess caregivers' perspectives regarding revealing HIV seropositive status to their children of school age.

While the importance of early and appropriate disclosure of HIV seropositive status to school-age children is widely recognized, implementation remains inconsistent and inadequate, particularly in resource-constrained settings such as the Mara Region of Tanzania. A critical gap exists in our understanding of the perspectives and experiences of parents/caregivers in navigating the complex disclosure process. This lack of knowledge hinders the development of effective interventions to improve disclosure rates and, ultimately, child health outcomes.

To my knowledge, no recent study has been conducted to explore caregivers’ perspectives in revealing HIV seropositive status to school-age children considering advances in pediatric HIV care and treatment. Therefore, this study aims to address that knowledge gap by exploring the perspectives of caregivers in addressing issues related to the disclosure of HIV seropositive status of school-age children in Mara Region, Tanzania.

1.4 Conceptual framework

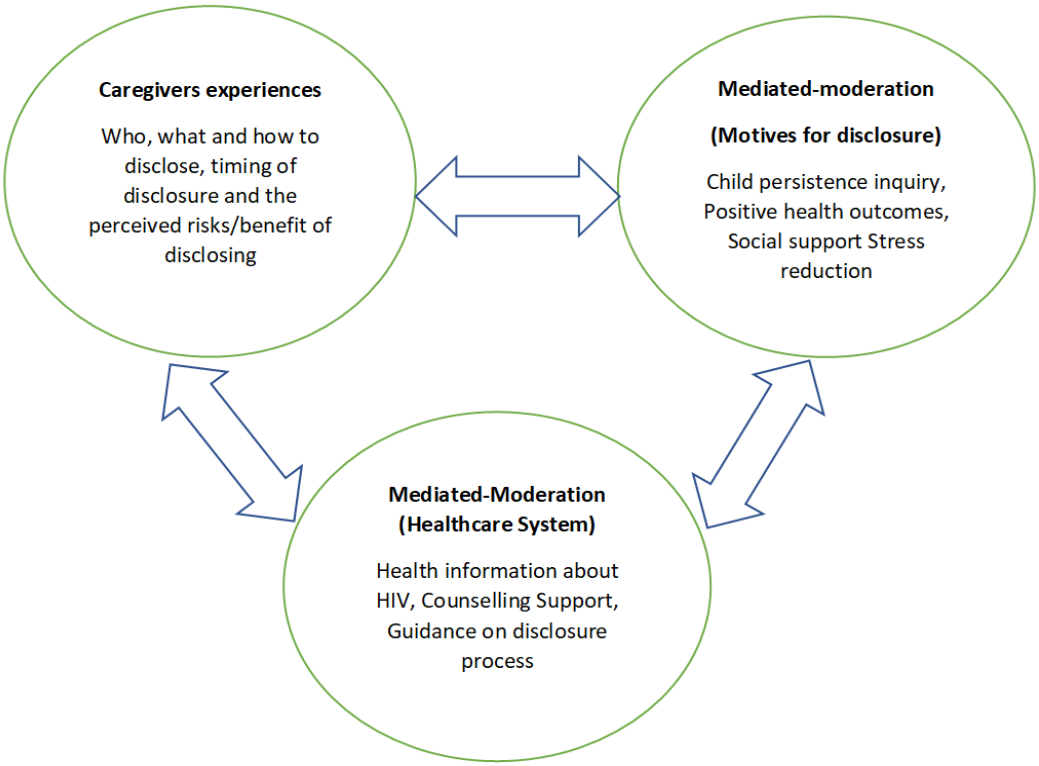


Figure 1: Conceptual framework; Perspectives and experiences of caregivers of school-age children attending ART in disclosing a child's HIV seropositive status (Adapted from Disclosure Process Model by Chaudoir and Fisher) (20)

As illustrated in fig 1, the conceptual framework outlines the complex dynamics of disclosing HIV seropositive status to children by caregivers, focusing on the factors influencing this process and its outcomes. It emphasizes critical considerations such as who should reveal the information, what specific details to include, and the optimal timing for disclosure. Caregivers must balance perceived risks, like potential stigma and emotional distress, against benefits, such as improved adherence to treatment and better health outcomes for the child. This decision-making process is deeply personal and influenced by the caregiver's experiences and the child's readiness.

The framework integrates the concept of mediated-moderation, highlighting the roles of motivation and healthcare systems in moderating and mediating the outcomes of HIV seropositive status disclosure. Community support, including social support and the child's persistent inquiries, can significantly influence the disclosure process. Positive health

outcomes and stress reduction are more likely when there is strong social support, as it helps caregivers manage the emotional burden and provides a supportive environment for the child. Effective communication and consistent support from the community can enhance the overall benefits of disclosure.

Similarly, the healthcare system is critical in providing necessary support and guidance. Comprehensive health information, counselling, and structured guidance on the disclosure process can empower caregivers, making them more confident and effective in handling the disclosure. The presence of healthcare professionals offering tailored advice and psychological support can moderate the stress associated with disclosure and mediate the relationship between disclosure and health outcomes. Thus, both community and healthcare systems are essential in facilitating a successful disclosure process, leading to better health and emotional well-being for both the caregiver and the child.

1.5 Rationale of the study

It is crucial to comprehend the factors influencing the disclosure of HIV seropositive status to children to improve disclosure rates and, therefore, enhance health outcomes for children living with HIV(17,19). The findings of this study can be utilized in various ways to improve practice, knowledge, and policy within the healthcare system.

In practice, the insights gained from caregivers' experiences and perspectives from this study's findings can inform the development of targeted interventions to support the disclosure process (21). Healthcare providers can use these findings to create facility-level structures and processes that support adequate guidance and counselling sessions tailored to the needs of caregivers and children. By addressing the specific challenges and concerns highlighted in the study findings, such as the appropriate timing and method of disclosure (17), healthcare practitioners can facilitate more effective and compassionate communication strategies for communities and beyond, ultimately leading to better adherence to Antiretroviral Therapy (ART) and improved health outcomes for children (5,22).

From a knowledge perspective, these study findings contribute to the existing literature on HIV disclosure practices, particularly in sub-Saharan Africa. It explains the socio-cultural

and psychological factors that impact caregivers' decisions and experiences (23). This study provides a critical foundation for future research on HIV disclosure by illuminating previously under-researched aspects of caregiver experiences and perspectives in resource-limited settings. These findings can inform the development and evaluation of more effective interventions and contribute to a richer understanding of the interplay between cultural, social, and individual factors affecting disclosure practices. Researchers and educators can utilize these findings to enhance training programs for healthcare providers, ensuring they have the necessary skills and knowledge to support families throughout the disclosure process. Additionally, the study findings highlight the importance of incorporating the children's perspective, which can guide future research on pediatric HIV care (23).

In terms of policy, the study's findings can inform policymakers on formulating and implementing national guidelines and policies related to HIV disclosure. Additionally, policymakers can use this evidence to advocate for comprehensive support systems, including ongoing counselling, social support mechanisms, and educational resources for caregivers and children. Furthermore, by prioritizing early and structured disclosure, policies can promote better health outcomes and reduce the stigma associated with HIV (24). Besides, establishing monitoring and evaluation systems to document disclosure outcomes and challenges will help refine and improve existing strategies, ensuring they are practical and responsive to the needs of affected families.

1.6 Research question

Considering advances made in pediatric ART, this study is going to answer the following main research question:

1.6.1 Main research question

What are the perspectives and experiences regarding disclosure of a child's HIV seropositive status among caregivers of school-age children attending ART clinics in Mara Region, Tanzania?

Specifically, the study will attempt to answer the following questions;

1. What are the experiences in disclosing a child's HIV seropositive status among caregivers of school-age children attending ART clinics in Mara Region, Tanzania?

2. What are the perspectives regarding motives for disclosing a child's HIV seropositive status among caregivers of school-age children attending ART clinics in Mara Region, Tanzania,
3. What are the perspectives regarding support needed from healthcare providers during disclosure of a child's HIV seropositive status among caregivers of school-age children attending ART clinics in Mara Region, Tanzania?

1.7 The objective of the study

1.7.1 Main objective

The main objective of this study is to explore the perspectives and experiences of caregivers of school-age children (6-14 years) attending ART clinics in Mara Region, Tanzania, in disclosing a child's HIV seropositive status.

1.7.2 Specific objectives

1. To explore the experiences in disclosing a child's HIV seropositive status among caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania.
2. To find out perspectives on motives for disclosing a child's HIV seropositive status among caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania.
3. To explore perspectives regarding support needed from healthcare providers during disclosure of a child's HIV seropositive status among caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Overview

This chapter provides a comprehensive context for the research, situating it within the broader field of study. It identifies gaps in existing knowledge that the current research aims to fill, establishes a theoretical framework by discussing fundamental theories and concepts, and offers methodological insights by reviewing the approaches used in previous studies. Additionally, it supports the research questions and arguments with evidence from existing literature, thereby enhancing the credibility and scholarly value of the dissertation.

2.2 Introduction

This study investigates the complex process of HIV seropositive status disclosure to school-aged children in the Mara Region of Tanzania, integrating elements of the Health Belief Model (HBM) and Disclosure Process Model (DPM) by Chaudoir and Fisher (20). The HBM framework guides the exploration of caregivers' perspectives regarding the benefits and risks associated with disclosure. Benefits include improved treatment adherence and better child health outcomes, while risks encompass the potential for stigma, emotional distress, and familial conflict. On the other hand, the modified DPM, as illustrated in the conceptual framework (Figure 1), highlights the interplay of caregiver experiences (e.g., prior interactions with healthcare providers, knowledge of HIV), child-related factors (e.g., developmental stage, level of inquiry), and system-level factors (e.g., access to healthcare support and community resources). These factors influence caregivers' decisions concerning who, what, how, and when to disclose.

The study aims to understand this intricate interplay by exploring perspectives on the decision-making processes and the lived experiences of caregivers navigating this critical process. The conceptual framework (Figure 1) emphasizes the mediated moderation of these variables. Factors like the child's persistence in inquiry, the availability of healthcare support, and community social support can significantly moderate the relationship between various influences (e.g., perceived risks vs. benefits) and final disclosure outcomes (e.g., stress levels, child's health, and adherence).

In Tanzania, HIV infection remains a significant public health challenge affecting individuals across all demographics, including children. It is estimated that 96,000 children under the age of 14 are living with HIV in Tanzania (25). The increased access to ART for children and advancements in pediatric HIV treatment formulations have significantly improved survival rates, allowing children to reach older ages (19). Consequently, disclosing HIV seropositive status has become a critical issue. Disclosing positive serostatus to children is believed to enhance their adherence to HIV medication (8). Children who are aware of their HIV seropositive status tend to exhibit higher self-esteem and engage in positive health behaviours (8,15,17). For caregivers, disclosure is associated with improved mental health and strengthened relationships with their children (16,19).

Although ART has played a crucial role in reducing HIV-related mortality and morbidity, disclosing HIV seropositive status remains essential in HIV care, especially for children living with the virus (15). HIV-positive children often rely on their caregivers, whether biological parents or others, to meet their daily needs, support hospital visits, and ensure medication adherence. However, disclosing children's HIV seropositive status can pose challenges for caregivers (26–28), and there is limited understanding of their experiences in doing so to children who attend HIV care and treatment clinics and require lifelong medication.

2.3 Caregivers experiences in disclosing a child's HIV seropositive status

Globally, caregivers, whether biological parents or primary guardians, are viewed as pivotal in disclosing the HIV seropositive status to their children because they are legally responsible and are seen as acting in the best interests of their children (15,29). Caregivers are ideally positioned to offer support to their children, assist them in coming to terms with their illness, ensure adherence to HIV management, and foster self-confidence as they transition into adolescence (13). However, caregivers often experience significant emotional complexity before, during, and after disclosing their children's HIV seropositive status (17,30).

