PERCEPTIONS AND BARRIERS TO DISCLOSURE OF HIV STATUS OF CHILDREN BY CAREGIVERS AT DONKERHOOK CLINIC, WINDHOEK, KHOMAS REGION, NAMIBIA.

A THESIS SUBMITTED IN PARTIAL FULFILMENT

OF THE REQUIREMENTS FOR THE DEGREE OF

MASTERS IN PUBLIC HEALTH

OF

THE UNIVERSITY OF NAMIBIA

BY

NDINOMUKULILI NDAEDEELAO LOMBOLENI

201508300

OCTOBER 2025

SUPERVISOR: PROF HONORE KABWEBWE MITONGA (UNIVERSITY OF NAMIBIA)

ABSTRACT

Children HIV disclosure remains a complicated process influenced by caregivers' perceptions, emotional readiness, stigma, and access to support systems. This study investigates the factors affecting caregivers' decisions regarding HIV status disclosure to children, with a particular focus on barriers, facilitators, and the role of structured disclosure programs. Grounded in the Social Ecological Model (SEM), the study applied a qualitative research design, using in-depth interviews with caregivers and healthcare providers at Donkerhoek Clinic, a local health facility in Windhoek, Namibia. Thematic analysis was conducted to identify key patterns in disclosure practices, emotional responses, and support mechanisms. Findings indicate that while some caregivers recognize the benefits of early disclosure, many opt for a delayed or phased approach due to concerns about the child's mental ability to understand their diagnosis, fear of emotional distress, and societal stigma. Limited access to structured disclosure counselling and inconsistent healthcare support further hinder disclosure efforts. On the other hand, caregivers with access to healthcare-led disclosure programs and peer support groups reported greater confidence and improved disclosure outcomes. The study also highlights that stigma remains a persistent barrier, emphasizing the need for community-driven interventions to promote positive disclosure environments. These findings highlight the necessity of integrating structured disclosure frameworks into children's HIV care services. Strengthening healthcare provider training, increasing caregiver support networks, and developing culturally sensitive disclosure strategies can facilitate timely and effective disclosure. Future research should explore children's post-disclosure experiences and the long-term psychosocial impact of disclosure on their well-being. By addressing these gaps, the study contributes to a more comprehensive understanding of children's HIV disclosure changing aspects and informs policy recommendations for improved disclosure practices in Namibia.

Keywords: *Peer Support Networks, Stigma, Antiretroviral Therapy, Community Perceptions, Social Ecological Model*

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ABBREVIATIONS AND ACRONYMS

HIV- Human Immunodeficiency Virus

AIDS- Acquired Immune Deficiency Syndrome

WHO- World Health Organization

DAPP- Development Aid from People to People

CBOs- Community-Based Organizations

CSOs- Civil Society Organizations

HCW- Health Care Worker

USAID- United States Agency for International Development

MoHSS- Ministry of Health and Social Services

MGECW- Ministry of Gender Equality and Child Welfare

UNICEF- United Nations International Children's Emergency Fund

ARV- Anti-Retroviral

ART- Anti-Retroviral Therapy

HAART- Highly Active Anti-Retroviral Therapy

ACKNOWLEDGEMENT

First and foremost, I would like to humbly express my profound gratitude to my living God for blessing me with the utmost strength, wisdom, and courage, and for being my guidance in every path I took that made it possible for me to complete this research, because without Him, this study would not have remained productive.

Secondly, I would like to extend my heartfelt gratitude to the Ministry of Health and Social Services for permitting me to conduct my study at the Donkerhoek Clinic, Donkerhoek, Windhoek.

Thirdly, I would like to appreciate my princess for being my biggest support system throughout my studies. Meitavelo Omwene-Etutunga Haipumbu, mommy is grateful for everything, and may you stay blessed, my princess. This is for you.

Additionally, I would like to recognize and appreciate my supervisor, Prof Mitonga, and my Mentor, Mr Sibangani Dube, for providing me with the necessary support and guidance throughout my years of study, and for every second, minute, hour, and day that they invested, I say thank you from the bottom of my heart.

Moreover, to all my family members, especially my mother, friends, and all those of you who made sure that I never fell apart while I was busy with my research study, I appreciate all kind of your support that you have rendered to me.

Finally, to all the participants who have participated in my research study, your willingness to participate in this study is of the utmost importance, because if it weren’t for your participation, this study wouldn’t have been completed. Therefore, thank you all.

DEDICATION

This study is devoted to my heavenly Father, who kept me going despite all the difficulties I have encountered throughout my studies. Secondly, I dedicate this triumph to my princess Meitavelo Omwene-Etutunga Haipumbu because she has been the light at the end of the tunnel for me throughout my studies. Moreover, I would like to dedicate this accomplishment to my wonderful mother, who stood by my side through every setback I encountered during this study and encouraged me to finish what I had started. Thank you, MPH family, for your love, true support, and the time you have invested in me over our academic years. To my dearest supervisor, I would like to express my gratitude for guiding me. Your efforts are much appreciated. Finally, I'd like to express my gratitude to all my participants for their help in completing my research study.

DECLARATION

I, Ndinomukulili Ndaedeelao Lomboleni, hereby declare that this study is my own work and a true reflection of my research, and that this work, or any part thereof, has not been submitted for a degree at any other institution.

No part of this thesis/dissertation may be reproduced, stored in any retrieval system, or transmitted in any form, or by means (e.g., electronic, mechanical, photocopying, recording or otherwise) without the prior permission of the author, or The University of Namibia on that behalf.

I, Ndinomukulili Ndaedeelao Lomboleni, grant The University of Namibia the right to reproduce this thesis in whole or in part, in any manner or format, which The University of Namibia may deem fit.

Ndinomukulili N Lomboleni	Lomboleni	October 2025
Name of Student	**Signature**	**Date**

CHAPTER 1: INTRODUCTION AND BACKGROUND OF THE STUDY

1.1. Introduction

HIV and AIDS remain significant public health challenges globally, with Sub-Saharan Africa bearing the highest burden of the disease (1). In Namibia, the HIV epidemic has had far-reaching implications for individuals, families, and communities. Despite considerable progress in combating the disease through various prevention, treatment, care, and support programs, challenges persist, particularly regarding HIV in children (2). Approximately 7,600 children aged 0–14 were living with HIV in Namibia, with a noteworthy number relying on caregivers for disclosure of their status.

Disclosure of HIV status to children by their caregivers is a compound and sensitive issue with implications for adherence to antiretroviral therapy (ART), psychosocial well-being, and long-term health outcomes (3). The World Health Organization (4) recommends gradual disclosure beginning in early childhood and complete disclosure by adolescence to improve treatment adherence and psychological adjustment. However, studies indicate that disclosure rates remain low in Namibia, influenced by stigma, fear of psychological harm, and lack of caregiver preparedness (5,6).

Namibia has made progress in its HIV response, with 90% of people living with HIV aware of their status, 96.4% on ART, and 91.3% achieving viral suppression (2). However, these achievements do not necessarily extend to children, particularly regarding disclosure. This study aimed to explore the perceptions and barriers surrounding HIV status disclosure among caregivers of children accessing services at Donkerhoek Clinic, Windhoek, Namibia. By examining caregivers' lived experiences, beliefs, and challenges, the research seemed to provide perceptions that can inform targeted interventions to improve disclosure practices and support mechanisms for children living with HIV.

1.2. Background of the study

HIV infection among children and adolescents remains a critical public health issue, with 1.7 million children under the age of 15 living with the virus globally as of 2022, 90% of whom reside in Sub-Saharan Africa (7). Namibia continues to be one of the hardest-hit countries in the region, with an HIV prevalence rate of 11.8% among adults aged 15–49 (2). Childhood HIV remains a concern, with 3,400 children under 15 estimated to be living with HIV in 2020 (1). The latest figures from the Namibia ART guidelines (8) indicate that paediatric ART coverage remains suboptimal despite overall treatment successes.

Disclosure of HIV status is associated with improved ART adherence, better psychological well-being, and enhanced social support structures (9). However, despite these benefits, disclosure remains infrequent in many low- and middle-income countries, including Namibia, due to concerns about stigma, the child's emotional readiness, and fear of discrimination (4). Studies have found that children who are aware of their HIV status have greater self-esteem and higher adherence to ART compared to those who are unaware (3).

In Namibia, factors influencing disclosure include caregivers’ fear that the child will not keep the diagnosis confidential, concerns about stigma and discrimination, and a lack of structured disclosure support within healthcare facilities (6). The Namibia ART Guidelines (8) recommend that caregivers gradually disclose HIV status to children with the support of healthcare workers. However, healthcare professionals remain underutilized in this process, and many caregivers struggle with how and when to disclose (5).

A global review of children's HIV disclosure found that rates of disclosure range from 0% to 69.2% in Sub-Saharan Africa (4). The variability emphasizes the need for country-specific strategies to address disclosure challenges. Studies show that structured disclosure approaches improve children's coping mechanisms, improve treatment adherence, and reduce psychological distress (4,6). In Namibia, a greater focus on improving disclosure strategies through caregiver training and healthcare worker involvement is crucial for improving ART outcomes in children.

1.3. Statement of the Problem

Namibia has made commendable progress in addressing HIV/AIDS, achieving high antiretroviral therapy (ART) coverage and viral suppression rates among adults (2). However, disclosure of HIV status to children remains a major gap, potentially undermining treatment adherence and long-term health outcomes. While studies indicate that paediatric ART coverage has improved, many children remain unaware of their HIV status, creating challenges in adherence and psychosocial well-being (4). According to the National Strategic Framework for HIV/AIDS Response (10), failure to disclose HIV status to children could hamper Namibia’s progress toward achieving the 95-95-95 targets and ultimately, the global goal of ending AIDS by 2030. Despite evidence that disclosure improves adherence and psychological adjustment, many caregivers in Namibia remain hesitant to inform children about their HIV status due to fear, stigma, and lack of structured disclosure support (5). Existing literature has explored various aspects of HIV disclosure; however, there is a paucity of research focusing specifically on the perceptions and barriers faced by caregivers in the context of Namibia, particularly within specific settings like Donkerhoek Clinic. This gap in the literature limits the development of targeted interventions to support caregivers in the disclosure process (35). This study, therefore, explored the perceptions and barriers to HIV status disclosure among caregivers of children receiving ART at Donkerhoek Clinic. Addressing this gap is critical in ensuring Namibia meets its national HIV targets and boosts the well-being of children living with HIV and their treatment outcomes.

1.4. Study Aim

The main objective of the study is to explore caregivers' perceptions of HIV status disclosure and the barriers they face at Donkerhoek Clinic in Windhoek, Khomas Region, Namibia.

1.4.1. Objectives of the Study

- To explore caregivers' perceptions of HIV status disclosure to children receiving ART at Donkerhoek clinic, Windhoek, Khomas Region.
- To identify and describe barriers that caregivers face in disclosing HIV status to children receiving ART at Donkerhoek clinic, Windhoek, Khomas Region.
- To identify and describe factors that could facilitate improved disclosure practices within the Healthcare settings

1.5. Study Significance

Understanding caregivers' perceptions and barriers to HIV disclosure is essential for developing interventions that promote timely and appropriate disclosure. The study's findings will inform healthcare providers, policymakers, and community organizations about effective strategies to improve disclosure practices.

For the Ministry of Health and Social Services (MOHSS), the study will provide evidence-based perceptions to strengthen HIV in children care policies. Healthcare workers will benefit from recommendations on supporting caregivers through structured disclosure processes. Additionally, the findings will be beneficial to organizations such as the Namibian Red Cross, Development Aid from People to People (DAPP), Faith-Based Organizations (FBO), and civil society groups involved in paediatric HIV care.

1.6. Study Limitations

The study faced challenges such as participants' reluctance to discuss sensitive information regarding HIV disclosure. To address this, confidentiality measures were emphasized. Language barriers also emerged, requiring the assistance of interpreters. Moreover, the sensitive nature of HIV disclosure contributed to participants' hesitation in sharing personal experiences. Despite implementing strict confidentiality protocols and conducting interviews in private settings to encourage openness, some participants may have withheld information. This hesitancy potentially limited the depth and richness of the data collected, thereby affecting the comprehensiveness of the findings.

Additionally, language barriers presented challenges during data collection. While interpreters were engaged to facilitate communication, there remains a possibility that nuances and cultural contexts were lost or altered in translation. Such discrepancies could have impacted the authenticity of the participants' responses and, consequently, the accuracy of the thematic analysis. Lastly, the study's scope was confined to Donkerhoek

Clinic in Windhoek. This geographical limitation restricts the generalizability of the findings to other settings, particularly rural areas or different urban contexts within Namibia. The unique socio-cultural dynamics of the study site may not reflect those of other regions, suggesting that the results should be interpreted with caution when considering broader applications. Additionally, findings were limited to Donkerhoek Clinic and may not be generalizable to other settings outside Windhoek and in rural areas.

1.7. Delimitation of the Study

The research was limited to caregivers of children receiving ART at the Donkerhoek clinic in Windhoek, Khomas Region, Namibia. The research does not extend to other HIV treatment facilities or broader caregiver populations. The focus is solely on perceptions and barriers to disclosure, excluding clinical outcomes related to HIV treatment adherence.

1.8. Chapter Summary

Chapter 1 introduces the study on caregivers' perceptions and barriers to HIV status disclosure among children receiving ART at Donkerhoek Clinic, Windhoek. It highlights the ongoing challenges of paediatric HIV disclosure despite Namibia's progress in HIV treatment, emphasizing that stigma, fear, and lack of structured support contribute to low disclosure rates. The study aims to explore these barriers, understand caregivers' perspectives, and identify factors that could facilitate improved disclosure practices. By providing insights into disclosure challenges, the research seeks to inform healthcare interventions, policies, and community support programs to enhance disclosure strategies. The chapter also outlines the study's significance, objectives, limitations, and delimitations, establishing the foundation for exploring how disclosure practices can be improved within Namibia's healthcare system. The next chapter will cover literature related to HIV disclosure in children.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. Introduction

A well-structured literature review provides an analytical summary of existing research, helping to identify gaps and justify the study's relevance (11,12). In the context of children's HIV disclosure, understanding previous studies enables a wide-ranging examination of existing frameworks, methodologies, and interventions. Several studies have explored the complications of disclosure, highlighting both benefits and challenges associated with revealing HIV status to children (3,5,4). This chapter synthesizes literature on the history of HIV status disclosure, existing disclosure practices, and barriers to disclosure. Additionally, a theoretical framework is introduced to provide a structured approach to understanding caregivers' disclosure experiences. Lastly, the chapter reviews strategies to improve disclosure practices, including structured disclosure programs and the integration of disclosure counselling into paediatric HIV care.

2.1.1. Literature Search Strategy

A systematic search strategy was adopted to identify relevant studies on children's HIV disclosure. The goal was to include studies that provide a broad yet focused perspective on disclosure barriers and facilitators in various contexts, particularly in Sub-Saharan Africa. Academic databases such as Google Scholar, PubMed, Science Direct, and JSTOR were used to access peer-reviewed journal articles. Keywords such as 'HIV disclosure in children,' 'caregiver perceptions of HIV disclosure,' 'Children HIV stigma,' and 'barriers to HIV disclosure' were applied to filter results. The search was refined to prioritize literature published between 2010 and 2024, ensuring the inclusion of the most recent findings, but also what was known before.

In addition to academic sources, national policy documents and guidelines were reviewed to provide an appropriate understanding of Namibia's HIV response. These included the Namibia Population-Based HIV Impact Assessment (2), the Namibia ART Guidelines (8), and the National Strategic Framework for HIV/AIDS Response (NSF, 2018-2022) (10). Reports from WHO and UNAIDS were also checked to compare Namibia's disclosure practices with global recommendations. Grey literature, such as unpublished research and reports from government agencies, was included where necessary to provide additional context.

The literature search also incorporated systematic reviews and meta-analyses on paediatric HIV disclosure, ensuring a comprehensive assessment of existing knowledge. Studies conducted in Sub-Saharan Africa, particularly in Zambia, South Africa, and Ghana, were reviewed due to their relevance to Namibia's socio-cultural and healthcare environment. The inclusion of both qualitative and quantitative studies ensured a well-versed understanding of the research topic. This literature review, therefore, serves to identify research gaps and highlight the significance of studying disclosure challenges in the Namibian context.

2.2. The History of HIV Status Disclosure to Children by Caregivers

Human Immunodeficiency Virus (HIV) diagnosis disclosure to infected children, according to (13), is a major clinical practice concern in the present because it offers several clinical and psychosocial benefits that aim to improve the quality of life for those living with and affected by HIV. A child learning of his or her HIV status is referred to as disclosure in the context of paediatric HIV (14). For moral and medical reasons, the American Academy of Paediatrics Committee (AAPC) and the WHO strongly advise disclosing an HIV diagnosis to older children who are school-age and older. In addition, the WHO advises that children of school age should be informed of their HIV-positive status and that younger children should be informed of their status gradually to account for their reasoning abilities and emotional maturity in preparation for full disclosure. This recommendation recognizes the importance of improving the quality of long-term care for this vulnerable population.

Effective disclosure is crucial because it is the first step in addressing the frequently repeated education needs of HIV-positive young people regarding daily life with the virus and how it will affect the decisions they make in their social lives, such as managing their health, disclosing to significant others, and sexual decisions. According to UNESCO's HIV and AIDS policy, when young children get older and become teenagers, knowing about their condition will help them make wise decisions about their personal lives, including those involving relationships, sex, and reproduction (15). Practices, perspectives, and barriers of HIV disclosure to children and adolescents by health care providers; in Addis Ababa health facilities, (15). Doat (34) found a connection between non-disclosure and poor adherence, which could result in treatment failure, an increase in viral load, a higher risk of early disease progression, or abrupt changes in the clinical course of HIV infection, and eventually a shorter survival time for these young people. Additionally, non-adherent teenagers who are HIV-positive run the risk of passing the drug-resistant virus to their partners through unprotected intercourse, spreading HIV more widely.

According to several studies, children who get complete disclosure develop their motivation to stick with ART and overcome obstacles to adherence. The effectiveness of

ART causes a substantial shift in the clinical course of HIV infection in young patients, lengthening their survival duration as a result. Adherence that is optimal and sustained is necessary for ART to be successful. However, it has been noted that one of the possible obstacles to optimal adherence, predominantly in children and adolescents, is the failure to disclose one's HIV status.

In the early stages of the pandemic, especially in sub-Saharan Africa (SSA), when access to ART was scarce, HIV/AIDS unfavourably affected the health and welfare of infected children, leading to an increase in fatalities (16). Few healthcare professionals were worried about telling these children the diagnosis because of the particularly poor survival rate. The HIV epidemic among children has reformed, though, in such resource-constrained situations, and most children now survive longer than they did in the past because of increasing access to ART and its efficacy in treating paediatric HIV in recent years.

This has prompted the need for a shift in the non-disclosure practice, and more caregivers must now be ready to tell their children. Contrary to what one might think, studies have found that the longer survival extents have made it more difficult for mothers to tell their HIV-positive children about their diagnosis, which is one of the most difficult psychological issues that family caregivers must deal with. Because of this, more caregivers are reluctant or unable to reveal, and many may decide to keep a child's HIV infection a secret for the rest of the child's life. Researchers on the topic concur that the carers' reluctance to reveal is particularly noticeable in underdeveloped countries and that not only family caregivers but also healthcare personnel are reluctant or find it difficult to disclose (17). HIV status disclosure to children is a vital component of paediatric HIV care, influencing treatment adherence and psychological well-being. Research has consistently demonstrated that children who are informed about their status show improved adherence to ART, enhanced coping mechanisms, and stronger social support systems (9,6). Despite these benefits, disclosure rates remain low across Sub-Saharan Africa, including Namibia. This indicates a significant gap in implementing disclosure strategies effectively.

Globally, disclosure rates vary widely, ranging from 0% to 69.2%, depending on cultural, social, and healthcare factors (4). In Namibia, the Namibia Population-Based HIV Impact Assessment (2) highlights that paediatric disclosure remains a challenge. Many caregivers hesitate to disclose due to stigma and fear of adverse emotional reactions in children. Studies conducted in Zambia and Ghana suggest that caregivers' reluctance is rooted in misconceptions about a child's ability to understand their diagnosis, as well as concerns about confidentiality (5,18). This trend reflects wider disclosure challenges faced by caregivers in resource-limited settings.

2.3. Theoretical Framework for HIV Disclosure

To understand the difficulty of HIV disclosure, this study adopts the Social Ecological Model (SEM) as a comprehensive framework to explore the multifaceted factors influencing HIV disclosure to children (19). SEM provides a multi-level approach to analysing how individual, interpersonal, community, and institutional factors interact to shape disclosure practices. This framework is particularly relevant for paediatric HIV disclosure, where decisions are affected by a confluence of personal, national, societal, and systematic factors (6).