Deciding whether to disclose a child's HIV seropositive status is a complex and personal choice influenced by factors such as the stage of the illness, the child's age, and other relevant considerations (30). Ultimately, it is the caregivers' entitlement to make this decision. If they choose to disclose, they are also free to determine how, when, where, and who will be involved in the disclosure process (31). However, in practice, many caregivers opt not to disclose due to concerns about their child's ability to comprehend and emotionally handle the diagnosis (32,33), as well as fears of potential stigma and discrimination (28,33–36) and perceived suboptimal support from healthcare workers (17, 37).

One of the main reasons caregivers decided to begin disclosure was their knowledge of the availability and accessibility of HIV medication (19). Additionally, children have the right to receive information, especially regarding their health (38). Disclosure may also be encouraged when a child with HIV struggles to adhere to antiretroviral therapy (ART) or consistently attend health care visits, even though they do not show obvious symptoms of the illness (30). Another facilitator of HIV disclosure is when the HIV seropositive child insistently asks questions about their health condition (39,40) or if another family member has a chronic health condition (38,41).

There is no consensus on the optimal timing of HIV disclosure, but current evidence generally supports disclosing information on time (42,43). The age of the child is often used as a critical factor in determining when to disclose information about their HIV seropositive status, with varying ages found in different reviewed literature, ranging from 5 to 15 years. As children grow older, disclosure rates tend to improve due to their increased cognitive maturity (11,35,36,44). Some studies have identified specific ages at which children are informed about their HIV seropositive status, ranging from as young as five years old (26), seven years (35), more than ten years (36), twelve years (18), and fifteen years (4).

The process of informing a child about their HIV seropositive status is intricate and requires careful consideration of various factors, such as the child's age, cognitive development, and social context (38,39,45). One of the crucial aspects of HIV disclosure to children is the timing of the disclosure. The WHO has recommended early disclosure as soon as the child can understand the disease's implications (4). As noted before, early disclosure has been linked with better clinical and psychological outcomes for children, including improved

adherence to antiretroviral therapy and fewer opportunistic infections (4). Additionally, children who learned about their HIV seropositive status at a younger age demonstrated a greater understanding of the disease and were less likely to experience psychological distress (3).

Disclosing HIV seropositive status to children is a challenging and multifaceted process that involves not only the child but also caregivers and healthcare providers. The literature has documented the diverse experiences of caregivers during this process. Various methods have been employed to disclose HIV seropositive status to children, including event-driven approaches where disclosure is prompted by HIV-related events such as a television program or the child experiencing an opportunistic infection (46).

Additionally, caregivers disclose their children's HIV seropositive status either directly or through a third-party individual, such as a family member or healthcare provider (46). A study conducted in Kenya highlighted several challenges faced by caregivers during the disclosure process, including fear of rejection by the child, lack of knowledge on how to disclose, and concerns about the child's psychological welfare. The study suggested that caregivers who received counselling and support from healthcare providers and peers were better equipped to manage the HIV seropositive status disclosure process and provide assistance to their children (47).

Caregivers have voiced the need for ongoing counselling and health education both before and after HIV disclosure, as well as the presence of healthcare providers during the disclosure process (38,41). However, fewer children have been informed of their HIV seropositive status using this method of disclosure (48). Studies conducted in similar contexts have shown varying preferences regarding the HIV seropositive status disclosure process. In a study in Tanzania, only 3.8% of 211 parents/caregivers participating in a health facility-based study preferred both themselves and healthcare providers to disclose the child's HIV seropositive status. The majority (65%) preferred to disclose on their own, while fewer (28%) chose healthcare providers to disclose without their involvement (13). In cases where caregivers preferred healthcare providers to inform, health facilities were reported as the most common setting for the child's HIV disclosure process (14,49). Conversely, when

caregivers chose to disclose their children's HIV seropositive status themselves, the household was deemed the more suitable environment (32).

Several studies examining "who should disclose" have shown a preference for caregivers to disclose the child's HIV seropositive status with support from healthcare providers (13,41). While some caregivers prefer to disclose the HIV seropositive status of an infected child personally, they have expressed concerns about their ability to do so, the child's willingness to accept the information, the risk of stigma from inadvertent disclosure by the child, and the need for additional support (38). Although the WHO has indicated there is no evidence favouring disclosure by either healthcare providers or caregivers as the preferred method, it emphasizes the importance of disclosing HIV seropositive status in a way that serves the child's best interests (3).

2.4 Caregivers' perspectives on support needed from healthcare providers

Healthcare providers play a crucial role in delivering HIV care and treatment services and addressing the challenges faced by children living with HIV. Effective care from healthcare providers is linked to better adherence to treatment (17,50). The WHO has recommended specialized training for healthcare providers to manage the complexities of pediatric HIV (3). However, healthcare providers often lack sufficient resources to offer optimal care and treatment to children and their caregivers (17). They have emphasized the need for greater involvement with caregivers in the treatment process, particularly in disclosing HIV seropositive status and assisting children through the transition process (51).

Previous research has shown that the relationship between patients and providers affects ART retention among children and adolescents (52). Caregivers have noted barriers to accessing HIV care and treatment services, citing a lack of adequate information necessary to help new patients navigate care and treatment centres (17). Recently, efforts have been made to help new clients manage the stress of learning their positive status. These efforts include improved assisted linkages to care and supporting caregivers in addressing issues related to HIV seropositive status disclosure (15).

To improve caregivers' ability to disclose their children's HIV seropositive status, healthcare providers must offer continuous HIV health education and counselling on the importance of

early disclosure and HIV counselling. Additionally, healthcare providers must help caregivers develop communication skills (13,17). Caregivers have recommended that healthcare providers be physically present during the disclosure of the child's HIV seropositive status (13,17). Although caregivers are encouraged to begin the disclosure process gradually at a young age to help the child emotionally prepare, they prefer to do this in hospital settings with the participation of healthcare providers (17,53).

2.5 Caregivers' motivation for HIV seropositive status disclosure to their children

One of the main reasons caregivers disclosed their children's HIV seropositive status was due to non-adherence to ART medication (30). As children grow older, they often ask why they need to take medication daily. Caregivers have responded by lying about the reasons or attributing the medication to less stigmatizing illnesses such as common colds or pneumonia (30).

Caregivers often disclose their children's HIV seropositive status because they believe that informed children will be more likely to take their medication correctly and take better care of themselves, reducing the burden on both the caregiver and the child. Some caregivers disclose to prevent accidental disclosure and have expressed the need for support from knowledgeable sources, such as healthcare providers when informing their children. The presence of healthcare providers ensures objectivity and additional health information and normalizes the child's reaction (30). Despite the reasons for non-disclosure, caregivers recognize their children's right to know their status (30,44,54).

Informing children about their positive HIV seropositive status is crucial for improving medication adherence, boosting self-esteem, and encouraging positive health behaviours. Caregivers are responsible for disclosing this information, but they often face emotional challenges and fear of stigma and discrimination. Factors facilitating disclosure include access to antiretroviral therapy, recognizing the child's right to know, and the child's persistent questions. The timing of disclosure depends on the child's cognitive development. The process of disclosing HIV seropositive status to children is complex, involving caregivers, children, and healthcare providers. Healthcare providers and peers can support caregivers during disclosure and help children understand the new information.

CHAPTER THREE

3.0 MATERIALS AND METHODS

3.1 Overview

This chapter describes the methods that were employed in the study. It includes research design, research approach, and geographical area. The chapter also presents the population sample size and sampling techniques, as well as the data collection and analysis instruments.

3.2 Study design

This was a descriptive phenomenology qualitative design to explore the perspectives for disclosing HIV seropositive status to CLHIV. The choice of this design aimed at describing how people experience a particular phenomenon (55), in this case, the perspectives of caregivers in disclosing HIV seropositive status to their children of school age in the Mara Region. The approach sought to uncover caregivers' experiences, the meanings they attach to their experiences, and how they make sense of them. Additionally, the design has been favourable because it provides rich data and a deeper understanding of the subject matter.

3.3 Study setting

This study was conducted in the Mara region, specifically in the Rorya district. Mara region is in north-eastern Tanzania. The region covers a 30,150 square meter area, of which 36% is water bodies, mainly Lake Victoria. Nearly 50% of the land mass is primarily restricted by Serengeti National Parks and other game reserves. The region is bordered to the North by Kenya and Uganda, to the west by Mwanza and Kagera, to the south by the Simiyu region, and to the east by the Arusha region (56). The region is divided into 6 Districts and nine councils with a total population of 2,372,015 (57). Agriculture accounts for 60% of the economic activities in the region. Other income-generation activities include mining, fisheries, and livestock (56). Mara region has 368 healthcare facilities, of which 33 are hospitals, 55 are health centres, and 280 are dispensaries.

In the Mara region, the HIV prevalence among adults aged 15 and older is 3.6%, with a reported viral suppression rate of 63.4%. Among children under 14, the prevalence is 0.3% (58). According to the National Bureau of Statistics (NBS), the Mara region is ranked second

in the burden of HIV among children (0.3%) across Lake Zone regions (58). Rorya district was purposively selected based on the prevalence of HIV and having a higher number of clients who are currently receiving Care and Treatment (CT) services, according to the Tanzania health management information system. Rorya district, according to the 2022 District Health Information System II (DHIS II), accounts for nearly 50% of all care recipients among PLHIV in the Mara region (59). The selected health facility, Shirati Kanisa la Mennonite Tanzania (Shirati KMT) Hospital, provides HIV care and treatment services to over a thousand clients.

3.4 Study population

The study population comprises caregivers of school-age children aged 6 to 14 attending care and treatment clinics in Rorya District, Mara region, Tanzania. This age band was selected based on the findings of the literature that most disclosures occurred (4, 22, 53, 57). Caregivers were those who are primarily responsible for providing care to children of school age (6 -14 years) living with HIV and receiving ART in care and treatment clinics at Shirati Kanisa la Mennonite Tanzania (Shirati KMT) Hospital in Rorya District, Mara region, Tanzania. They were directly involved in the child's care (such as staying with the child and escorting the child to the clinic), over 18 years old, regardless of the HIV seropositive status disclosure of their children, and they participated in the study willingly.

3.5 Sampling and sample size

A purposive sampling was used to select 15 caregivers of children attending CTC at Shirati KMT Hospital (61). Participants chosen for this study were caregivers with a child between 6 and 14 years old who are receiving HIV medication at the Care and Treatment Clinic (CTC) in Rorya district, Mara region in Tanzania.

After receiving permission from the council and hospital management, the principal researcher reviewed clinic appointments using appointment registers and the Tanzania National CTC electronic database at Shirati KMT hospital to verify the appointment status of selected participants. Caregivers were then recruited to participate in the study through two methods. One research assistant contacted the selected participants via telephone using numbers available at the health facility for those without scheduled appointments.

Additionally, Community Health Workers (CHWs) at Shirati KMT Hospital CTC tracked participants who could not be reached by phone. Caregivers with scheduled appointments were asked to participate in the study after attending their appointments. A total of 15 caregivers were interviewed. Interviews were stopped after the 15th participant when new data no longer provided significant additional insights, and the themes were well established (62).

3.6 Data collection

3.6.1 Data collection tool

Researchers used an in-depth interview (IDI) guide to collect data. The guide consisted of semi-structured questions to gather data from study participants. IDIs were used to explore the perspectives and experiences of caregivers regarding disclosing the HIV seropositive status of their children while receiving care and treatment services.

The interview guide included questions that focused on personal experiences and challenges that caregivers face when revealing to their school-age children that they are HIV seropositive, understanding the reasons and motivations behind caregivers' decisions to disclose their child's HIV seropositive status, and types of support that caregivers need from healthcare providers when disclosing their child's HIV seropositive status. Follow-up questions prompted caregivers to describe their experiences disclosing their HIV-positive status to their children. The interview guide was created in English and then translated into Kiswahili to ensure it was understandable in Kiswahili, Tanzania's national language. The Swahili translation was rigorously checked for accuracy by back-translating it into English. The back-translation process ensures the final translated version is as accurate and authentic as the original content.