At the individual level, caregivers' knowledge, emotional readiness, and perceptions of HIV disclosure impact their willingness to disclose. At the interpersonal level, family support systems and social norms shape disclosure behaviours. At the community level, societal stigma and cultural beliefs affect how HIV is perceived, which in turn influences disclosure practices. Finally, at the institutional level, the role of healthcare workers, the availability of disclosure guidelines, and national policies play a substantial role in facilitating or hampering disclosure (9,4). The SEM model directed the entire research program. During protocol development, the researcher developed aims explicitly framed to examine factors related to HIV disclosure at multiple SEM levels, with an added emphasis on obtaining a comprehensive approach toward understanding the disclosure process. Instruments, such as semi-structured interview guides, were constructed to extract data that would pertain to the predetermined SEM levels (e.g., intrapersonal beliefs and feelings, interpersonal relationships, community-level norms, and institutional policies that may influence disclosure (36).

During data analysis, the thematic coding was applied to the SEM levels: individual, interpersonal, community, and institutional. This grounded approach also enabled us to appreciate the interplay of factors at different levels that shape caregivers' disclosure practices. For example, we found that institutional policies (or lack of) were associated with individual caregivers' decisions to disclose, indirectly influenced by community stigma and interpersonal support. These findings contributed to the study's recommendations for multilevel interventions targeting barriers at each SEM level to improve rates and outcomes of disclosure (37). By applying SEM, this study explored how these complex factors impact disclosure decisions among caregivers in Namibia.

2.4. The Role of Caregivers in HIV Disclosure Decision-Making

Caregivers play a fundamental role in determining when and how children learn about their HIV status. Their decisions are influenced by multiple factors, including cultural beliefs, personal experiences with HIV, and access to disclosure resources (5). Studies indicate that caregivers often struggle with the emotional burden of disclosure, fearing the child's reaction, stigma, and the potential blame associated with transmission (19). The reluctance to disclose can be attributed to caregivers' desire to protect children from psychological distress and the fear that disclosure may lead to unintentional disclosure to others (13).

Several studies highlight the importance of equipping caregivers with the skills and confidence needed to disclose in a supportive manner. Research in Zambia and South Africa found that caregivers who received disclosure training were more likely to disclose in a structured and gradual way (4,5). This aligns with the Namibia ART Guidelines (8), which recommend that caregivers be provided with disclosure counseling as part of routine pediatric HIV care. However, many caregivers report limited access to healthcare professionals trained in disclosure counseling, leading to delays in disclosure (20). Addressing these challenges requires targeted caregiver support programs that provide structured guidance on how and when to disclose.

The Social Ecological Model (19) further supports the need for caregiver empowerment, emphasizing that individual-level decisions, such as disclosure, are influenced by broader social and institutional factors (6). By ensuring caregivers are adequately supported through healthcare interventions, disclosure rates can be improved, benefiting both caregivers and children.

2.5. Psychosocial and Developmental Impact of Disclosure on Children

The psychosocial impact of HIV disclosure on children is an area of growing research interest. Additionally, studies indicate that children’s reactions to disclosure vary depending on their age, cognitive development, and how disclosure is conducted (3). While some children experience distress, confusion, or anger, others demonstrate resilience, particularly when disclosure is accompanied by appropriate psychological support (21). The WHO (4) recommends a phased disclosure approach, allowing children to gradually process information over time rather than receiving it as a single event. Moreover, evidence suggests that children who are informed about their HIV status early tend to have better treatment adherence and mental well-being compared to those who learn about their status later in adolescence (9). A study conducted in Uganda found that children who were aware of their HIV status were more likely to develop coping mechanisms that helped them manage their health effectively (22). In contrast, delayed or incomplete disclosure was associated with non-adherence to ART, increased anxiety, and difficulties in forming trusting relationships with caregivers and healthcare providers (20). Furthermore, disclosure plays a crucial role in shaping children's self-perception and future decision-making. Adolescents who are fully aware of their status and its implications tend to make more informed choices about relationships, sexual health, and ART adherence (5). However, disclosure also presents risks, including potential social isolation if confidentiality is not maintained (18). To mitigate these risks, studies recommend that disclosure be accompanied by continuous psychological support and peer-led interventions to help children adjust and develop a positive outlook on their diagnosis (9). These findings underscore the need for tailored disclosure interventions that not only inform children about their status but also provide ongoing emotional and psychological support to facilitate adjustment and long-term well-being.

2.6. Barriers to the Disclosure of HIV Status to Children

2.6.1. Child's Age and Cognitive Readiness

The age and cognitive development of the child play a crucial role in influencing the caregivers' decision about disclosing the HIV status to children. Many caregivers often delay disclosure until adolescence due to concerns about the child's thinking ability to understand the implications of their HIV status (18,3,4). Moreover, this apprehension often stems from concerns about the child's ability to keep the information confidential, as well as the potential psychological distress that could arise from disclosure. Numerous studies across Sub-Saharan Africa indicate that caregivers delay disclosure due to these worries (38). WHO (4) advocates for a phased disclosure approach, beginning in early childhood and progressing toward full disclosure by adolescence. However, adherence to these guidelines remains inconsistent, as some caregivers prefer indefinite non-disclosure (5). This highlights the need for better education and support mechanisms to help caregivers deal with disclosure at an appropriate developmental stage.

2.6.2. Fear of Stigma and Social Consequences

HIV-related Stigma remains one of the most persistent barriers to disclosure in Namibia and across Sub-Saharan Africa. Many caregivers often fear that disclosing a child's HIV status will expose them to discrimination from peers and community members, social ostracism, or psychological harm for the child (20). A study conducted in Ghana found that caregivers delayed disclosure due to concerns that their child might accidentally reveal their status, leading to social rejection (18). Additionally, feelings of guilt may arise if caregivers are the source of the child’s infection, further complicating the disclosure process. This combination of factors fosters a culture of silence that hampers effective communication and can negatively impact the child’s treatment and overall well-being (44). In Namibia, similar concerns exist, where stigma is deeply rooted in cultural norms (9). These findings indicate the need for stigma-reduction interventions to create a more supportive environment for disclosure.

2.6.3 Caregiver Readiness and Knowledge Gaps

Another significant obstacle is the lack of preparedness and knowledge among caregivers. Many caregivers struggle with how to approach the topic of disclosure, fearing they will not manage their child's emotional reactions or the questions that may arise from the conversation. This uncertainty is often worsened by a lack of resources and training, leaving caregivers ill-equipped to handle the complexities of disclosure (41). Moreover, healthcare providers also report challenges in supporting caregivers due to time constraints and insufficient training in paediatric HIV disclosure guidelines. Therefore, addressing these gaps is crucial for developing robust training programs and resources that empower both caregivers and healthcare professionals in facilitating meaningful disclosure (46).

2.6.4 Sociocultural Impact

Disclosure behaviours are heavily influenced by cultural and community norms. In many societies, stigma surrounding illness, particularly HIV, leads to reluctance in discussing health matters with children (39). The culture of silence, coupled with fears of public disgrace, often results in caregivers delaying or avoiding disclosure altogether. Understanding and addressing these cultural dynamics is essential for creating interventions that are culturally responsive and effective (42).

2.7. Strategies to Improve Disclosure Practices

2.7.1. Structured Disclosure Programs

Structured disclosure programs have been shown to boost adherence to ART and improve psychosocial well-being among children living with HIV (9). In Namibia, initiatives such as child-friendly disclosure tools, cartoon books, and peer-support groups have facilitated gradual and supportive disclosure (9). These programs aim to provide information at developmentally appropriate and sensitive levels, reducing anxiety and enhancing children's understanding. Evaluations of these interventions have demonstrated improvements in ART adherence and psychosocial outcomes for children (40).

2.7.2. Integration of Disclosure Counselling into Paediatric HIV Care

Integrating disclosure counseling into standard paediatric HIV care is vital for helping caregivers and children engage in the disclosure process. Additionally, the World Health Organisation (WHO) (4) and the Namibia ART Guidelines (8) advocated for the incorporation of disclosure support within health services, emphasizing the need for healthcare worker training in this area. Cross-sectional studies in various Sub-Saharan African countries have shown that including cognitive counseling in paediatric HIV care leads to higher disclosure rates, improved adherence, and better psychosocial adjustment for children. This holistic approach ensures that caregivers receive ongoing support and guidance, enabling them to manage the disclosure experience more effectively (5).

2.7.3 Community Participation and Destigmatization

Community-based interventions aimed at reducing HIV-related stigma are essential for fostering an environment conducive to disclosure (45). Engaging community leaders, educators, and peer support groups is crucial for shifting societal perceptions and encouraging open discussions about HIV (43). Moreover, prevention education and community dialogue have played significant roles in dismissing myths and creating a more supportive atmosphere for those living with HIV. By addressing stigma within communities, these initiatives can alleviate caregivers' concerns and encourage timely disclosure (47).

2.8 Rationale for the Study

Despite available recommendations and support, disclosing HIV status to children remains a challenging and burdensome task for caregivers, especially in low-resource settings. In Namibia, while programs have been implemented, evidence regarding their effectiveness and the specific barriers faced by caregivers is limited. This study aims to investigate the perceptions and experiences of caregivers at Donkerhoek Clinic in Windhoek. Understanding these perspectives is crucial for developing targeted interventions that address the unique challenges faced by this group and promote the well-being of children living with HIV (48).

2.9 Chapter Summary

This chapter provided a comprehensive review of existing literature on paediatric HIV disclosure, highlighting the historical context, barriers, and strategies for improving disclosure practices. The discussion established that while disclosure is essential for treatment adherence and psychological well-being, it remains a complex issue influenced by multiple factors, including caregiver concerns, child cognitive readiness, and societal stigma. Theoretical underpinnings, particularly the Social Ecological Model (SEM), were introduced to analyze the interplay of individual, interpersonal, community, and institutional factors shaping disclosure decisions. Additionally, the role of caregivers as central figures in disclosure was explored, emphasizing their emotional burden and the need for structured guidance. Studies indicate that while global and national guidelines advocate for early and gradual disclosure, implementation remains inconsistent, particularly in low-resource settings like Namibia. The review further examined the psychosocial impact of disclosure on children, noting that while some children adjust well, others experience distress, underscoring the need for supportive interventions.

Despite the growing body of literature on paediatric HIV disclosure, significant research gaps remain. Existing studies largely focus on disclosure rates and caregiver perceptions, with limited exploration of how healthcare systems and cultural dynamics influence disclosure. While structured disclosure programs have been recommended, evidence on their effectiveness in Namibian healthcare settings is lacking. Furthermore, most research has been conducted in broader Sub-Saharan African contexts, with fewer country-specific studies that address Namibia’s unique socio-cultural and healthcare challenges. The literature also points to a need for more longitudinal studies examining the long-term outcomes of disclosure, particularly its impact on ART adherence, mental health, and social integration. Addressing these gaps will be essential in formulating evidence-based policies and interventions that support both caregivers and children through the disclosure process. The next chapter discusses the research methodology applied in this study.

CHAPTER 3: RESEARCH METHODOLOGY AND DESIGN

3.1. Introduction

Research methodology refers to the systematic approach used in conducting a study, including data collection, analysis, and interpretation (50). This study adopted a qualitative research methodology, which is appropriate for exploring caregivers' perspectives on disclosing HIV status to children. A research paradigm is a set of beliefs and assumptions that guide the research process (23).

3.2. Research Design

This study adopted a qualitative research approach to explore caregivers’ perceptions and barriers to HIV disclosure. A qualitative approach is particularly suitable for studies that seek to understand human experiences, emotions, and social phenomena in depth (24). Unlike quantitative research, which focuses on numerical data and statistical analysis, qualitative research emphasizes subjective experiences, providing rich, descriptive insights into the complexities of human behaviour. Given the sensitive nature of HIV disclosure, qualitative research allowed for a detailed investigation of the psychological, social, and cultural dimensions that shape caregivers’ decision-making processes.

Within qualitative research, multiple methodological design approaches exist, including grounded theory, ethnography, narrative research, and action research (23). However, this study applied a phenomenological design, as phenomenology focuses on capturing participants’ perceptions and subjective realities (49). The phenomenological approach was considered most appropriate because it seeks to describe and interpret individual perceptions, rather than develop new theoretical frameworks, as seen in grounded theory

(25). In the context of this study, phenomenology provided a framework for understanding how caregivers navigate, perceive, and emotionally process the disclosure of HIV status to children. This approach allowed participants to express their fears, motivations, and barriers in their own words, offering deep comprehension into the psychological and social factors influencing disclosure decisions.

This research design helped identify common themes and patterns in caregivers' experiences, thereby contributing to a wider understanding of the factors influencing HIV disclosure. Additionally, it provided a holistic perspective by integrating caregivers' voices, an approach that is often missing in quantitative studies that focus primarily on statistical trends. By prioritizing personal storylines and lived experiences, this study contributes to the growing body of literature advocating for context-sensitive and caregiver-informed disclosure strategies in care for HIV among children.

3.2.1. Population

The population in a research study refers to the whole group of individuals or subjects that the investigator is interested in reviewing (26). The study population consisted of caregivers of children aged 12 – 18 years living with HIV and receiving ART at Donkerhoek clinic in Windhoek, Khomas Region, Namibia. These caregivers were responsible for health care and well-being of HIV-positive children and played key role in the disclosure process. Healthcare providers, social workers, and legal guardians were also considered if they played an active role in caregiving.

3.2.2. Study setting

This study was conducted at Donkerhoek Clinic’s ART unit in Windhoek, Khomas Region, Namibia. Donkerhoek Clinic is a key primary healthcare facility that provides wide-ranging HIV/AIDS care and treatment to the local community. Given its role in paediatric HIV care, understanding disclosure practices within this setting is essential for improving support services in the Khomas Region and beyond. This aligns with Namibia’s Vision 2030 and the global 95-95-95 targets, which aim for 95% of the population to know their HIV status, 95% of those diagnosed to be on ART, and 95% of those on treatment to achieve viral suppression.

3.3. Sample

A purposive sampling method was used to select participants who could provide diverse and insightful information regarding the disclosure of HIV status to children. Specifically, the focus was on caregivers of HIV-positive children aged 6 to 12 years who were receiving antiretroviral therapy at Donkerhoek Clinic in Windhoek, Namibia. This strategy ensured that the researcher engaged individuals with first-hand experience relevant to the research topic.

The determination of the sample size was guided by the principle of data saturation, which occurs when additional interviews yield no new information or themes. Saturation is a widely recognized criterion for assessing sample adequacy in qualitative research. In this study, saturation was reached after conducting 25 interviews; however, we conducted two additional interviews to verify the consistency of the data, resulting in a total of 37 participants. This sample size aligns with guidelines for phenomenological research, which suggest that between 5 and 25 participants are sufficient to capture the depth and complexity of experiences.

3.3.1. Inclusion and exclusion criteria:

To ensure that the study targeted relevant participants, specific inclusion and exclusion criteria were established. Caregivers were eligible to participate if they were actively caring for children aged 12 to 18 who were receiving ART at Donkerhoek Clinic. This age range was selected because children in this stage of development are at a crucial point for disclosure, where intellectual and emotional maturity may influence their understanding of their HIV status. Additionally, only caregivers who expressed a willingness to participate in face-to-face interviews were included, as the study required detailed qualitative insights that could only be gathered through direct interaction. Moreover, participants needed to have the capacity to provide informed consent, ensuring that ethical considerations and voluntary participation were upheld.

Additionally, caregivers of children outside the specified age range (i.e., above 18 years of age) were excluded, as disclosure dynamics may differ significantly for younger children or older adolescents. Additionally, individuals who declined to participate for any reason were not included in the study, as ethical research practices necessitate that participation remains voluntary and free of compulsion. These criteria helped ensure that the study focused on caregivers with relevant experiences, ultimately contributing to a more meaningful investigation of HIV disclosure challenges and practices.

3.4. Research instrument

Data for this study were collected using self-administered questionnaires to gather in-depth information on caregivers' experiences and perspectives regarding the disclosure of HIV status to children. The questionnaire combined both open-ended and closed-ended questions, allowing for quantifiable data on caregivers' knowledge and attitudes, as well as rich qualitative narratives (26).

To ensure the instrument's validity and reliability, a systematic development process was followed, including a literature review, expert panel feedback, and a pilot study to refine the questions. The final questionnaire comprised four sections: demographics, knowledge and attitudes about disclosure, perceived barriers and facilitators, and personal disclosure experiences. Participants completed the questionnaire through face-to-face interviews, accommodating their schedules to enhance response honesty and reduce bias. This comprehensive tool aimed to capture the complexities surrounding HIV status disclosure to children.

The interview guide was developed based on the study objectives and an extensive review of existing literature on HIV disclosure among caregivers. The questions were designed to capture caregivers' perceptions, barriers to disclosure, and sources of support, aligning with previous research methodologies used in similar studies (3,5).

The interview guide covered key areas such as:

- Understanding of HIV disclosure.
- Perceptions and concerns regarding disclosure.
- Barriers to disclosure.

- Sources of support and coping mechanisms.

3.5. Data Collection Procedures

Data collection took place over two weeks at Donkerhoek Clinic, following ethical clearance from the Ministry of Health and Social Services (MoHSS) and approval from the clinic management. The researcher worked closely with clinic authorities, particularly those overseeing the ART program, to ensure smooth coordination and minimize disruption to routine healthcare services. Meetings were held with the sister in charge, HAART division personnel, nurses, and community health counselors to discuss study procedures, ethical considerations, and the importance of informed consent. These preliminary engagements facilitated the efficient recruitment of participants and ensured that data collection aligned with the clinic's workflow.

To identify potential participants, healthcare workers assisted in purposive sampling by directing the researcher to caregivers who met the inclusion criteria. Before their consultation, caregivers were approached privately, and the study's objectives, procedures, and ethical considerations were explained in detail. Participation was entirely voluntary, and caregivers were assured that their responses would remain confidential. The informed consent process included a discussion of potential risks and benefits, and caregivers were encouraged to ask questions before providing their signed consent. The study adhered to strict confidentiality protocols, ensuring that personal details were anonymized and that no patient information was accessed from electronic records such as ePMS or PCBs.

Interviews were conducted in a private consultation room at the clinic to uphold confidentiality. Each session lasted approximately 30 to 45 minutes, allowing caregivers sufficient time to express their thoughts without feeling rushed. The researcher employed a semi-structured interview format, integrating open-ended questions to encourage caregivers to share their experiences freely. This approach provided a flexible yet structured framework, enabling the researcher to probe deeper into key themes while allowing participants the freedom to introduce relevant concerns or personal reflections. The researcher also paid close attention to tone, pauses, and non-verbal cues, which offered additional insights into caregivers' feelings, anxieties, and uncertainties about disclosure.

Interviews were audio-recorded with participant consent to ensure accurate transcription and analysis. To maintain data security, all recordings were anonymized, transcribed verbatim, and securely stored in a locked cabinet. Digital data was encrypted and stored in password-protected files, accessible only to the researcher. In cases where caregivers became emotional or distressed, the researcher handled the situation with sensitivity and care, offering support resources or referring them to available counseling services at the clinic.

To integrate data collection with the clinic workflow, the researcher strategically scheduled interviews to minimize disruption to daily operations. Pre-study coordination efforts involved working within the clinic’s client flow system, which dictates the sequence of services received by patients. Interviews were conducted between patient consultations to avoid interfering with medical services. In some cases, staggered appointments were arranged to prevent congestion and ensure a steady flow of participants.

After completing the interviews, the researcher held a debriefing session, thanking participants for their time and contributions. The researcher also outlined the next steps in the study and reassured caregivers that their input would help enhance disclosure practices and support systems for children living with HIV. A feedback mechanism was established with the clinic staff, allowing for real-time adjustments if the study affected clinic operations. The data collection process was conducted ethically, systematically, and with full respect for participant confidentiality, ensuring a rich, meaningful, and well-documented understanding of caregivers' experiences with HIV disclosure.

3.6. Data analysis

The data analysis process began with data cleaning, which involved correcting typographical errors and refining responses to enhance clarity and coherence. Once the transcripts were cleaned, they were uploaded into Atlas. Ti Web, a qualitative data analysis software that facilitates systematic coding and theme identification.

The data analysis process followed Braun and Clarke’s six-step thematic analysis framework (27), ensuring a structured and rigorous approach to identifying key patterns and themes in caregivers' narratives. The researcher began by immersing themselves in the data, carefully reviewing interview transcripts multiple times to develop a comprehensive understanding of the caregivers’ experiences. This familiarization process helped identify recurrent ideas, emotions, and perspectives expressed by participants.

Following this, the researcher proceeded with initial coding using Atlas. Ti, where significant phrases, concepts, and patterns related to HIV disclosure challenges, motivations, and emotions were systematically labeled. Each piece of data was assigned a code to categorize similar responses, ensuring that emerging insights were captured efficiently. Once the coding was completed, similar codes were grouped to form broader themes that represented key aspects of caregivers' experiences. This stage involved looking for commonalities and relationships between different codes, allowing the researcher to identify major themes that encapsulated caregivers' perspectives on disclosure.

To ensure accuracy and coherence, the researcher then reviewed and refined the themes, cross-checking them against the original transcripts. This step involved eliminating redundant or overlapping themes and ensuring that each category genuinely reflected participants' lived experiences. Once validated, the researcher proceeded with defining and naming the themes, ensuring that each theme was clearly articulated and aligned with the study's objectives.