3.6.2 Data collection procedures

A research assistant, a certified clinical officer with over two years of experience in a CTC setting, was oriented by the principal researcher on the research materials and methods for one week before data collection. The research assistant supported the recruitment of caregivers to participate in this study, arranged the interview room, listed and pre-arranged

the flow of caregivers to the interview room, and ensured all caregivers with scheduled appointments were attended before the interview.

After receiving permission from the council and the hospital management, the principal researcher reviewed clinic appointments using appointment registers and the Tanzania National CTC electronic database at Shirati KMT hospital to verify the appointment status of selected participants. Caregivers were then reached to participate in the study through two methods. One research assistant contacted the selected participants via telephone using numbers available at the health facility for those without scheduled appointments. Additionally, Community Health Workers (CHW) at KMT Hospital were responsible for tracking individuals who could not be reached by telephone. Caregivers who had scheduled appointments were invited to participate in the study after they completed their appointments.

The interviews took place at the care and treatment clinic in a private and comfortable setting. All participants were interviewed using the same interview guide to ensure consistency and dependability of the findings. The principal researcher in Kiswahili conducted the interviews, which are the official language of Tanzania, and all participants were fluent in Kiswahili. Each interview lasted for an average of 30 to 60 minutes. All in-depth interviews were digitally audio-recorded with consent from the study participants. Short notes were documented in writing as a backup or to capture body language and other relevant issues.

3.7 Trustworthiness

This study examined and evaluated qualitative research's trustworthiness, credibility, dependability, transferability, and confirmability. The interview guide was initially developed in English but was translated into Kiswahili to aid communication between the interviewer and the participants. Consequently, the interviews were conducted in Kiswahili to ensure the collection of thorough and detailed information from participants who were fluent in Kiswahili. By translating the interview guide into Kiswahili and conducting the interviews in a language the participants are fluent in, the researchers ensure that the data collected is accurate and reflective of the participants' actual experiences and perspectives. This enhances the study's credibility by minimizing misunderstandings and providing

authentic and detailed responses. Two peer researchers, junior researchers, and the supervisory team reviewed the findings through member checking and debriefing, strengthening the study's credibility. The principal investigator also conducted ongoing member checking throughout data collection and interpretation, verifying findings with participants via telephone summaries and feedback requests to guarantee accurate representation of their perspectives (63).

Confirmability or neutrality of the findings was achieved by the researcher practising reflexivity and documenting biases, assumptions, and influence on the research process. To minimize bias, the researcher openly addressed personal beliefs, knowledge, and perceptions about HIV disclosure through peer review and debriefing before data collection. Peers and the supervisory team also reviewed data collection and interpretation methods to ensure the findings accurately reflected the data (63,64).

To ensure dependability, the researcher shared the data collection and interpretation process with two supervisors, including audio records, a detailed codebook, and other research activities from the field. Furthermore, dependability was ensured by documenting all changes during the research process and shared with the supervising team. Daily briefing between researcher and research assistant to identify changes in the study's methodology.

To ensure the transferability of this study, the researcher employed several vital strategies. A detailed description of the research context, participants, and processes is shared to allow readers to assess the applicability of the findings to other settings. Thorough documentation of the research design, data collection methods, and analysis processes enhances transparency and enables others to evaluate the study’s rigour. Additionally, purposive sampling ensured that participants and settings were relevant to the research questions and offered rich information. The researcher reached back to participants for feedback and clarity to ensure that the results echoed the opinions of those studied, increasing their authenticity. Further, research findings were compared with existing literature, which positions the study within a broader context and highlights its contributions and relevance (63,64).

3.8 Data management and analysis

3.8.1 Data management

Additionally, all the notes gathered during data collection were compiled and stored in a folder to maintain confidentiality. Researchers labelled the audio recordings and notes with dates and numbers, omitting personal identifiers.

Furthermore, all identifiers directly related to the participants or children were omitted during transcription. Researchers created verbatim transcripts of the in-depth interview audio recordings to include all participant information in the final data analysis. The researchers translated the transcripts into English and then back-translated them into Kiswahili to check for any information lost during translation. Then, the transcripts were reviewed by listening to the audio adjacent to reading them.

3.8.2 Data analysis

The principal researcher verbatim transcribed the data and then identified initial codes to label it. These codes were used to identify themes, patterns, and categories within the data, grouping related codes into broader concepts and themes. A six-stage thematic analysis (Braun and Clarke) guided this process: familiarization, initial coding, theme identification, theme review, and results presentation (65). NVivo 12 version computer software was used to aid data analysis process data. The presented findings capture the essence of the data with quotes directly from participants (66).

Thematic data analysis approach is popular in phenomenological qualitative designs because it provides a logical and transparent approach to data analysis that enhances the reliability of the study findings. By staying close to the data and generating findings grounded in the participants' experiences, thematic analysis provides insights relevant to the research question and objectives (66).

3.9 Ethical considerations

Muhimbili University of Health and Allied Sciences Institutional Review Board reviewed the study proposal for ethical issues and approved for data collection (Ref. No.DA.282/298/01.C/1740). The Mara Regional Authority granted permission to conduct the study (Ref. No.: FA 190/227/01A/28). Rorya district council permitted data collection at Shirati KMT through a letter with Ref. No: RM 10/31/VOL. II/7.

Researchers informed all participants that participation was voluntary, withdrawal was possible without explanation, and withdrawal would not affect their clinic. Participants were informed about all measures to ensure anonymity and confidentiality, including the non-use of identifiers and digital information security in a password-protected computer. Participants then signed the consent form, indicating their understanding of the provided information and their willingness to participate. The researchers maintained confidentiality throughout, omitting all names and identifiers.

Data collected was not shared with anyone else apart from those involved with the research and was only used exclusively for this study. Electronic and paper-based data and information were secured in a password-protected computer and locked cabinets, respectively, with limited access granted only to those directly involved.

CHAPTER FOUR

4.0 FINDINGS

4.1 Overview

This chapter presents the results and findings of the experience of caregivers of school-aged children in the Mara region. Generally, this section presents the demographic characteristics of the study participants, perspectives of the caregivers of the school-aged children regarding the motives for disclosure of their children's HIV seropositive status, and their perspectives regarding the support needed from the healthcare providers during the HIV seropositive status disclosure to the children.

4.2 Demographic characteristics of the participants

This study included 15 participants with a mean age of 46 years. All participants were women residing in rural areas. Most of the participants (12/15) had primary education, and two-thirds of them were peasants. Of all participants, one-third (5/15) were widowed and were either grandmothers or an aunt to the child whose HIV seropositive status was supposed to be disclosed. The table below summarizes the socio-demographic information of the participants included in this study.

Table 1: Socio-demographic characteristics of participants

Participant	Age (Years)	Education Level	Marital Status	Economic Activity	Relationship with the child
1	27	Secondary	Widowed	Peasant	Biological Mother
2	53	Primary	Widowed	Peasant	Biological Mother
3	53	Primary	Widowed	Employed	Biological mother
4	42	Primary	Widowed	Peasant	Biological Mother
5	36	Primary	Married	Housewife	Aunt
6	25	Primary	Married	Peasant	Biological mother
7	32	Secondary	Married	Peasant	Aunt

8	39	Primary	Married	Peasant	Biological mother
9	55	Primary	Separated	Employed	Aunt
10	40	No formal education	Married	Peasant	Grandparent
11	41	Primary	Married	Self-employed	Biological mother
12	40	Primary	Married	Self-employed	Biological mother
13	60	Primary	Married	Peasant	Aunt
14	69	Primary	Widowed	Peasant	Grandparent
15	37	Primary	Divorced	Peasant	Biological Mother

Based on the study's objectives, three predetermined themes, with twelve subthemes, are summarised in Table 2 below. Detailed descriptions of the subthemes are in Appendix IV.

Table 2: Summary of themes and subthemes

Theme	**Subthemes**
Experiences on HIV seropositive status disclosure among caregivers of school-age children	1. Learning the child's HIV status 2. Age of Disclosure 3. Disclosure process 4. Reaction of the child after disclosure 5. Challenges before, during, and after disclosure
Perspectives on motives for disclosing a child's HIV seropositive status among caregivers	1. The caregivers' concerns before and during disclosure, 2. The perceived risks and benefits of disclosing the HIV seropositive status, 3. Social-cultural norms around disclosing the serostatus to the child. 4. Perceived support from the community in disclosing the HIV seropositive status to the child.
Perspectives regarding support needed from healthcare providers during disclosure among caregivers.	1. Perceived roles of the healthcare providers HIV disclosure to the child. 2. Guidance and Psychological support the caregiver received from the healthcare provider before and during disclosing the HIV seropositive status to the child. 3. Tools needed or received to facilitate disclosure of the HIV seropositive status to the child.

4.3 Caregivers experiences in disclosing a child's HIV seropositive status

This theme includes all statements describing the caregiver's experience in disclosing and or revealing the child's HIV seropositive status, including when and how they disclosed. It is further divided into five sub-themes, which include statements related to how the caregiver discovered the child's serostatus, the child's reaction, the frequency of disclosure, the difficulties encountered during disclosure, and how these challenges were addressed.

4.3.1 Finding out the serostatus of the child

This study revealed that caregivers discovered the HIV seropositive status of the children in various circumstances. Many biological mothers narrated that they learned about it a few months after childbirth, while grandmothers and aunts learned through the deaths of the child's parents. One caregiver described learning about her child's HIV status through routine antenatal care visits, explaining,

"I used to attend antenatal clinic routinely. I don't recall precisely when during my pregnancy, but while travelling to Tanga for delivery, I gave birth at home, attended by traditional birth attendants. When we returned to Dodoma, he started getting sick. They tested him and found that he had an HIV infection. He was one and a half years old at the time." (A 47-years-old widow).

In other situations, some of the caregivers (women) discovered the child's HIV seropositive status after the death of their partners, who had been taking ART medication without their knowledge. It was further revealed that the participants decided to be tested together with their children, and they were found to be HIV-infected. Similarly, other caregivers who were not biological mothers to the children found out about their serostatus after frequent illnesses following the children's parents' deaths.

"*I took him at the age of four (4) years old after her mother passed. Later, he started to get sick frequently, and I had to bring him to the hospital. I told them to do all kinds of tests so that I know what was wrong with him. The results showed that it is HIV infected. So, they referred me to the care and treatment clinic to start* medication" (A 36-years-old married caregiver (aunt).

Generally, most of the caregivers who were HIV positive found out about the serostatus of their children after frequent unexplainable sickness. In the quest to understand what is wrong

with their children, they underwent several tests, including HIV, and that's when they found out that their children were HIV positive as well.
"I learned about children's status when they were 5 and 12 years respectively. I knew the older one when he was 12 years old. They were frequently getting sick, so I decided to test them for HIV. I found they were all infected." (Female, 39-years-old, married).

The different ways in which caregivers learned about their children's HIV status emphasize the pivotal role of unexpected events, like illness or death, in initiating the disclosure process. These events heightened caregivers' perception of the seriousness of the situation, shaping their decisions around whether and when to disclose. This aligns with the HBM, which suggests that a higher perceived severity of a health issue can strongly motivate individuals to take action, such as the initiation disclosure process.

4.3.2 Age of disclosing the serostatus of the child

This study discovered that the age at which caregivers disclose the child's serostatus varies based on their judgment. Many participants reported clarity and awareness as reasons for their decision to disclose. While some caregivers opted to disclose the child's serostatus after the age of ten years, others revealed it as early as five years old.

"He was about five years old. So, I sat with him and disclosed. He said this is how it will be, and I told him you are not alone. Many children use drugs. He accepted and said okay, then take me to a place where I can find treatment." (53-years-old widow).

Based on the child's self-awareness, clarity, and cognitive ability, some caregivers think disclosing the serostatus to the child after age ten is suitable. This tendency is more common among caregivers who are not biological mothers, who often disclose the serostatus to their children earlier than aunts and grandmothers.

"I have not told him up to now. I still think he is young. He is not able to process the information. I will tell him when he is 12 years old, he will be self-aware, and be able to take care of himself" (A 36-years-old married caregiver (aunt)).

Additionally, some caregivers were uncertain about the age at which they should disclose the child's serostatus. Instead, they were prompted to act by the child's cognitive

development, such as when children asked questions about their scheduled clinic visits and daily medications or mentioned words from their peers suggesting they might have HIV because of the daily medicines they take.

“He was 5 years old and had developed the ability to recognize himself and question things. He had started asking questions about his daily medication, unlike other children, so I believed it was the right time to have a conversation with him” (A 55-year-old divorced aunt).

Caregivers differed in the timing of disclosing a child's HIV seropositive status, depending on the child's age and cognitive ability. Disclosure occurred anywhere from as young as five to about ten or twelve years old. Early disclosure was emphasized to prevent the child from discovering their status independently, which could have emotional repercussions, underscoring the complexity of this process.

4.3.3 The disclosure process

The disclosure process for caregivers informing children about their HIV seropositive status is profoundly personal and influenced by various factors. The majority of study participants noted that disclosing the child's HIV seropositive status was a gradual process based on the child's cognitive development. However, the methods used varied among caregivers. Caregivers often chose times when they felt emotionally ready and when the child was most receptive. Study participants narrated the emotional and spiritual preparation they undergo, underscoring the role of faith, which is often overlooked.

"I will seek strength from God to muster the courage to share this with my child, hoping for their acceptance” (A 25-year-old, married female).

Study participants preferred to disclose the information at home, after dinner, and during the evening. This time was favoured for several reasons, including being free from the day's work or school, maintaining secrecy, and ensuring comfort. It is when most caregivers take their medication that it creates a conducive atmosphere for discussing and disclosing the serostatus to the child. Caregivers often chose routine moments, such as after evening prayers or family gatherings, to disclose the information, believing these settings provided a conducive environment.

“That was the time when we were all home. I get out of my work, and they are off from school. It is easy to meet for the night prayer. After we had finished dinner and evening prayers, I told him I feel that you are sick like me” (A 47-year-old widow).

This approach was echoed by other caregivers who chose to disclose during evening conversations:

"*We were having evening talks as a family at around 8 pm and eventually reached that topic"* . (A 42-years-old, widow)

However, this study found that some caregivers did not plan the disclosure. Often, it occurred spontaneously during conversations or in direct response to the child's questions about their daily medication and routine clinic visit.

"He started asking questions about his daily medication, so I decided to disclose. I told him that he was born with the disease". (A 32-years-old, married caregiver).

Despite the differences in approach, the common motivation was preparing a conducive environment where information can be contained, preventing the child from learning their status on their own. It was essential to adequately prepare the child to help them process and handle the information.

The choice of home and evening settings for disclosure (as reported by several participants) reflects the importance of creating a conducive atmosphere that reduces emotional burdens. This demonstrates the influence of contextual factors highlighted in the modified DPM, emphasizing the importance of social and environmental cues on the caregiver's decision to disclose.

4.3.4 Children's reactions

Participants noted positive responses to the children's reactions after disclosure. There was either no change in behaviour or the child became more positive and careful about their health and that of others around them. Disclosure even catalyzed these children to adhere to their medication schedule and attend various HIV-related events to learn more about their condition.

"He was not worried. When I explained the issue to him, he responded, "Yes, Mother, if that was the case, then there is no problem. I will go take the medicine" (A 53-year-old widow).

Some caregivers encountered the difficulty of adverse reactions from their children, such as anger and refusal to attend school for several days. However, having conversations with their children and stressing the importance of medication and self-care helped the children accept their conditions. Additionally, caregivers who were HIV-positive themselves provided moral support to their children by demonstrating that they were also taking medication. This gesture motivated their children to continue treatment after disclosure.

"At first, he was sad. So, I told him that I have the same problem, that is why I am taking medication and I look normal, working, supporting him. Therefore, if you take your (medicine), you will be fine, going to school and even playing football. No one will know that you are sick. Other children are taking medication as well. He agreed to start clinic" (A 53-years-old widowed)

Caregivers who haven't disclosed the serostatus to their children face questions from them. Many still inform the children that the medications are for another medical condition, not HIV.

"I just tell him that he is sick, that is, he has typhoid, we are taking typhoid medicine. So, he does not know that the medicine is for something else." (A 36-years-old, married female caregiver)

4.3.5 Disclosure challenges

The disclosure process varies among caregivers, with some preparing to disclose the serostatus to their children differently. Some participants reported that disclosing the serostatus to their children primarily involved summoning the courage to have the conversation, hoping their children would accept the situation and continue with the medication. Other participants agreed to turn to prayers and prepared special meals to foster the bond between them and the children and create a comfortable environment for the disclosure.

“On that day, I prepared rice and beef and bought him a pair of shoes. In the evening, we sat down, and I complimented him on how good he looked. Then, I mentioned that I wanted to discuss the matter he had raised earlier, and that's when I disclosed the information.” (A 32-year-old, married female caregiver)

Caregivers faced challenges before initiating disclosure, particularly in deciding whether to involve other family members or manage the situation alone. This difficulty in finding the right approach was evident as they considered their options.

“The only challenge is how I start; from the bottom of my heart, I start thinking about how to start. Should I start like this? Should I call his grandmother when I tell her? I do not know what to do or just tell him myself?” (A 47-years-old widow).

Participants reported concerns about confidentiality and the potential for stigma. Participants further elaborated that they were hesitant to disclose the serostatus to their children due to fear that the child might share the information with peers, leading to stigmatization at school. This led to either delayed disclosure or no disclosure at all.

"There is no obstacle, but I think if I tell him about his HIV status, maybe he will share the *information with his colleagues, resulting in stigmatization from his peers or even teachers at school.”* (A 36-years-old, married female caregiver)

Stigma concern was echoed by other caregivers, who delayed disclosure to avoid the risk of the child facing insults and isolation from classmates.

“Certainly. If they divulge this to their friends, there is a risk of facing insults and abuse from peers, potentially leading to episodes of depression. I informed her later when I was confident he could handle the information discreetly” (A 40-year-old, married female caregiver).

During actual disclosure, participants expressed practical challenges they experienced, such as managing the child's understanding and acceptance of their condition and emotional responses. Some participants recounted encountering a strong emotional response, with the child expressing feelings of betrayal and blame, prompting them to apologize and explain the circumstances of the infection.

"He asked this, now why were you careless and infected me? And I was just apologizing" (A 47-years-old mother)

Additionally, some participants reported facing difficulties when the child started refusing medication, requiring additional efforts to explain the necessity of the treatment. Furthermore, participants reported facing some emotional challenges in dealing with their children after disclosure.

"The difficulties I encountered initially involved his emotional response. He seemed saddened, probably due to the uncertainty about the future and the passing of his father. I reassured him that everything would be fine". (A 42-years-old widow)

In some cases, caregivers reported no significant challenges during the disclosure process, indicating a range of experiences. Some participants said they don't face challenges revealing serostatus to the children. They further described that the process can vary greatly depending on individual circumstances. This was echoed by other participants who vested in pre-disclosure preparations to mitigate potential challenges.

"I did not encounter any obstacles after educating him. After I created that conducive environment, I did not encounter any challenges". (A 55-years-old female caregiver).

4.4 Caregivers perspectives regarding motives for disclosing a child's HIV seropositive status

The second theme of this study is based on the objective of investigating perspectives of caregivers of school-age children attending ART clinics in Mara Region, Tanzania, regarding motives for disclosing a child's HIV seropositive status. Under this theme study, findings regarding motivation for or against disclosure are highlighted under the following subthemes: concerns on the disclosure of the serostatus to the child, the risks and benefits of disclosing the serostatus to the child, the sociocultural norms around revealing, and the support needed or received during disclosure.

4.4.1 Concerns on HIV seropositive status disclosure

Participants in this study expressed concerns before disclosing the serostatus to their children. Many mentioned that self-stigmatization was a barrier to disclosure, as they feared

being judged by their children and worried that their children might believe they deliberately infected them with HIV. They expressed apprehension about disclosing their child's status to them. One caregiver described feelings of shame and self-blame, citing a fear of judgment from their children.

"I was ashamed, and I also thought that I would hurt him. I felt that he was going to doubt if his father was responsible for me getting infected or if I just got it and then infected him after his father passed. I was self-stigmatized that maybe I am the reason" (A 47-year-old widow).

Similarly, some caregivers have refrained from disclosing the serostatus to the child due to fear of stigma. One caregiver expressed concerns that the child might share the information with friends, leading to stigma from the neighbourhood towards the child and the family. This fear has prevented the caregiver from disclosing the serostatus to the child.

"I am scared because I did not want our neighbours in the village to know that the child was sick. It would be detrimental, especially in our village, where stigmatisation may occur. He might face discrimination while playing with other children, as some might label him based on their hearing. He may confide in his friends. (A 60-year-old, married caregiver).

In addition to caregivers' self-stigma about disclosing the serostatus to their children, the fear of stigma from others was also a challenge. Some caregivers hesitated to disclose the serostatus to their children due to concerns about confidentiality. However, these participants noted that despite their children's young age, caregivers have resorted to obtaining some form of assurance from their children to keep the information about their serostatus confidential.

"I had that fear, but when I questioned him, he said, 'Mother, that is my secret. I cannot go and share it with anyone. I asked him, will you share it with people that you are taking medicine? He replied, 'Mom, I can not. It is my secret" (A 53-years-old widow).

Contrary to the fear of stigma, some of the caregivers were comfortable disclosing the serostatus to their children without any fear or concerns. One of the caregivers pointed out that even though she has not disclosed the serostatus to her child, the reason is not related to

fear but the planning of the best time and circumstances to disclose the serostatus to the child.

"There is no concern. He is my child; how can I be afraid? I do not have any fear. I have just not planned the time to explain it to him properly". (A 42-year-old mother).

Moreover, some participants reported being hesitant to disclose the serostatus to the children due to the absence (death) of the children's parents. This situation would further complicate matters, adding to the burden of disclosing the child's HIV seropositive status.

*"The absence (death) of a mother and the current living arrangement without his father contribute to my concerns. I am contemplating that discussing this information with him now may potentially make the situation not as good as it is now." (*A 60-year-married caregiver).

Additionally, some of the participants highlighted a concern related to adherence reasons since most of the children were questioning the medication they were taking. In line with the children's curiosity, self-awareness, and exploration, some of the participants reported having disclosed their children's serostatus so that they wouldn't stop taking their medications.

*"...Considering it is a lifelong condition, I was concerned that he might refuse medication unknowingly. Hence, I found it necessary to inform him. If he comprehends his condition, he will adhere to his medication effectively." (*A 69-years-old, female caregiver).

The pervasive fear of stigma emerged as a significant barrier to disclosure, with many caregivers expressing concerns about social isolation and rejection should their child's status be revealed.

4.4.2 Risks and benefits of disclosure

When asked about the risks and benefits of disclosing the serostatus to their children, most participants in this study pointed out that it was in line with their concerns about adherence to the medication upon children finding out their serostatus on their own. One participant said she made the right decision disclosing the serostatus because the child has improved physically and takes their medications timely. She added that if it were not for disclosure,

the child would probably die as his health was deteriorating due to poor medication adherence.

"I believe I made the right decision because if I had not taken those steps, his condition might have worsened or died. Observing his progress as he continues his life, I recognize that I made a positive impact. He is healthy, eats well, performs his duties, attends school, and I can see that if I had not disclosed the information, the outcome might have been much worse, possibly leading to his death." (A 53-years-old widow).

Also, some caregivers, especially those who have disclosed the serostatus to children around the age of 10, reported that they disclosed it due to the protection of others. They added that their children were close to having sexual relations, so telling them about their condition would act as a precautionary and preventive measure.

"At the age he is now. He might have entered relationships without disclosing his status, potentially putting others at risk, even if he did not share that information with you. He understands his actions can impact his peers and has taken proactive steps to protect himself and others" (A 47-year-old widow).

Interestingly, participants shared the belief that it is beneficial for the child to be aware of his condition. However, she has not disclosed the status yet. She added that when the child understands that he did not acquire HIV on his own but rather it was passed on to him from his parent, it will help him comprehend the situation better and take better care of himself. Despite this belief and understanding of the benefits of disclosure, the caregiver still believes the risks outweigh the benefits.