Finally, the themes were synthesized into a coherent narrative, with participant voices integrated through direct quotes to illustrate key findings. These quotes provided authentic and compelling insights, reinforcing the emotional and psychological dimensions of caregivers' experiences with HIV disclosure. Through this structured analytical approach, the study successfully identified key barriers, motivations, and support mechanisms influencing caregivers' decisions on disclosing HIV status to children.

Using Atlas.ti Web, the researcher was able to proficiently organize the data, visualize emerging patterns, and ensure a thorough and transparent analysis process. This approach enhanced the credibility and reliability of the findings, ensuring that they accurately captured caregivers' perspectives on HIV disclosure.

3.7. Trustworthiness

Instead of reliability and validity (which are quantitative concepts), this study ensured trustworthiness by addressing:

To ensure the rigor and credibility of the research findings, several measures were taken to enhance trustworthiness. Credibility was established through member-checking, where participants were allowed to review and validate their responses, ensuring that their perspectives were accurately captured. Additionally, prolonged engagement with participants allowed the researcher to build rapport, gain deeper insights, and ensure that the findings truly reflected caregivers' experiences with HIV disclosure.

Transferability was achieved by providing rich, detailed descriptions of the study setting, participants, and findings. This enables other researchers and practitioners to determine the applicability of the results to similar contexts. By thoroughly outlining the disclosure challenges and perceptions of caregivers in Namibia, the study offers insights that may be relevant in other sub-Saharan African settings with comparable socio-cultural and healthcare landscapes.

To ensure dependability, a systematic and consistent approach to data collection and analysis was maintained. The researcher adhered to a structured methodology, ensuring that interviews were conducted uniformly, and data analysis followed (27- thematic analysis framework. This consistency enhances the reliability of the findings and ensures that the study can be replicated in similar settings.

Finally, conformability was ensured by maintaining an audit trail that documented all stages of the research process, from data collection to thematic analysis. This included keeping detailed records of interview transcripts, coding decisions, and analytical memos, allowing for transparency in how conclusions were drawn. By applying these trustworthiness criteria, the study ensures that its findings are well-founded, reflective of participants' experiences, and contribute meaningfully to the discourse on HIV disclosure in paediatric care (25).

3.8. Ethical Considerations

Ethical considerations are essential in research, particularly when investigating sensitive topics such as HIV disclosure. This study followed the fundamental ethical principles of Respect for Persons, Beneficence and Non-Maleficence, and Justice, as outlined in the Belmont Report (28). These principles ensured that participants' autonomy, well-being, and rights were safeguarded throughout the research process.

Furthermore, the study adhered to the ethical guidelines of the University of Namibia Ethics Committee and the Ministry of Health and Social Services (MoHSS), which provided ethical clearance (see Appendix 1 and Appendix 2). The reference numbers for ethical approval were recorded and documented as required by these institutions (DEC OSH 0116, dated 16/04/2024).

Respect for Persons

The principle of Respect for Persons emphasizes the right of individuals to make autonomous decisions about their participation in research. This principle requires researchers to uphold informed consent, ensuring that participants voluntarily agree to take part in the study after being fully informed about its purpose, risks, and benefits (28).

In this study, caregivers were provided with detailed information about the study, including its objectives, procedures, and their right to withdraw at any stage without consequences. Before participating, caregivers were required to sign an informed consent form confirming their voluntary participation.

To accommodate caregivers with limited literacy, the researcher verbally explained the consent form in their preferred language. Participants were also allowed to ask questions and seek clarification before signing. This ensured that consent was based on genuine understanding and willingness, rather than coercion.

Beneficence and Non-Maleficence

The principle of Beneficence obligates researchers to maximize benefits while minimizing potential harm to participants (29). In contrast, Non-Maleficence emphasizes the need to prevent any harm from occurring as a result of research participation (29).

Given that HIV disclosure is a sensitive and potentially distressing topic, several measures were implemented to protect participants from emotional harm. Interviews were conducted in a private, confidential setting at Donkerhoek Clinic, ensuring that participants felt comfortable discussing their experiences without fear of judgment or exposure.

Furthermore, the interview process was designed to be empathetic and non-intrusive, allowing caregivers to share their perspectives, challenges, and emotions at their own pace. The semi-structured format enabled participants to skip any questions they found distressing, further reducing potential psychological harm.

In cases where participants displayed signs of emotional distress, the researcher provided psychosocial support resources and referred them to trained counsellors at Donkerhoek Clinic. This ensured that participants had access to professional support if needed. Additionally, participants were assured that the study's findings would contribute to improving HIV disclosure guidelines and caregiver support mechanisms, thereby maximizing the broader benefits of the research.

Justice

The principle of Justice requires that research participants be equitably selected to ensure fair representation and prevent exploitation or exclusion (29).

This study adhered to this principle by ensuring that all eligible caregivers, regardless of socio-economic status, gender, or ethnicity, had an equal opportunity to participate.

Participants were recruited equitably from diverse socio-economic backgrounds to ensure that the study's findings reflected a broad spectrum of caregiver perceptions. The selection process was free from discrimination, and participants were not coerced through financial or material incentives.

Additionally, the findings of this study will be shared with relevant stakeholders, including MoHSS and healthcare practitioners, to inform policies and programs that support caregivers in the HIV disclosure process. By ensuring that the research benefits both caregivers and the broader healthcare system, the study upheld the ethical principle of Justice.

Confidentiality and Data Protection

Ensuring confidentiality was a critical component of this study, given the stigma associated with HIV status disclosure. To maintain participant anonymity, all interview transcripts were de-identified, with names and personal identifiers replaced with unique codes.

Data was stored securely in password-protected files on encrypted devices (computers), ensuring that unauthorized individuals could not access sensitive information. Hard-copy consent forms and interview notes were stored in a locked cabinet, accessible only to the researcher.

Additionally, pseudonyms were used when presenting direct quotes from participants in the final report, further ensuring anonymity. Participants were assured that their responses would remain confidential, and that the data would be used solely for research purposes.

3.9. Chapter Summary

This chapter outlined the research methodology used in the study, detailing the systematic approach used to explore caregivers' perceptions and barriers to HIV disclosure to children. The study adopted a qualitative research methodology within an interpretive paradigm, which allowed for a deep investigation of caregivers' lived experiences. A phenomenological research design was selected to capture personal narratives and subjective meanings associated with disclosure, ensuring that the study went beyond statistical trends to understand the emotional and psychological dimensions of the disclosure process. The study was conducted at Donkerhoek Clinic in Windhoek, Khomas

Region, a primary healthcare facility providing wide-ranging HIV/AIDS services, making it an ideal setting for understanding disclosure challenges within the Namibian context.

The study targeted caregivers of children aged 12–18 years receiving ART, as this age range represents a critical stage for disclosure. Purposive sampling was used to ensure that only caregivers actively involved in the disclosure process participated, while healthcare workers assisted in identifying eligible participants. Semi-structured interviews served as the primary data collection method, allowing for open-ended discussions while maintaining a structured exploration of key themes. Data collection occurred over two weeks, with interviews conducted in private consultation rooms to uphold confidentiality. Ethical considerations, including informed consent, voluntary participation, and data security, were strictly adhered to, ensuring that participants felt safe and respected throughout the study.

To ensure trustworthiness, the study incorporated credibility through member-checking and prolonged engagement with participants. Transferability was achieved through rich, detailed descriptions, while dependability was ensured via a consistent and systematic approach to data collection and analysis. Conformability was maintained through an audit trail, ensuring transparency in coding, theme development, and interpretation. Data was analyzed using (27) 27-step thematic analysis framework, utilizing Atlas.ti Web for systematic coding and theme identification. Ethical principles of Respect for Persons, Beneficence, Non-Maleficence, and Justice were upheld throughout the research, ensuring that participants' rights, dignity, and well-being were prioritized.

The chapter has specified an all-inclusive summary of the methodology exercised in this study. The qualitative research approach was chosen to offer a holistic understanding of the challenges faced by caregivers taking care of children living with HIV and on ARV therapy in Namibia at Donkerhoek Clinic. The following chapter will present the findings and analysis based on methodology employed in this chapter.

CHAPTER 4: FINDINGS OF THE STUDY

4.1. Introduction

This chapter presents the findings of the study based on the analysis of data collected from caregivers of children living with HIV and receiving ART at Donkerhoek Clinic in Windhoek, Namibia. The results are structured into two main sections: Demographic and Respondent Characteristics and Thematic Findings on HIV Disclosure. This chapter focuses solely on presenting the data without interpretation or discussion. The next chapter will discuss and interpret the results concerning the literature, whilst concluding.

4.2. Demographics and Respondent Characteristics

This section provides an overview of the demographic profile of the study participants, including age distribution, gender, and educational background.

4.2.1. Age Distribution of Caregivers

The caregivers who participated in this study ranged in age from 20 to 60 years. Table 1 provides the frequency and percentage distribution of the caregivers' ages.

Table 1: Age Distribution of Caregivers

Age Group (Years)	Frequency (n)	Percentage (%)
20-30	10	28.6
31-40	15	42.9
41-50	7	20.0
51-60	3	8.5
Total	35	100

The mean age of caregivers was 35.65 years (SD = 8.63), indicating that most caregivers were in their early to mid-adult years. The majority (42.9%) fell within the 31-40 age range, while the smallest group (8.5%) was between 51-60 years.

4.2.2. Gender Distribution of Caregivers

Table 2 presents the gender distribution of the participants.

Table 2: Gender Distribution of Caregivers

Gender	**Frequency (n)**	**Percentage (%)**
Female	**23**	**65.7**
Male	**12**	**34.3**
Total	**35**	**100**

The study found that female caregivers (65.7%) represented the majority of respondents, while male caregivers (34.3%) formed a smaller proportion.

4.2.3. Educational Background of Caregivers

Table 3 outlines the educational levels of caregivers.

Table 3: Educational Background of Caregivers

Educational Level	Frequency (n)	Percentage (%)
High School	**19**	**54.3**
University	**16**	**45.7**
Total	**35**	**100**

All caregivers had at least a high school education, with 54.3% having completed high school and 45.7% holding university-level qualifications.

The demographic results indicate that the majority of caregivers were aged 31-40 years, predominantly female, and had completed at least high school education. This demographic data provides context for understanding the perspectives and experiences captured in the next section, which focuses on thematic findings related to HIV disclosure.

4.2. Demographics and Respondent Characteristics

This section provides a descriptive overview of the backgrounds of the caregivers who participated in the study. Understanding their demographic profiles helps to contextualize the insights they shared regarding HIV status disclosure to children.