"Certainly, it has advantages. He will develop an awareness of his condition and realize that it is not something he acquired on his own; rather, he was born with it. This understanding will contribute to his comprehension and help us care for him. But, a big advantage in not telling him now" (A 36-year-old married caregiver).

Caregivers' emphasis on improved adherence to medication as a primary benefit of disclosure (as seen in several quotes) directly reflects the HBM's focus on perceived benefits and the anticipated positive consequences of the disclosure decision.

4.4.3 Socio-cultural norms on disclosure

In most situations, socio-cultural norms affect how things are approached and done. Disclosing HIV-positive serostatus is one among many things that are affected by norms and social aspects in one way or another. This study found that most caregivers were not affected by the socio-cultural norms around them when it came to disclosing the serostatus of their children. Few participants narrated to believe in God and, thus, don't take the sociocultural aspects into account when it comes to HIV infection.

"I do not even think about those issues. I only believe in God." (A 40-year-old married mother).

Few study participants pointed out that the norms that have affected them are related to stigma. One of the participants mentioned that being a widow and having a sick child might lead to stigma. At one point, that made her hesitate to disclose the serostatus to their child, fearing the information might spread; however, she had disclosed to the child at thirteen (13) years of age despite knowing the serostatus from the age of one (1) year.

"There is a tradition of widow inheritance I often oppose due to the associated stigma. There is this perception that when you are stigmatized, it extends to your child who did not anticipate contracting the disease. Having lost your partner and being a widow, you must maintain a positive appearance in the community. But, when someone discovers that you and your child are affected, it becomes a problem" (A 47-year-old widow).

4.4.3 Social support during HIV seropositive status disclosure

In this study, it was found that most of the caregivers did not seek social support during disclosure. However, at some points before disclosure, they consulted people whom they thought would support them in different ways. One of the reasons they pointed out to involve these people was whether it is right to disclose the status to the child at that age. It was noted that a caregiver would include someone who knows about the child's status before revealing it to the child. The seropositive mothers involved their treatment supporters in consultation to disclose the serostatus to the child.

"There is a relative who is my treatment supporter. He was helping me attend the clinic. So, I involved him in the matter concerning my son as well. However, during the disclosure, it was just me and my son" (A 53-year-old widow).

Furthermore, most participants reported involving household members like siblings during disclosure to support the child. The participants added that involving siblings in disclosure would help care for the child's health and prevent everyone else from contracting the disease.

"His brothers were also present… I decided to involve them all in our treatment so that they could help each other. You never know if he was left alone, he may encounter health problems." (A 42-year-old widow).

Contrary to involving the household members or siblings in disclosure, some of the caregivers reported that they had opted not to involve the relatives around for fear of stigma and confidentiality of the serostatus.

"It was just the two of us. Currently, I live with another granddaughter. Sometimes, when I leave the house, I ask her to administer the medicine to the child, even though she is unaware of the reason. She inquired about the purpose, and I explained it was for the skin patches on his head." (A 65-years-old female caregiver).

In addition to family support, some participants reported receiving support from other social groups. Some participants stated that they disclosed their status to their children due to the influence gained from the widow social group they were members of. They usually have seminars and other education sessions where they are taught and encouraged to disclose the children's serostatus early.

"I often attend these various concerts for widows; they encouraged us to disclose serostatus to our children before they find out for themselves. If they do, it will be difficult to address their concerns. They encouraged and empowered us to prepare for disclosure and address some issues." (A 47-years-old widow).

Some of the caregivers were brave enough to use the presence of the healthcare providers to reveal the serostatus to their children. They affirmed that they would disclose the serostatus of the child upon receiving their results. They continued elaborating that after that, in the

consultation room, the doctor cemented what the serostatus was to the child so that they could accept the situation.

"At first, I was alone after receiving results; it was him and I alone. Then, the doctor also repeated and explained what I told him. I brought the child; they were the ones who contributed to the disclosure. Fortunately, the child accepted the situation." (A 53-years-old widow, mother).

4.5 Caregivers perspectives regarding support needed from healthcare providers during disclosure of a child's HIV seropositive status

The third theme of this study was linked to objective three, aimed to elicit perspectives of caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania, regarding support needed from healthcare providers during disclosure of a child's HIV seropositive status by caregivers. Under this theme, the subthemes were the role of the healthcare providers in disclosure, guidance, and psychological support in disclosing the serostatus of the child and the tools needed or provided for disclosure.

4.5.1 The role of healthcare providers on HIV seropositive status disclosure

Participants reported believing that the healthcare providers' role in disclosing the child's serostatus is to educate the caregivers and encourage them to inform the status. Most participants added that the healthcare providers are educated and more knowledgeable on the subject matter, making them an excellent advisor to the parent on when and how to disclose the serostatus to the child. In addition to believing in the role of healthcare providers in educating the caregivers, few caregivers have declared that they are receiving education and counselling from the healthcare providers.

"They can help us because they are experts in that work, and they have taught us" (A 42-year-old widow).

Some participants further recounted that the healthcare providers should help disclose the serostatus to the child. It was mentioned that the healthcare provider should initiate the disclosure, and the caregiver would later add on the topic, making the child more attentive and caring for their condition.

"I hope that maybe the health workers would be able to disclose to him." (A 60-years-old married caregiver).

Even those who have not disclosed yet were inclined to seek support from healthcare providers

"My husband and I will discuss the situation with him, but the nurses, being experts in this field, are better equipped to offer more detailed explanations." (A 25-years-old married mother)

Furthermore, most participants have pointed out that it is not the healthcare provider's responsibility to disclose the serostatus to the child. Being a parent or caregiver puts the person in a better position to disclose the serostatus to the child they care for. Other caregivers supported this, saying they needed support from the healthcare provider, but it was not their responsibility to disclose the serostatus to the child.

*"Parents (are responsible for disclosing the HIV serostatus to the child), because healthcare providers just provide a guide in disclosure" (*A 69-years-old widow, caregiver).

The basis on which most of the caregivers felt that the responsibility of disclosing is upon the caregiver was due to care of the child. It was further mentioned that if the caregiver can accompany the child to the care and treatment centre, they should be capable of disclosure.

"They can help us because they are experts in that work and have taught us" (A 42-year-old widow).

4.5.2 Guidance and psychological support on HIV seropositive status disclosure

Most participants, especially those who have already disclosed the serostatus to the child, mention that they were capable and confident in revealing it to the child with minimal support from healthcare providers. Almost all study participants believed that healthcare providers play a role in supporting caregiver-led disclosure.

"Just education. To give education to the guardian or parent, to give them the courage and confidence to disclose the HIV serostatus to children." (A 55-year-old divorced caregiver).

Despite this consensus, participants still believe that the support provided by healthcare workers did not specifically influence their disclosure timing and the process itself. When asked whether they received any guidance, participants said they either received no support at all or nonspecific guidance from healthcare providers.

"They just encouraged me to disclose the HIV serostatus to my child. But it was not specific on how to go about it". (A 39-years-old married mother).

Nevertheless, few participants reported receiving some education and guidance on disclosure from healthcare providers. Additionally, some of the participants added that they were encouraged by the healthcare providers to disclose the serostatus to their children early. Likewise, participants reported receiving training and being educated on how to care for the children in terms of diet and other things that would help their health. Some participants reported receiving guidance on managing the consequences of disclosing their HIV status to their children.

"*They advised us to sit down with the children and talk. Following that, we should be vigilant for any potential risks the child may face. Some may react by wanting to harm themselves immediately after being told, while others may accept the news well and simply ask why we did not disclose it earlier*" (A 37-year-old divorced mother).

Some healthcare providers actively supported caregivers in disclosing their HIV status to their children. One of the participants mentioned that she confided in the healthcare provider who supported her and was present during the disclosure of the serostatus to her children.

"I sought out a nurse, my confidante who often guides during counselling sessions. I confided in her, and she advised me to share the information with him when I felt prepared. Fortunately, she was on my side during a conversation with my children." (A 42-years-old widow).

4.5.3 Tools and materials from healthcare providers for HIV seropositive status disclosure

Most caregivers noted that they did not receive specific tools to assist them in disclosing the serostatus to their children. However, many participants mentioned receiving education and

counselling about serostatus disclosure to their children. Additionally, some caregivers received flyers or guidelines to assist with the disclosure process.

"At the hospital, they gave us leaflets and pamphlets with information about HIV, and they were advising us to tell our children what is wrong with them" (A 47-year-old widow).

Although many participants reported not being given tools, e.g. flyers and booklets, to assist in disclosing the serostatus to their children, some of them have emphasized the necessity of having such tools and a structured approach taught to them on how and when to disclose the serostatus to the child. They further affirmed that this would boost the caregivers' confidence and improve their knowledge during the serostatus disclosure process.

"Perhaps in the future, we might reach a point where there's a structured approach, but nowadays, you are simply asked about your issue…There is no structured support for parents and guardians. But, if available, it may help build support and confidence for parents and guardians to disclose." (A 40-year-old married mother).

CHAPTER FIVE

5.0 DISCUSSION

5.1 Overview

This chapter discusses the results of this study and compares these results with other study findings obtained elsewhere regarding the disclosure of the serostatus to the child. This discussion of results addresses three study objectives: caregivers' disclosure experiences, their motivations for disclosure, and their perceived need for healthcare provider support. Also, this chapter highlights the strengths and limitations of this study.

5.2 Introduction

This study investigated the perspectives and experiences of caregivers of school-age children attending ART clinics in Mara Region, Tanzania, in disclosing a child's HIV seropositive status. Specifically, the study assessed the experience of caregivers before, during, and after disclosure, motives and compelling factors for disclosure or non-disclosure, and the caregivers' perspective regarding the role of healthcare providers in supporting disclosure. It sheds light on pediatric HIV disclosure issues as perceived by caregivers.

The Tanzania National Guideline for the Management of HIV/AIDS recommends disclosing HIV seropositive status to children as a critical component of HIV care, as it enhances participation in treatment and helps reduce HIV-related stigma and discrimination. All people living with HIV (PLHIV) enrolled in HIV care should receive disclosure counselling and support in disclosing their HIV seropositive status through assisted disclosure (15). To prepare for disclosure, health service providers should identify a primary committed parent or caregiver and provide them with thorough counselling. They should also discuss with the parent or caregiver the disclosure of the children's or adolescent's HIV seropositive status. Early and beneficial disclosure can lead to increased participation in treatment and is considered favourable for adherence (15). Conversely, non-disclosure can hinder adherence, and identifying barriers to adherence is essential for implementing supportive strategies for caregivers and clients to maximize adherence to antiretroviral regimens (17).

5.2.1 Caregivers' experiences in disclosing a child's HIV seropositive status

The study found out that most of the caregivers knew children's HIV seropositive status earlier on, though the events preceding their discovery vary from one caregiver to the other. Most caregivers reported finding out about children's serostatus after frequent unexplained illness of their children. For biological parents who are aware of their serostatus, these clinical events have prompted them to take their children for testing earlier on. Despite the availability of the recommended HIV testing algorithm for infants and children, this study noted that the serostatus of the child mainly was an incidental finding for the caregiver rather than the standard follow-up done as recommended by the National guideline (15). While early infant HIV testing was not the scope of this study, it is worth noting that early testing and diagnosis pave the way for early planning for disclosure. Children need to be tested as early as 6 weeks of age for HIV using available antigen tests. When access to these tests is scarce, most children are diagnosed based on frequent illness and other supporting signs and symptoms of HIV/ AIDS they encounter (15). This shows that efforts are still needed to encourage the utilization of available knowledge and technology to improve children's care quality.

Also, this study found that the caregivers' process of disclosing their status to their children varied despite their similarities. Regarding the age at which the disclosure process began, some of the caregivers disclosed as early as five years of age, whilst others did not disclose even past 10 years of age. Caregivers who are biological parents tend to disclose earlier information, which is contrary to older studies (67–69). Despite earlier knowledge of their children's HIV seropositive status, caregivers have reported opting for disclosing when the child has developed the ability to comprehend and process the information, which is consistent with other studies (17,70,71). Caregivers in this study were hesitant to cite specific age for starting disclosure, although there was consensus that the earlier, the better. These findings align with a study in India showing that caregivers lacked consensus on the optimal age for HIV disclosure to children. (70). The finding further cements the notion that caregivers prioritize the cognitive maturity of their children rather than age. Other quantitative studies show that children aged ten and older are more likely to be informed of their HIV-positive status than younger children (13,72–75). This trend may be attributed to

caregivers' perception that younger children lack the maturity to comprehend the disease, which is consistent with this study's findings.

Participants reported initiating disclosure conversations at home, often in the evenings, though some also disclosed spontaneously at diagnosis with healthcare providers present. Caregivers in this study reported home-based disclosure due to convenience and a conducive environment to contain possible adverse reactions. This is consistent with findings from South Africa, where caregivers often plan to disclose their children's HIV seropositive status at home but are sometimes prompted to disclose spontaneously due to the child's questions about their medication (60). Caregivers reported planned disclosure to their children, but in most cases, they were ambushed by their children asking questions about their daily medication.

In this study, caregivers sought support from relatives or healthcare providers during the planning and the actual disclosure process, unlike studies in Dar es Salaam and South Africa, which reported robust support systems(30,76). This difference may be due to efforts to avoid stigma. In some cases, siblings of a child were available during disclosure. A study in the Democratic Republic of Congo (DRC) reported a similar pattern where family members were present during disclosure (77). In this study, caregivers favoured including siblings in the care process, allowing them to support the infected child by promoting treatment adherence and relieving them from tasks considered too strenuous. Religious beliefs play a significant role during the initiation of disclosure, building rapport, preparing the child to accept God's plans, and managing the child's well-being after disclosure. The role of faith has rarely been reported in previous studies and may be attributed to participants receiving care from faith-based health facilities. However, the role of caregivers' faith in supporting disclosure needs further investigation.

Participants pointed out that their children's reactions were positive after disclosure. There was little to no change in behaviours, or the child became more positive and careful to care for their health and those surrounding them. Only two caregivers reported that their children skipped school a day after disclosure. This finding is consistent with other studies elsewhere (17,30,53,76). Disclosure became even a catalyst for these children to take their medication timely and attend different events regarding HIV to learn more about their condition. This

finding is consistent with previous studies (17,30,53,76). It highlights the importance of motivating caregivers to disclose, as concerns about the child's reactions have been noted to delay or hinder the disclosure process. This is expected of the emotional cascade to process the information by the child; however, it should not be prolonged, as the caregivers pointed out in this study.

5.2.2 Caregivers perspectives on motives for disclosing a child's HIV seropositive status

Caregivers expressed several concerns that influenced their decision to disclose or not. These concerns, whether justified or not, contributed to delayed disclosure or even non-disclosure. Surprisingly, these concerns are not new as they align with previous studies (78,79) showing that little has changed over time regarding caregivers' worries about disclosing their children's HIV seropositive status. This suggests a need for new innovative strategies and approaches to address the concerns of caregivers, who are critical stakeholders in the care of children living with HIV.

Caregivers who have not disclosed the serostatus to their children pointed out the fear of adverse reactions from the children and potential stigma. These findings correlate with the studies conducted in South Africa and Ghana and a systematic review in sub-Saharan Africa, where concerns of the caregivers on stigma and adverse reactions of the children draw them back from disclosing the serostatus to their children (35,36,60). This necessitates the need to adequately provide support to caregivers before disclosure and managing post-disclosure issues.

In this study, caregivers agreed that the benefits far outweigh the risks, aligning with similar studies conducted in Africa and globally, where disclosing the serostatus to the child catalyses treatment compliance, medical adherence, and improved health outcomes (73–75). Caregivers who supported this view and reported no concerns and positive reactions from their children offer a valuable opportunity to use their positive experiences to encourage hesitant caregivers to learn from their peers. Previous research hasn't extensively explored faith's role in facilitating disclosure. Therefore, support for caregivers should consider this factor, and further research is needed.

In addition to treatment adherence, most caregivers in the Mara region emphasized the importance of children understanding their serostatus, particularly those aged ten and above, to enable them to protect others when they enter into intimate relationships. Caregivers also observed that some children who knew their HIV status took steps to protect others, such as avoiding sharing household items. These findings are consistent with similar studies highlighting the benefits of disclosure, especially to adolescents (27,79,80). Specifically, results from Zambia highlighted that adolescents refrained from engaging in sexual relationships after learning about their serostatus (71). This finding could significantly motivate caregivers to disclose, creating a mutually beneficial situation.

In this study, caregivers reported little or no influence of traditional or social-cultural norms on whether to disclose serostatus to children. However, revealing the serostatus to the child would jeopardise the secrecy of the family to the community and can lead to stigma as a norm of the community in Mara. A study in Northern Uganda that focused on reducing HIV-related stigma through school-based interventions found that cultural and social norms play a significant role in shaping stigma and discrimination, which in turn can affect disclosure practices (82).

Concerning social support, caregivers did not turn to relatives outside their immediate family for help disclosing their serostatus to their children, which contrasts with findings from other studies (83–85). This finding could be due to the caregiver's attempt to keep the diagnosis confidential, indicating an increase in both personal and social stigma. However, some caregivers did consult with various individuals, including supportive relatives and healthcare providers, before and during the disclosure process. Those who sought socio-psychological support felt empowered and encouraged to disclose their serostatus to their children.

5.2.3 Caregivers perspectives regarding support needed from healthcare

This study also explored the caregivers' perspective regarding the role of healthcare providers in disclosing the serostatus to school-aged children. Caregivers in this study split on the issue of who is supposed to reveal HIV seropositive status to the child. This conflict also emerged when surveying healthcare providers. An Indian study showed that healthcare providers often disclosed children's HIV status, suggesting caregiver reluctance to do so themselves (27).

While most caregivers in this study mentioned that it is the responsibility of healthcare providers to offer them the education and counselling needed for disclosing the serostatus to their children and, to some extent, participate in the actual disclosure process, only a few of them reported receiving specific guidance on disclosure and involving providers during the actual disclosure. This echoes findings from similar studies conducted in South Africa, where peripheral involvement of healthcare workers was reported (22,81). However, other studies have reported caregiver-healthcare provider interactions during disclosure (17,75).

This study highlighted the support needed from healthcare providers, which is the caregivers' support during disclosure and encouragement. For the caregivers who did not perceive disclosure of the serostatus to the child as the role of the healthcare providers, they needed to be supported by the healthcare providers to disclose. This finding is consistent with similar studies where healthcare providers reported suboptimal disclosure skills among caregivers as a barrier to early (17,71,75). However, other studies in Sub-Saharan Africa have indicated that healthcare providers were expected to offer services and education but not to participate in disclosing the serostatus to the child (17,80). This uncertainty regarding the role of healthcare providers and who initiates disclosure needs to be resolved and documented in tools meant to support both healthcare providers and caregivers.

Caregivers were sparingly provided with the flyers to educate themselves and prepare for disclosure, but there were nonspecific tools to be utilized during disclosure. In a study conducted to review the tools, models, and resources to aid the disclosure of HIV seropositive status to children in six different countries (86), different models and tools were documented. These available resources can be customized to fit the local context and utilized to address this gap. Careful thought must be given to assist in the disclosure process while protecting children from harmful disclosure practices.

5.3 Study limitations and mitigation measures

Due to the nature of the study design, the reliability of the findings might be limited during sampling, data collection, and analysis. The study focused on caregivers living with HIV-positive children in the Mara region of Tanzania; therefore, the sampled participants' experiences may not be generalizable to other populations, regions, or countries. Researchers used convenience sampling to select the study area and purposeful sampling to choose participants with relevant knowledge and experience.

During in-depth interviews, participants may have provided answers they believe are socially desirable rather than their actual beliefs or experiences. Participants were encouraged by the researcher to be honest and open in their responses by assuring confidentiality during recruitment. Additionally, probing questions and neutral words were used to elicit sensitive issues.

The researcher who conducted the in-depth interviews may have preconceived notions or biases that could influence the participants' responses. To mitigate interviewer bias, the researcher acknowledged and set aside his preconceptions, prejudices, and assumptions about serostatus disclosure to children and strives to remain neutral and non-judgmental during the interviews.

The translation of the interview guide and responses from Kiswahili to English may have led to misunderstandings or inaccuracies in the data. To mitigate translation bias, the interviewer was bilingual, and all participants were fluent in Kiswahili.

The researcher may inadvertently introduce bias during the data analysis process by interpreting the data to align with their preconceived notions or prejudices. To mitigate data analysis bias, the researcher conducted peer debriefing and member checking to ensure that the data analysed reflected the participants' opinions. Furthermore, research processes were shared with the supervising team.

CHAPTER SIX

6.0 CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

This study sheds light on the complex dynamics surrounding the disclosure of HIV seropositive status to school-age children in Tanzania and beyond from the perspectives of caregivers. Caregivers' experiences in disclosing a child's HIV seropositive status are highly individualized and influenced by various factors. No two caregivers are equal in terms of their experiences. This fact underscores the need for tailored support to assist caregivers in navigating disclosure's complex emotional and practical aspects, leveraging perceived enablers.

A balance of perceived risks and benefits drives caregivers' motives for disclosing HIV seropositive status to their children. Overwhelming evidence has been presented in previous studies and in this study regarding the critical need to educate caregivers about the potential benefits of disclosure to counteract the prevailing misconceptions surrounding it. It is high time for healthcare systems to leverage perceived benefits in facilitating early and successful disclosure.

The study calls for the urgent development and utilization of structured tools and training for healthcare providers to enhance their ability to support caregivers effectively. Last but equally important, it is crucial to eliminate uncertainties about the roles of caregivers and healthcare providers in the disclosure process.

6.2 Recommendations

The Ministry of Health (MOH)

1. Develop and implement training programs for healthcare providers on effective communication strategies and psychological support techniques to enhance the support offered to caregivers during the disclosure process. This training will improve their ability to support caregivers during the disclosure process by boosting their skills and confidence to handle the emotional and practical aspects of the disclosure, which is crucial for optimizing the support provided to caregivers.

2. Significantly increase funding for comprehensive education programs aimed at reducing the stigma surrounding HIV/AIDS. These programs must reach a wide range of individuals, including healthcare workers, community members, educators, policymakers, and those living with HIV. Use culturally appropriate methods such as community discussions, interactive workshops, media campaigns, and peer support to address misconceptions, foster empathy, and create a more inclusive environment that supports disclosure.

3. **Council and Hospital management teams (CHMT/HMT)**

1. Invest in expanding and enhancing child-friendly HIV clinics, including extending services to weekends to accommodate school-aged children better. These clinics should provide ample time for open communication and collaborative discussions between caregivers, healthcare providers, and children regarding HIV disclosure. The design should prioritize a supportive and non-judgmental environment that fosters open dialogue, addresses children's specific concerns and questions, and ensures they feel safe and empowered throughout the disclosure process. Clinics should also provide resources and ongoing support to families navigating this complex issue, supporting the child's well-being and successful social integration.

2. Mandate the consistent and effective use of existing resources and materials designed to support caregivers in disclosing their HIV status to their children. Implement a robust monitoring and evaluation system to track caregiver utilization of these resources and assess their effectiveness in facilitating successful disclosure. This system should include regular feedback mechanisms from caregivers to identify areas for improvement and ensure that support materials remain relevant and readily accessible. Furthermore, the system should proactively identify caregivers requiring additional support or specialized intervention, ensuring that no family is left without the necessary assistance to navigate the challenges of HIV disclosure.

Healthcare providers

1. Should utilize existing resources to create a comprehensive, tailored support system for caregivers facing the challenges of HIV disclosure to their children. Services provided should address identified gaps within the current healthcare system by providing safe, confidential spaces where caregivers can share their experiences, receive individualized guidance on effective disclosure strategies, and access emotional and practical support. The support should be culturally sensitive and address the unique needs of diverse caregiver populations.