4.2.1. Age of Caregivers

The caregivers who took part in this study spanned a broad age range, from early adulthood through to late middle age. Most of them were in their early to mid-adult years, with a notable concentration of participants in their thirties. This age range suggests that many caregivers were in a stage of life where they may be balancing caregiving responsibilities with other adult roles, such as employment or parenting. A smaller number of older caregivers also participated, offering potentially different generational perspectives on caregiving and HIV disclosure.

4.2.2. Gender of Caregivers

Women made up the majority of the participants, with men comprising a smaller portion of the group. This gender distribution reflects broader caregiving trends observed in many communities, where women often assume primary caregiving roles. Their voices dominate the narratives in this study, offering a lens shaped largely by female experiences and perspectives on caregiving and HIV disclosure.

4.2.3. Educational Background of Caregivers

All the caregivers who participated had attained at least a high school education, and a significant number had progressed to university-level studies. This relatively high level of educational attainment among participants may have influenced their understanding of HIV, their approaches to caregiving, and their decisions around when and how to disclose HIV status to children. Education appeared to play a role in shaping not only their awareness of the condition but also their confidence in managing disclosure.

Summary

The demographic profile of participants revealed that caregivers were mostly women in their thirties with at least a secondary education. These characteristics provided a foundation for the caregivers’ narratives and offered valuable insight into how age, gender, and educational background may shape attitudes and practices around HIV disclosure. The following section builds upon this context by exploring the thematic findings drawn from their lived experiences.

4.3. Thematic Findings on HIV Disclosure

The thematic analysis was conducted using Atlas.ti Web, which facilitated the identification of recurring patterns and themes in the caregivers' responses. The analysis revealed several key themes regarding the experiences, challenges, and strategies related to HIV disclosure to children. These themes are presented below, detailing what each includes.

- **To explore caregivers' perceptions of HIV status disclosure to children receiving ART at Donkerhoek clinic, Windhoek, Khomas Region.**

1. Importance of Disclosure:

This theme highlights caregivers' recognition of the significance of informing children about their HIV status. It explores their understanding of the benefits of disclosure, including improved adherence to antiretroviral therapy (ART), psychological well-being, and the child's ability to manage their health. Additionally, it reflects caregivers' perspectives on the right time and manner to disclose, balancing medical recommendations with personal beliefs.

2. Fear and Stigma:

A central barrier to disclosure, this theme examines caregivers' concerns about societal stigma and potential discrimination against their children. It digs into how fear of negative reactions from family, peers, and the community influences caregivers' reluctance to disclose. This theme also incorporates concerns about breaches of confidentiality and how disclosure might impact the child’s social interactions.

3. Emotional Preparedness and Caregiver Readiness:

This theme focuses on caregivers’ emotional state and psychological readiness to disclose. Many caregivers struggle with their fears, guilt, and uncertainties, making the disclosure process emotionally overwhelming. It explores the internal conflicts caregivers experience as they weigh the benefits of disclosure against the potential distress it may cause the child.

4. Need for Support and Education:

This theme captures caregivers' reliance on healthcare professionals, social workers, and educational resources to guide them in the disclosure process. It discusses the role of structured programs, counseling services, and disclosure toolkits in helping caregivers feel more confident and prepared. Additionally, it highlights the importance of peer support networks and training sessions for caregivers.

5. Developmental Considerations and Timing of Disclosure:

This theme explores how caregivers take into account the child’s age, cognitive ability, and emotional maturity when deciding when and how to disclose. It examines the preference for phased disclosure, where children receive basic health information at a young age and progressively learn more about their condition as they mature. The theme also considered concerns about how children interpret and react to the information based on their developmental stage.

6. Strategies for Managing Disclosure:

This theme focuses on the different approaches caregivers use to disclose HIV status, ranging from gradual storytelling to direct communication. It also covers the involvement of healthcare workers in the disclosure process and the role of family discussions in supporting children after disclosure. The theme highlights caregivers' adaptive strategies in response to individual child needs and social contexts.

These themes provide a complete framework for understanding the multilayered nature of HIV disclosure and highlight the need for structured support systems to facilitate effective disclosure practices. The results from these themes are as described below:

4.3.1. Understanding of Disclosure

Participants expressed varying interpretations of what HIV disclosure means, with most caregivers defining it as the act of revealing confidential health information, specifically a child's HIV status. Some caregivers described disclosure as "revealing secret information," emphasizing that it involves sharing a previously unknown fact about the child's health condition. Others theorized disclosure as more than a one-time event, instead viewing it as an ongoing process that unfolds over time. One caregiver explained, *"It is not something that you just say once and forget, but something that happens over time as the child grows"* (Participant 4).

The way caregivers outlined disclosure was influenced by their understanding of HIV and their perception of the child's ability to handle the information. Some caregivers believed that disclosure required careful timing and preparation, as they considered the child's emotional and cognitive maturity. Others emphasized that it should be handled as a sensitive issue to avoid overwhelming or distressing the child. For example, a participant stated, *"It is not just about telling the child they have HIV; it is about making sure they understand what it means and how to live with it without being scared"* (Participant 7).

Concerns about confidentiality emerged as a substantial aspect of how caregivers understood disclosure. Many caregivers stressed that disclosure requires a high degree of trust and caution, as revealing the child’s status could have unintentional consequences. One caregiver noted, *"You have to be very careful how you say it because once you tell them, you cannot take it back"* (Participant 6). Others echoed this sentiment, explaining that once a child knows their status, there is a possibility that they might accidentally disclose it to others, leading to stigma or discrimination. This concern was particularly strong among caregivers who had personally experienced stigma or who feared that their child might face rejection from peers and the community at large.

The findings also indicate that caregivers' understanding of disclosure is shaped by cultural and social factors. Some caregivers saw disclosure as a necessary step toward ensuring the child’s adherence to antiretroviral therapy (ART), while others associated it with a potential loss of control over sensitive information. A few participants indicated that they struggled with the decision to disclose due to cultural norms that discourage open discussions about illness, particularly HIV. One caregiver remarked, *"In our culture, we don’t always talk about these things with children. We try to protect them for as long as we can"* (Participant 9).

For some caregivers, disclosure was not just about informing the child of their diagnosis but also about preparing them for managing their health. Several participants noted that they had searched for guidance from healthcare workers or other caregivers before beginning with disclosure. A caregiver explained, *"I didn't know how to say it, so I asked the nurse to help me. She gave me some advice on what to say and how to explain it in a way that the child would understand"* (Participant 3).

Overall, caregivers' descriptions of disclosure varied based on their personal experiences, cultural beliefs, and concerns about confidentiality. While some viewed it as a necessary step in the child's healthcare journey, others approached it with apprehension, fearing the potential emotional and social consequences.

4.3.2. Motivations for Disclosure

Caregivers provided a range of reasons for choosing to disclose a child's HIV status, emphasizing the importance of adherence, trust, and ethical responsibility in their decision-making process.

One of the most frequently cited reasons for disclosure was ensuring the child's adherence to antiretroviral therapy (ART). Many caregivers believed that understanding the purpose of medication would encourage the child to take it consistently. As one caregiver explained, *"If the child knows why they are taking medication, they will not forget or refuse to take it"* (Participant 8). Caregivers who prioritized medication adherence viewed disclosure as a useful necessity, distinguishing that an informed child is more likely to cooperate with their treatment regimen. Some caregivers noted that non-disclosure often led to children questioning why they had to take medication daily, which sometimes resulted in resistance or refusal to adhere to their ART routinely.

For other caregivers, disclosure was seen as a way to nurture trust and strengthen the caregiver-child relationship. They believed that silencing such serious health information could disturb or destroy their bond with the child in the future. One caregiver expressed this sentiment by stating, *"The child must hear it from me, not from others, because I want them to trust me"* (Participant 10). These caregivers saw disclosure as an act of honesty and transparency, which could help the child feel supported rather than deceived. Additionally, some participants shared that they disclosed their child's status to prevent the child from accidentally learning the truth from someone else, which they believed could cause emotional harm or feelings of betrayal.

A few caregivers also viewed disclosure as a legal and ethical obligation. They felt that, as children grew older, they had the right to know their health status so they could take ownership of their condition and make informed decisions. One participant stated, *"When they grow up, they must know the truth about their health because it is their right"* (Participant 12). Caregivers who held this perspective stressed that children deserve autonomy over their health and should be given the necessary information to steer life with HIV.

Some caregivers also considered the child's emotional readiness before deciding to disclose, balancing their right to know with concerns about psychological impact. A few mentioned consulting healthcare workers or support groups to ensure that disclosure was handled appropriately. While most caregivers agreed on the necessity of disclosure at some point, their timing and approach differed based on their child's maturity, emotional flexibility, and external influences such as family and community support.

Overall, caregivers disclosed their child's HIV status for a combination of medical, relational, and ethical reasons, aiming to nurture adherence, build trust, and support the child’s right to health information. However, their decisions were also shaped by personal experiences, cultural beliefs, and broader societal attitudes toward HIV.

- **To identify and describe barriers that caregivers face in disclosing HIV status to children receiving ART at Donkerhoek clinic, Windhoek, Khomas Region.**

4.3.1. Challenges Faced in HIV Disclosure

Caregivers reported multiple challenges in the process of disclosing a child’s HIV status, with emotional distress, stigma, uncertainty about timing, and lack of support emerging as major barriers.

One of the most frequently mentioned challenges was the fear of emotional suffering. Many caregivers worried about how their child would react to learning their HIV status, fearing that it could lead to feelings of betrayal, sadness, or confusion. As one caregiver expressed, *"I fear that my child will not understand and will feel like I betrayed them"* (Participant 14). Some caregivers were particularly concerned that disclosure could cause their child to feel hopeless, leading to withdrawal, depression, or even anger toward the caregiver. This emotional burden made disclosure a discouraging process, with many caregivers postponing it to avoid worrying about their children.

Stigma and discrimination were also key barriers to disclosure. Many caregivers feared that once a child knew their status, they might reveal it to others by mistake, exposing them to social rejection and discrimination. One participant shared, *"I worry that society will treat these children differently from others and discriminate against them"* (Participant 16). The wider societal stigma surrounding HIV meant that caregivers often held back from disclosing for fear that their child would be detested or bullied at school, in the community, or even within their extended family. Some caregivers noted that they had personally experienced stigma and did not want their child to withstand similar treatment.

Another common challenge was uncertainty about the suitable age for disclosure. Caregivers struggled to determine the right time to inform their child about their HIV status, with some fearing that early disclosure might be overwhelming while delayed disclosure could lead to mistrust. One caregiver admitted, *"I do not know if my child is old enough to understand, or if I should wait longer"* (Participant 17). This uncertainty often led to caregivers delaying disclosure until further notice, hoping that a more appropriate time would present itself in the future. However, many also acknowledged that waiting too long could make disclosure more difficult as children might already suspect something was being hidden from them.