2. They should leverage the perceived benefits of disclosure, as reported by caregivers, while addressing their specific concerns, such as fear of stigma, potential negative reactions, and the child's capacity to comprehend the information. By highlighting the advantages and addressing the risks associated with disclosure, caregivers can be more encouraged and supported in disclosing their child's HIV status early and successfully.

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APPENDICES

Appendix I: In-depth Interview Guide

A: Introduction

Dear informant, I am Salehe J. Mlangwa, an MPH student at Muhimbili University College of Health and Allied Sciences (MUHAS). I am conducting a study on "Perception and experiences of caregivers in disclosing HIV positive serostatus to children of school age in Mara region, Tanzania."

This study aims to investigate the perceptions and experiences of caregivers in disclosing the HIV seropositive status of their children attending care and treatment clinics in Mara region, Tanzania. The findings of this study will contribute to the understanding of the challenges and support needed by caregivers in disclosing HIV seropositive status to their children living with HIV and inform the development of interventions to enhance the process of disclosure.

Your opinions and suggestions are highly appreciated. You are free to participate, respond to or not to respond to any question. All information to be collected will remain confidential and used only for this study.

B: Demographic Information

1. Age: ……..
2. Sex: ……..
3. Religion …….
4. Occupation: ……..
5. Marital status: ……..
    a. Married/Single
    b. Widow/Widower
    c. Divorced
6. Level of Education: ……
7. Residence: Ward …… Village/Street …..……

8. Number of children living with HIV …….and their age ……..……
……...……
……
…….
9. Relationship with the child/Children living with HIV …….
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……
……

C: Questions per Specific Objectives of the Study

Specific objective number one: To explore the experiences of caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania, in disclosing a child's HIV seropositive status.

1. Please explain your experience in the revelation of your child's HIV-positive status to the child living with HIV.

Probes:

a. When did you find out that your child/children are HIV positive?
b. How did you find that your child was HIV positive?
c. Have you done HIV serostatus disclosure to a child? If yes, please tell us about your experience with your child.
d. How did you start doing so?
e. What did you tell the child?
f. What was their reaction?
g. How many times have you conducted HIV seropositive status disclosure to a child?
h. How old was the child/children at the time of revelation? How old are they now?
i. Why did you decide to reveal at this age?
j. What class was the child at the time of disclosure?
k. What things or issues have made you fail to reveal to a child about their status of being HIV infected earlier?

l. In your opinion, what are the difficulties experienced during revelation? Please explain how you addressed these difficulties/challenges.

2. Please explain the process followed while revealing the child's HIV-positive status.

Probes

a. Please explain your and your child's moods at the time of revelation.
b. What was the location you were at the time of revelation?
c. Why did you choose such a location?
d. Please narrate how you started revealing the child's HIV-positive status to the child living with HIV. Which words did you exactly say?
e. What was the child's response to the disclosure?
f. Who else helped you during the disclosure? Please explain how they help you.
g. What time/age did you consider best for revealing a child's HIV-positive status to the child living with HIV? And why?

3. How did the child (children) react after learning that he/she/they are HIV infected?

Probes

a. What new behaviours did you observe in your child (children) after you revealed the child's HIV-positive status to the child living with HIV? How do you handle that behaviour?

Specific objective number two: To investigate perspectives of caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania, regarding motives for disclosing a child's HIV seropositive status.

1. What made you reveal/not reveal the child's HIV-positive status to the child living with HIV? Please explain your reasons.

Probes

a. Please tell me more about your thought process when deciding whether or not to disclose the child's HIV seropositive status.
b. Please tell me your concerns or fears that influenced your decision to disclose or not disclose the child's status.
c. What kind of support or information did you receive from people around you that helped you decide to disclose the HIV seropositive status to your child?

d. Please explain if any cultural or social norms affected your decision. If any, please describe them and how you solve them.
e. Looking back, what are your thoughts regarding the decision to disclose the HIV seropositive status of the child to them?
f. How did you weigh the potential benefits and risks of disclosing/not disclosing the child's status?

2. In your opinion, what are specific situations or circumstances that you believe may necessitate the revelation of a school-age child's HIV seropositive status?

Probes:

a. Why is it important to disclose a child's HIV seropositive status to caregivers?
b. What else would you like to share regarding the motives for disclosing a child's HIV seropositive status?

Specific objective number three: To elicit perspectives of caregivers of school-age (6-14 years) children attending ART clinics in Mara Region, Tanzania, regarding support needed from healthcare providers during disclosure of a child's HIV seropositive status.

1. Please explain any support that you received from the healthcare provider before, during and after the revelation of the child's HIV-positive status to the child living with HIV.

Probes

a. Please explain your experience with healthcare providers leading up to the revelation of the child's HIV seropositive status, specifically regarding information and guidance.
b. Please describe how healthcare providers supported you and the child (resources and tools) during the revelation.
c. How did healthcare providers help you and the child cope with the emotional and psychological effects of the revelation?
d. Looking back, tell me your thoughts regarding the healthcare provider's role in the revelation process.

2. What type of support do you believe caregivers need from healthcare providers during the revelation process?

Probes

a. What specific information or guidance would you like healthcare providers to provide before, during, and after the revelation process?
b. How can healthcare providers help caregivers manage their emotions and reactions during the revelation process?
c. What recommendations or suggestions do you have for healthcare providers to improve their support to caregivers during the revelation of HIV seropositive status to the school-age child process?
d. Are there any specific resources or tools that you believe would be helpful for caregivers during the revelation of a child's HIV seropositive status? If yes, please mention them.
e. Please explain (if applicable) how social stigma or discrimination related to your child's HIV seropositive status influences the decision to involve healthcare providers in assisting disclosure.
f. If there is anything related to HIV disclosure to school-age children that we have not discussed today, please share it with me now before we close this interview.

We have reached the end of our interview. Thank you for your time and cooperation. Thank you very much.

Appendix II: Kiambatanisho namba II: Mwongozo wa mahojiano ya kina

A: Utangulizi

Mpendwa mshiriki, Jina langu ni Salehe J. Mlangwa, mwanafunzi wa shahada ya udhamili afya ya jamii katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili (MUHAS). Ninafanya utafiti juu ya "Mawazo na uzoefu wa walezi katika kufichua hali ya maambukizi ya VVU kwa watoto wa umri wa shule katika mkoa wa Mara, Tanzania."

Lengo la utafiti huu ni kuchunguza mawazo na uzoefu wa walezi katika kufichua hali ya maambukizi ya VVU ya watoto wao wanaohudhuria kliniki za huduma na matibabu katika mkoa wa Mara, hususani wlaya ya Musoma na Rorya. Matokeo ya utafiti huu yatasaidia katika kuelewa changamoto na msaada unaohitajika kwa walezi katika kufichua hali ya maambukizi ya VVU kwa watoto wao, na pia kutoa mwongozo katika maendeleo ya mikakati ya kuimarisha mchakato wa kufichua katika hali ya maambukizi ya VVU kwa watoto wanaoishi na VVU.

Maoni na mapendekezo yako ni muhumu sana sana. Una uhuru wa kushiriki, kujibu au kutokujibu maswali yoyote. Taarifa zote zilizokusanywa zitabaki kuwa za siri na zitatumiwa tu kwa madhumuni ya utafiti huu.

B: Taarifa za awali

1. Umri: ……..
2. Jinsia: ……..
3. Dini: ……..
4. Kazi: ……..
5. Hali ya ndoa: ……..
    a. Ndoa/ Kutokuwa na Ndoa
    b. Mjane
    c. Amewahi kuoa/kuolewa lakini sasa yuko peke yake
6. Kiwango cha Elimu: ……..
7. Makazi: Kata …….. Kijiji/Mtaa …….

8. Idadi ya watoto wanaoishi na virusi vya VVU……. umri wao ……
   ……
   ……..
9. Uhusiano na mtoto/Watoto wanaoishi na VVU ……
   ……
   …….

C: Maswali kulingana na malengo mahususi ya utafiti

Lengo Mahususi la Kwanza

1. Tafadhali eleza uzoefu wako katika kufichua hali ya maambukizi ya VVU ya mtoto kwa mtoto anaeishi na VVU.

Dadisi:

a. Lini ulijua kwamba mtoto/ watoto wako ana/wana maambukizi ya VVU?
b. Ulijuaje kwamba mtoto/watoto wako ana/wana maambukizi ya VVU?
c. Je, umeshawahi kufichua hali ya maambukizi ya VVU kwa mtoto/watoto wako? Ikiwa ndiyo, tafadhali tuambie uzoefu wako wa kufanya hivyo kwa mtoto/watoto wako?
d. Ulianza vipi kufanya hivyo?
e. Ulimwambia nini mtoto?
f. Mtoto alipokeaje taarifa hizo?
g. Mara ngapi umefanya ufichuzi wa hali ya maambukizi ya VVU kwa mtoto?
h. Mtoto/watoto walikuwa na umri gani wakati wa ufichuzi? Sasa ana umri gani?
i. Kwa nini uliamua kufichua katika umri huu?
j. Mtoto alikuwa darasa la ngapi wakati wa unamwambia hali ya maambukizi?
k. Mambo gani au masuala yamekusababishia kushindwa kufichua kwa mtoto hali yake ya kuwa na maambukizi ya VVU mapema?
l. Kwa maoni yako, ni vikwazo gani ulivyokutana navyo wakati wa ufichuzi? Tafadhali eleza jinsi ulivyoshughulikia vikwazo na changamoto hizo.

2. Tafadhali eleza hatua ulizofuata wakati wa kufichua hali ya maambukizi ya VVU kwa mtoto.

Dadisi :

a. Tafadhali eleza hisia yako na hisia za mtoto wakati wa ufichuzi.
b. Ulikuwa eneo/sehemu gani wakati unafichua hali ya maambukizi ?
c. Kwa nini ulichagua eneo hilo?
d. Tafadhali eleze jinsi ulivyoanza kufichua hali ya maambukizi ya VVU kwa mtoto aliye na maambukizi ya VVU ? Ulitumia maneno gani hasa ?
e. Mtoto Alipokeaje taarifa hizo ?
f. Ni nani mwingine aliyekusaidia wakati wa ufichuzi ? Tafadhali eleza jinsi alivyo/walivyokusaidia.
g. Ni wakati/umri gani unaona ni bora kufichua hali ya maambukizi ya VVU kwa mtoto aliye na maambukizi ya VVU ? Kwa nini unafikiri hivyo ?

3. Je, mtoto/watoto alipokeaje taarifa kuwa a/wameambukizwa VVU ?

Dadisi:

a. Ni tabia mpya gani ulizoziona kwa mtoto (watoto) baada ya kufichua hali ya maambukizi ya VVU ya mtoto/watoto wako?

Lengo Mahususi la pili

1. Je, nini kilikusukuma kufichua / kutofichua hali ya mtoto kuwa na maambukizi ya HIV kwa mtoto aliyeambukizwa? Tafadhali eleza sababu zako?

Dadisi:

a. Tafadhali toa maelezo ya ziada juu ya mchakato wako wa mawazo ulipokuwa unafikiria ikiwa utafichua au kutofichua hali ya mtoto ya HIV?
b. Tafadhali nielezee kuhusu wasiwasi au hofu zako ambazo zilichangia uamuzi wako wa kufichua au kutofichua hali ya mtoto?
c. Je, ulipokea aina gani ya msaada au habari kutoka kwa watu walio karibu nawe ambao walisaidia kufanya uamuzi wa kufichua hali ya maambukizi ya VVU kwa mtoto wako?
d. Tafadhali eleza ikiwa kulikuwa na mila na desturi ambazo zilichangia katika uamuzi wako? Ikiwa ndiyo, tafadhali eleza hizo mila na desturi na jinsi ulivyozitatua.
e. Ukirejea nyuma, je, una mawazo gani kuhusu uamuzi wa kufichua hali ya maambukizi ya VVU kwa mtoto?
f. Ulipima vipi faida na athari za kufichua/ kutofichua hali ya mtoto?

2. Kwa maoni yako, ni hali au mazingira gani maalum unafikiri yanaweza kulazimisha ufichuzi wa hali ya maambukizi ya VVU kwa mtoto wa umri wa shule?

Dadisi:

a. Kwa nini ni muhimu kufichua hali ya maambukizi ya VVU ya mtoto kwa walezi?
b. Je, kuna chochote kingine ungependa kusema kuhusu sababu za kufichua hali ya maambukizi ya VVU ya mtoto?

Lengo mahususi la tatu

1. **Taf**adhali eleza msaada wowote ambao umepokea kutoka kwa mtoa huduma za afya kabla, wakati, na baada ya kufichua hali ya mtoto kuwa na maambukizi ya virusi vya UKIMWI?

Dadisi:

a. Tafadhali eleza uzoefu wako na watoa huduma za afya kabla ya kufichua hali ya mtoto kuhusu maambukizi ya UKIMWI, hasa kuhusu kupewa taarifa na mwongozo?
b. Tafadhali elezea jinsi watoa huduma za afya walivyokusaidia (rasilimali na zana) wewe na mtoto wakati wa unafichua hali ya maambukizi?
c. Watoa huduma za afya walikusaidiaje wewe na mtoto kukabiliana na athari za kihisia na kisaikolojia baada ya kufichua hali ya maambukizi?
d. Ukirejea nyuma, ni mawazo gani unayo kuhusu jukumu la watoa huduma za afya katika kusaidia mchakato wa kufichua hali ya maambukizi?

2. Kwa maoni yako, unafikiri aina gani ya msaada walezi wanahitaji kutoka kwa watoa huduma za afya wakati wa mchakato wa kufichua?

Dadisi:

a. Taarifa au mwongozo gani maalum ungependa watoa huduma za afya watoe kabla, wakati wa, na baada ya mchakato wa kufichua hali ya maambukizi?
b. Kwa maoni yako, jinsi gani watoa huduma za afya wanaweza kusaidia walezi katika kudhibiti hisia zao na za mtoto wakati akipokea taarifa wakati wa mchakato wa kufichua hali ya maambukizi?
c. Una mapendekezo au ushauri gani kwa watoa huduma za afya ili kuboresha msaada wao kwa walezi wakati wa mchakato wa kufichua hali ya maambukizi ya VVU kwa mtoto wa umri wa shule?

d. Je, kuna rasilimali au zana maalum unazoamini zitakuwa na manufaa kwa walezi wakati wa kufichua hali ya maambukizi ya VVU ya mtoto? Ikiwa ndio, tafadhali zitaje.
e. Tafadhali elezea (ikiwa imekutokea) jinsi unavyoamini unyanyapaa au ubaguzi wa kijamii unaohusiana na hali ya maambukizi ya VVU ya mtoto wako unaathiri uamuzi wa kushirikisha watoa huduma za afya katika kusaidia kufichua hali ya maambukizi kwa mtoto?
f. Kama kuna kitu chochote kinachohusiana na kufichua hali ya maambukizi ya VVU kwa watoto wa umri wa shule ambacho hatukujadili , tafadhali kiseme sasa kabla hatujamaliza mahojiano haya.

Tumefikia mwisho wa mahojiano yetu. Nakushukuru kwa muda wako na ushirikiano wako. Asante sana.

Appendix III: Codebook

PERCEPTIONS AND EXPERIENCES OF CAREGIVERS IN DISCLOSING HIV SEROPOSITIVE STATUS TO SCHOOL-AGE CHILDREN IN MARA REGION, TANZANIA

Name	**Description**
THEME 1_ Experiences on HIV seropositive status disclosure among caregivers of school-age children	All statements describing the caregiver's experience in disclosing and or revealing the child's HIV seropositive status, including when and how they disclosed. This includes statements related to the reaction of the child, frequency of the disclosure, difficulties experienced during disclosure, and how they are addressed.
Age of Disclosure	All statements describing the caregiver's age and time disclosed the serostatus to the child. This includes the age at the disclosure, now, and the class the child was at during disclosure. Also, include the reasons why they did not disclose earlier or later.
Child Reaction	All statements describe the child's behaviour after the serostatus's revelation. Include both negative and positive behaviours narrated. Also, the way the caregiver handles the behaviour of the child should be included.
Disclosure challenges	All statements regarding the challenges or difficulties the caregiver faced during disclosure of the serostatus to the child. This includes the way they address these challenges.
Disclosure of the Status to the Child	All statements related to disclosing the serostatus to the child, including the reasons why and why not, have disclosed the serostatus, how the participant started disclosing, the frequency of the disclosure, and the reaction of the child during the revelation.

Name	**Description**
Disclosure Process	Statements describing the process that the caregiver used to disclose the serostatus of the child, including their mood and the mood of the child, as well as the location and the words they used during revelation. Also, include who helped them disclose the information.
Finding Out the Serostatus of the Child	All statements describing when and how the participants found out about the child's serostatus
THEME 2_ Perspectives on motives for disclosing a child's HIV seropositive status among caregivers	All statements, including the motives of the caregiver, reveal or do not disclose the serostatus of the child. This includes thoughts, concerns, and cultural norms regarding revealing serostatus to the child.
Concerns on the Disclosure	All statements describe the caregiver's concerns about disclosing the child's serostatus. Also, include the whole process of thoughts on whether or not to disclose the status as well as any fears related to revealing the child's status.
Risk and Benefits of Disclosure	All statements describing potential risks and benefits the caregiver considered when disclosing serostatus to the child. This includes the benefits and risks of non-disclosure.
Socio-cultural Norms on Disclosure	All statements describe the social and cultural norms of the caregiver regarding disclosing serostatus to the child. Also, include the statements related to how the caregiver addresses these cultural norms.

Name	**Description**
Support on Disclosure	All statements describing the support the caregiver needed, sought or obtained during the disclosure of the serostatus of the child. For those who have not disclosed, include the support they need to inform the child's status.
THEME 3_ Perspectives regarding support needed from healthcare providers during disclosure among caregivers	All the statements describe the caregivers' perspectives regarding the support needed during the disclosure of the child's serostatus. Include the statements of the support the caregiver needs in case of non-disclosure.
Guidance on Disclosure	All statements describing the healthcare provider leading up to the revelation of the child serostatus. Include statements that are specific to the information and guidance on disclosure.
Psychological Support on Disclosure	All statements describe the healthcare providers' support for the child in coping with the emotional and psychological effects of the serostatus disclosure.
Role of the Healthcare Provider in Disclosure	All statements that describe the role of the healthcare providers in the disclosure process of the child's serostatus.
Tools for Disclosure	All statements describe the tools the healthcare provider provided the caregiver to disclose the child's serostatus.

Appendix IV: Ethical Clearance and Introduction Letter from – MUHAS

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/1740 Date: 15/06/2023

MUHAS-REC-06-2023-1740
Salehe Juma
Shool of Public Health and Social Sciences
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: PERCEPTIONS AND EXPERIENCES OF CAREGIVERS IN DISCLOSING HIV SEROSTATUS TO CHILDREN OF SCHOOL AGE IN MARA REGION, TANZANIA

Reference is made to the above heading,

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 15/06/2023
EXPIRATION DATE OF APPROVAL: 15/06/2024

STUDY DESCRIPTION:
Purpose:
The purpose of this cross-sectional facility based phenomenological study using qualitative approach is to explore the perceptions and experiences of caregivers of school age children attending HIV clinics in Mara Region Tanzania in disclosing a child's HIV positive serostatus.

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:
https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2014774.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain material transfer agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country,
8. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
9. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
10. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/.

Dr. Nahya S. Masoud

Chairperson, MUHAS Research and Ethics Committee



Appendix V: Introduction letter

THE UNITED REPUBLIC OF TANZANIA
PRESIDENT'S OFFICE
REGIONAL ADMINISTRATION & LOCAL GOVERNMENT

MARA REGION
Tel. No.028-2622005, 2622004,
2622305

Fax No.028-2622324/2622764
E-mail: ras.mara@tamisemi.go.tz

Ref. No. FA 190/227/01A/28

REGIONAL COMMISSIONER'S OFFICE,
13 BOMA ROAD,
P.O. BOX 299,
31101 MUSOMA.
TANZANIA.

03 July, 2023

District Administrative Secretary,
MUSOMA DISTRICT.

District Administrative Secretary,
RORYA DISTRICT.

RE: **INTRODUCTION LETTER FOR SALEHE JUMA**

Reference is made to the above mentioned subject.

2. The above named Student from from Muhimbili University of Health and Allied Sciences applied for Permission to conduct research titled **"PERCEPTIONS AND EXPERIENCES OF CAREGIVERS IN DISCLOSING HIV SEROSTATUS TO CHILDREN OF SCHOOL AGE IN MARA REGION; CASE STUDY OF MUSOMA MUNICIPAL COUNCIL AND RORYA DISTRICT COUNCIL".**

3. Permission is hereby granted to conduct research from 15th June, 2023 to 15th June, 2024.

4. Please accord him with all necessary assistance.

Msalika Robert Makungu
REGIONAL ADMINISTRATIVE SECRETARY
M A R A

Copy: District Executive Director,
RORYA DISTRICT COUNCIL.

" " Municipal Director,
Musoma Municipal Council.

Appendix VI: Permission letter

JAMHURI YA MUUNGANO WA TANZANIA
OFISI YA RAIS
TAWALA ZA MIKOA NA SERIKALI ZA MITAA

MKOA WA MARA
Anwani ya simu: "Admin"
E-mail: rasmara@pmoralg.go.tz
Unapojibu tafadhali taja

OFISI YA MKUU WA WILAYA,
01 BARABARA YA HALMASHAURI
31311 INGRI JUU-RORYA.

Kumb. Na. RM 10/31/VOL.II/7

TAREHE 18/07/2023.

Mganga Mkuu
KMT Hospital
S.L.P. 18 **Shirati.**
RORYA – MARA

YAH: KIBALI CHA UTAFITI KWA BW. SALEHE JUMA.

Rejea somo tajwa hapo juu.

2. Namtambulisha kwako mtajwa hapo juu ambaye ni mwanachuo kutoka **"Muhimbili University of Health and Allied Sciences"**, ambaye kwa sasa anafanya utafiti unaohusu;

"PERCEPTIONS AND EXPERIENCES OF CAREGIVERS IN DISCLOSING HIV SEROSTATUS TO CHILDREN OF SCHOOL AGE IN MARA REGION; CASE STUDY OF MUSOMA MUNICIPAL COUNCIL AND RORYA DISTRICT COUNCIL".

3. Kwa barua hii unajulishwa kuwa kibali kimetolewa kwa mtajwa hapo juu ili afanye utafiti katika Hospitali yako kuanzia mwezi Julai **2023** hadi Novemba 2023.

4. Tafadhali naomba apewe ushirikiano anaohitaji ili akamilishe utafiti wake

Boniphace M. Chambi
KATIBU TAWALA WILAYA
RORYA

Nakala:

Katibu Tawala Mkoa
Ofisi ya Mkuu wa Mkoa
MKOA WA MARA
13 Barabara ya Boma,
S.L.P 299,
31101 MUSOMA -

Barua Kumb. Na FA 190/227/01A/28 ya tarehe 03/07/2023 yahusika.

Appendix VII: Digital receipt

turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author:	Salehe Juma
Assignment title:	Dissertation Reports
Submission title:	Perceptions and Experiences of Caregivers in Disclosing HIV...
File name:	a__Dissertation_Report_Final_arranged_-28_June_2024_09_7_...
File size:	1.37M
Page count:	101
Word count:	23,904
Character count:	138,742
Submission date:	09-Jul-2024 05:14PM (UTC+0300)
Submission ID:	2414279255



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Appendix VIII: Plagiarism report

Perceptions and Experiences of Caregivers in Disclosing HIV Serostatus to School Children Age in Mara Region, Tanzania

ORIGINALITY REPORT

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SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

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