The lack of guidance and support was another major challenge. Many caregivers felt unprepared for the disclosure process and expressed difficulty in finding the right words to explain HIV in a way that their child could understand. One caregiver explained, *"I do not know the right words to use, and I feel like I am doing it alone"* (Participant 19). Several caregivers noted that healthcare workers provided little to no assistance in guiding them through the disclosure process, leaving them to deal with it independently. Some caregivers wished for structured support systems, such as counseling services, workshops, or peer support groups, to help them with disclosure.

Overall, caregivers faced significant emotional, social, and logistical obstacles in disclosing a child's HIV status. Their fears of emotional distress, stigma, uncertainty about timing, and lack of professional guidance highlighted the complexity of the disclosure process and highlighted the need for structured support to help caregivers manage this challenging responsibility.

- **To identify and describe factors that could facilitate improved disclosure practices within the Healthcare settings**

3.3.4 Strategies Used for Disclosure

Caregivers made use of various strategies to steer the simple and often sensitive process of disclosing a child's HIV status. Their approaches were molded by concerns about emotional impact, understanding, and maintaining trust, leading many to adopt gradual, supportive, and medically guided disclosure techniques.

One of the most commonly reported strategies was gradual disclosure, where caregivers introduced HIV-related discussions over time rather than revealing the full diagnosis in one go. This approach allowed children to process information in a manageable way, reducing the risk of overwhelming them. One caregiver described their method: "*I started by telling my child that they have a condition that requires medicine, and later, I will explain more*" (Participant 21). By first introducing the concept of a chronic health condition and gradually adding details about HIV, this way caregivers aimed to build understanding and acceptance over time.

Another important strategy caregivers engaged in was seeking professional guidance from healthcare providers. Recognizing their limitations in explaining HIV in an age-appropriate and reassuring manner, some caregivers opted to involve trained medical professionals in the disclosure process. One caregiver noted, *"I asked the nurse to explain it to my child because I was afraid I would not do it properly"* (Participant 23). Healthcare professionals were seen as reliable sources of information who could provide medically accurate explanations and emotional support, making the disclosure process less intimidating for caregivers and children.

Additionally, some caregivers used comparative framing, comparing HIV to other manageable chronic illnesses to reduce fear and normalize the condition. One participant explained, *"I told my child that it is just like diabetes or asthma—you take your medicine and you stay healthy"* (Participant 25). By comparing HIV to conditions that are widely accepted and understood, caregivers aimed to minimize stigma and reassure children that they could live a normal, healthy life as long as they adhered to treatment.

These strategies highlight caregivers' efforts to make the disclosure process as supportive and constructive as possible. Whether through phased communication, seeking professional assistance, or reframing the illness as a manageable condition, caregivers aimed to ensure that children received information in a way that promoted acceptance, trust, and adherence to treatment.

4.3.2. Emotional and Psychological Impact on Caregivers

The process of disclosing a child’s HIV status was emotionally challenging for many caregivers, suggesting a range of psychological responses that accentuated the complexity of their role in the disclosure journey. Feelings of anxiety and fear were commonly reported, particularly in anticipation of the disclosure conversation. Many caregivers struggled with uncertainty about how the child would react, whether they would understand, and how the relationship might change. One caregiver shared, *"I could not sleep the night before telling my child because I was so nervous"* (Participant 27). This intensified anxiety reflects the emotional burden caregivers carry as they navigate disclosure, many at times without clear guidance or support.

Guilt and self-blame emerged as another dominant theme, especially among biological parents who had transmitted HIV to their children at birth. These caregivers expressed strong feelings of responsibility, struggling with the emotional burden of having to explain a condition they felt personally accountable for. One caregiver stated, *"I feel like I am the one who gave this to my child, so how can I tell them without feeling guilty?"* (Participant 29). This internal conflict often hindered disclosure, as caregivers hesitated to initiate conversations that would force them to confront their own emotions.

However, despite the distress and hesitation, some caregivers reported experiencing a sense of relief after disclosure. For these caregivers, finally having an open discussion about the child's HIV status lifted a significant emotional burden. One participant explained, *"I feel lighter now that my child knows the truth, and we can talk openly about their treatment"* (Participant 31). This feeling highlights the potential benefits of disclosure, where open communication nurtures trust, strengthens the caregiver-child relationship, and allows for better management of the child's health, particularly HIV.

Overall, caregivers' emotional responses reflected the high stakes of HIV disclosure, where fear, guilt, and uncertainty co-occurred with relief and strengthened relationships. Their experiences emphasize the need for psychological support and structured guidance to help them manage their own emotions while ensuring the well-being of the children in their care.

4.3.3. Support Systems and Resources

Caregivers identified various support systems that played a crucial role in helping them navigate the emotionally complex process of disclosing a child’s HIV status. Among the most frequently mentioned sources of support were healthcare providers, including doctors, nurses, and social workers. Many caregivers uttered appreciation for the assistance of medical professionals, who not only provided medical care but also guided them on how to approach disclosure sensitively. One caregiver shared, *"The doctor helped me find the right words to use, and that made it easier"* (Participant 33). These professionals helped build caregivers' confidence, ensuring that disclosure was handled in a way that minimized distress for both the child and the caregiver.

Peer support groups also emerged as a crucial resource, offering emotional and practical support from others who had gone through similar experiences. Caregivers found relief in sharing their struggles and learning from others who had already dealt with the disclosure process. One caregiver stated, *"Talking to other caregivers who have been through the same thing helped me feel less alone"* (Participant 35). These groups provided a safe space for caregivers to express their concerns, ask questions, and receive reassurance, reinforcing the importance of community-based interventions in pediatric HIV care.

In addition to medical and peer support, religious and community organizations were also mentioned as valued sources of encouragement. Some caregivers turned to faith-based communities for emotional strength and guidance, particularly in overcoming fears associated with disclosure. One participant explained, *"My church helped me pray and gave me strength to tell my child"* (Participant 37). These institutions provided moral support, a sense of belonging, and a spiritual foundation that helped caregivers cope with the emotional burden of disclosure.

The presence of multiple support systems, such as healthcare professionals, peer networks, and religious communities, helped caregivers feel more empowered in their disclosure journey. However, access to these resources varied, highlighting the need for more structured and widely available support programs to assist caregivers through this critical process.

4.4. Chapter Summary

This chapter presented the study's findings, focusing on caregiver demographics and thematic insights into HIV disclosure. Most caregivers were women aged 31-40 years with at least a high school education. The analysis highlighted caregivers’ understanding of disclosure, motivations, challenges, strategies, emotional impact, and support systems. Key concerns included fear of emotional distress, stigma, and uncertainty about timing, while strategies like gradual disclosure and professional guidance were commonly used. These findings set the stage for the next chapter, which discusses their implications for existing literature.

CHAPTER 5: DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

5.1 Introduction

This chapter provides a comprehensive discussion and interpretation of the findings presented in Chapter 4, examining them within the context of existing literature on HIV disclosure to children. The discussion is structured around the three main research objectives: exploring caregivers' perceptions of HIV status disclosure, identifying barriers to disclosure, and examining factors that could facilitate improved disclosure practices. The findings reveal complex dynamics surrounding HIV disclosure decisions, highlighting the multifaceted nature of this critical healthcare communication process.

The study's findings contribute to the growing body of literature on paediatric HIV disclosure, particularly within the African context, where cultural, social, and healthcare system factors create unique challenges and opportunities for effective disclosure practices. This discussion synthesizes the study's key themes with established theoretical frameworks and empirical evidence to provide insights that can inform policy and practice improvements. The chapter also presents the conclusions and recommendations.

5.2 Caregivers' Perceptions of HIV Status Disclosure

5.2.1 Understanding of Disclosure as a Process

The findings reveal that caregivers conceptualize HIV disclosure not as a single event but as an ongoing process that unfolds over time. This perception aligns with established literature suggesting that effective disclosure should be viewed as a developmental process rather than a one-time revelation (Hogwood et al., 2021; Luo et al., 2022). The caregivers' understanding that disclosure "happens over time as the child grows" reflects contemporary best practices that advocate for age-appropriate, phased disclosure approaches.

This process-oriented understanding demonstrates caregivers' intuitive recognition of developmental considerations in disclosure timing. Research by Kawuma et al. (2014) supports this approach, emphasizing that children's cognitive and emotional capacity to understand HIV-related information develops gradually. The caregivers' recognition that disclosure requires careful preparation and timing suggests an inherent understanding of child development principles, even without formal training.

However, the variation in caregivers' understanding of what constitutes appropriate disclosure highlights the need for standardized guidance. While some caregivers viewed disclosure as simply "revealing secret information," others recognized the complexity of ensuring children understand both the medical and social implications of their diagnosis. This disparity suggests that healthcare systems need to provide clearer frameworks for disclosure education.

5.2.2 Cultural and Contextual Influences on Perception

The study revealed significant cultural influences on caregivers' perceptions of disclosure, with some participants noting that "in our culture, we don't always talk about these things with children." This finding resonates with African cultural contexts where illness discussions, particularly regarding stigmatized conditions like HIV, are often avoided with children (Paintsil et al., 2015; Vreeman et al., 2014).

The tension between cultural protective practices and medical recommendations creates a complex decision-making environment for caregivers. Traditional African child-rearing practices often emphasize protecting children from adult concerns and burdens, which can conflict with HIV disclosure recommendations (Kidia et al., 2014). This cultural consideration is crucial for healthcare providers working in African contexts, as it affects not only disclosure timing but also the methods and language used in disclosure conversations.

The findings suggest that caregivers are navigating between traditional cultural values and modern medical recommendations, creating internal conflicts about appropriate disclosure practices. This navigation process requires culturally sensitive support from healthcare systems to help caregivers reconcile these competing perspectives while prioritizing children's best interests.

5.2.3 Confidentiality Concerns and Trust

Caregivers' emphasis on confidentiality concerns reveals a sophisticated understanding of the social risks associated with HIV disclosure. The recognition that *"once you tell them, you cannot take it back"* demonstrates awareness of the permanence of disclosure decisions and their potential consequences. This concern aligns with literature highlighting the irreversible nature of disclosure and the need for careful consideration before proceeding (Toska et al., 2015).

The fear that children might "accidentally disclose it to others" reflects legitimate concerns about secondary disclosure and its potential consequences. Research by Ngeno et al. (2019) supports these concerns, noting that children's developmental stage affects their ability to maintain confidentiality about sensitive health information. This finding underscores the importance of including confidentiality education as part of the disclosure process, teaching children when and with whom it is appropriate to share their health information.

5.3 Barriers to HIV Status Disclosure

5.3.1 Emotional and Psychological Barriers

The study identified significant emotional barriers to disclosure, with caregivers expressing fears about causing emotional distress to children. The concern that children might *"feel like I betrayed them"* reflects the complex emotional dynamics inherent in delayed disclosure decisions. This finding aligns with research by Greyling and Marais (2020), who identified caregiver emotional distress as a primary barrier to paediatric HIV disclosure.

The fear of causing psychological harm represents a protective instinct but may paradoxically increase risks for children who remain unaware of their diagnosis. Literature suggests that children who discover their HIV status inadvertently often experience greater emotional trauma than those who receive planned, supportive disclosure (Rochat et al., 2015). The caregivers' protective intentions, while well-meaning, may inadvertently delay necessary disclosure conversations.

Guilt and self-blame, particularly among biological parents who transmitted HIV perinatally, emerged as significant emotional barriers. The statement "I feel like I am the one who gave this to my child" illustrates the complex intersection of parental guilt and disclosure anxiety. Research by Ssali et al. (2019) identifies maternal guilt as a significant factor influencing disclosure decisions, often leading to delays that may compromise children's health outcomes.

5.3.2 Stigma and Discrimination Concerns

The pervasive fear of stigma and discrimination represents one of the most significant barriers to disclosure identified in this study. Caregivers' concerns that "*society will treat these children differently"* reflect the continued presence of HIV-related stigma in many communities. This finding is consistent with extensive literature documenting stigma as a primary barrier to HIV disclosure across diverse contexts (Kimera et al., 2019; Casale et al., 2019).

The anticipation of discrimination extends beyond individual attitudes to institutional settings, with caregivers fearing that children might face bullying or exclusion at school or in community activities. Research by Zhao et al. (2016) supports these concerns, documenting instances of discrimination against HIV-positive children in educational settings. This fear creates a protective motivation among caregivers that can override medical recommendations for disclosure.

The intergenerational aspect of stigma is particularly notable, with caregivers who had personally experienced discrimination being especially reluctant to risk exposing their children to similar treatment. This suggests that stigma reduction efforts must address both individual and community-level attitudes to create environments where disclosure can occur safely.

5.3.3 Systemic and Support-Related Barriers

The lack of professional guidance emerged as a critical barrier, with caregivers expressing that they "*feel like I am doing it alone*." This finding highlights significant gaps in the healthcare system's support for disclosure processes. Research by Biadgilign et al. (2016) emphasizes the importance of healthcare provider training and support systems for effective paediatric HIV disclosure.

The absence of structured support programs, such as counseling services or peer support groups, leaves caregivers without essential resources for navigating disclosure challenges. International best practices recommend multidisciplinary support teams including social workers, psychologists, and trained counselors to assist with disclosure processes (World Health Organization, 2018). The current study's findings suggest that such resources are insufficient or inaccessible in the study setting.

Uncertainty about appropriate timing represents another systemic barrier, with caregivers struggling to determine when children are developmentally ready for disclosure. The lack of clear guidelines or assessment tools for evaluating disclosure readiness leaves caregivers making crucial decisions without adequate support. Research by Vreeman et al. (2014) emphasizes the need for systematic approaches to disclosure timing based on developmental milestones rather than arbitrary age cutoffs.

5.4 Factors Facilitating Improved Disclosure Practices

5.4.1 Gradual and phased disclosure approaches

The study identified gradual disclosure as a commonly employed and effective strategy, with caregivers recognizing the benefits of introducing HIV-related information progressively. This approach aligns with developmental theories of child psychology and established best practices in paediatric HIV care (Gachanja & Burkholder, 2016; Luo et al., 2022). The strategy of initially explaining that the child "has a condition that requires medicine" before providing full diagnostic information demonstrates a sophisticated understanding of developmental readiness.

Phased disclosure allows children to process information at their own pace while building trust and understanding over time. Research by Damoyi et al. (2019) supports this approach, showing improved psychological adjustment among children who receive gradual rather than sudden disclosure. The caregivers' intuitive adoption of this strategy suggests that with proper support and guidance, many caregivers can implement effective disclosure practices.

The success of gradual approaches also suggests the importance of preparing caregivers with specific language and strategies for each phase of disclosure. Healthcare systems could develop structured protocols outlining age-appropriate information and communication strategies for different developmental stages.

5.4.2 Professional healthcare support

The involvement of healthcare professionals in disclosure processes emerged as a crucial facilitating factor. Caregivers who sought professional guidance reported feeling more confident and better prepared for disclosure conversations. The statement that "the doctor helped me find the right words to use" illustrates the importance of professional expertise in disclosure communication.

Healthcare providers offer several advantages in disclosure processes, including medical expertise, communication skills training, and emotional neutrality that can reduce caregiver anxiety. Research by Fetzer et al. (2015) demonstrates that healthcare provider involvement in disclosure conversations improves both process quality and outcomes for children and families.

However, the findings also suggest that not all caregivers have access to adequate professional support, highlighting the need for healthcare system improvements. Training programs for healthcare providers on paediatric HIV disclosure, development of disclosure protocols, and integration of mental health professionals into HIV care teams could significantly improve support availability.

5.4.3 Normalisation and comparative framing

The strategy of comparing HIV to other manageable chronic conditions represents an innovative approach to reducing stigma and fear associated with diagnosis. Caregivers who explained that HIV "is just like diabetes or asthma" demonstrated effective communication techniques that normalize the condition while emphasizing treatability.

This comparative framing approach has theoretical support in health communication literature, which emphasizes the importance of familiar reference points in helping patients understand new health information (Xu et al., 2017). By comparing HIV to widely accepted chronic conditions, caregivers can reduce the perceived threat and stigma associated with the diagnosis.

The effectiveness of this approach suggests that healthcare systems could develop standardized comparison frameworks and communication tools to help caregivers implement similar strategies. Educational materials that highlight similarities between HIV and other chronic conditions could support this approach.

5.4.4 Peer Support and Community Networks

The value of peer support groups emerged as a significant facilitating factor, with caregivers finding comfort and practical guidance from others with similar experiences. The statement that "talking to other caregivers who have been through the same thing helped me feel less alone" illustrates the importance of experiential knowledge and emotional support.

Peer support provides several unique benefits, including practical advice based on lived experience, emotional validation, and reduced isolation. Research by Mupambireyi et al. (2014) demonstrates that peer support interventions can significantly improve outcomes for families affected by paediatric HIV. The shared experience creates a foundation for trust and understanding that professional support alone may not achieve.

The findings suggest that structured peer support programs could significantly enhance disclosure support systems. Healthcare facilities could facilitate support groups, train peer mentors, and create networks that connect families at different stages of the disclosure process.

5.4.5 Spiritual and Community Resources

The role of religious and community organizations in supporting disclosure processes represents an important but often overlooked resource. Caregivers who turned to faith-based communities for "strength to tell my child" demonstrate the importance of spiritual support in managing disclosure anxiety.

Religious organizations can provide several forms of support, including emotional comfort, moral guidance, and community acceptance that reduces stigma concerns. Research by Nel et al. (2021) shows that spiritual coping mechanisms can significantly improve psychological adjustment to chronic illness in both adults and children.

The integration of spiritual and community resources into disclosure support systems could enhance their effectiveness, particularly in contexts where religious faith plays a central role in family life. Healthcare systems could develop partnerships with religious organizations to provide holistic support for families navigating HIV disclosure.

5.5 Implications for Healthcare Practice

5.5.1 Need for Structured Disclosure Protocols

The findings highlight the urgent need for standardized disclosure protocols that provide clear guidance for healthcare providers and caregivers. Such protocols should include developmental guidelines, communication strategies, timing recommendations, and support resources. The World Health Organization (2018) recommends systematic approaches to paediatric HIV disclosure, but implementation remains inconsistent across healthcare settings.

Effective protocols should address cultural considerations, provide flexibility for individual circumstances, and include ongoing support mechanisms. Training programs for healthcare providers should emphasize disclosure communication skills, cultural sensitivity, and emotional support techniques.

5.5.2 Integration of Mental Health Support

The emotional impact of disclosure on both caregivers and children necessitates the integration of mental health professionals into HIV care teams. Counselors, social workers, and psychologists can provide specialized support that medical providers may not be equipped to offer. This multidisciplinary approach aligns with best practices in paediatric HIV care (Vale et al., 2018).

5.5.3 Community Stigma Reduction Efforts

The pervasive fear of stigma requires community-level interventions to change attitudes and reduce discrimination. Public education campaigns, school-based programs, and community leader engagement can help create more supportive environments for HIV-positive children and their families.

5.6 Study Limitations

While this study provides valuable insights into HIV disclosure dynamics, several limitations should be acknowledged. The study was conducted at a single clinic, which may limit the generalizability of findings to other healthcare settings or regions. The sample size, while appropriate for qualitative research, may not capture the full diversity of caregiver experiences and perspectives.

Additionally, the study focused exclusively on caregiver perspectives without including children's voices or healthcare provider viewpoints. Future research should employ multi-perspective approaches to provide more comprehensive understanding of disclosure processes.

5.7 Study summary

This discussion reveals the complex nature of HIV disclosure decisions among caregivers, highlighting significant barriers including emotional distress, stigma concerns, and lack of professional support, while identifying effective strategies such as gradual disclosure, professional guidance, and peer support. The findings emphasize the need for comprehensive support systems that address both individual and systemic factors influencing disclosure practices.

The study contributes to understanding HIV disclosure dynamics within African healthcare contexts and provides evidence for developing improved support interventions. The next chapter will present conclusions and recommendations based on these findings and their implications for healthcare practice and policy.

5.1. Conclusion

This study provides valued insights into the difficulties and challenges surrounding HIV status disclosure to children among caregivers in Namibia. The findings reaffirm that disclosure is not a single event but rather a dynamic and multilayered process influenced by emotional, social, cultural, and structural factors. Stigma, emotional readiness, lack of professional guidance, and concerns about the child's ability to cope emerged as significant barriers to disclosure. Many caregivers expressed anxiety and fear, citing concerns about emotional distress, social discrimination, and uncertainty regarding the appropriate timing for disclosure. However, despite these challenges, some caregivers recognized the necessity and benefits of disclosure, particularly in nurturing trust, empowering children to manage their health, and improving adherence to ART.

The significance of this study lies in its contribution to understanding the difficulties caregivers encounter and the strategies they adopt when disclosing a child's HIV status. By identifying key obstacles such as stigma, lack of structured guidance, and emotional burden, this research highlights the urgent need for structured and well-integrated disclosure support programs. The findings suggest that healthcare professionals, peer support networks, and culturally sensitive community interventions play a vital role in facilitating disclosure in a manner that is both supportive and empowering for caregivers and children. Integrating disclosure counseling into routine pediatric HIV care can provide caregivers with the necessary knowledge, skills, and emotional support to navigate this sensitive process with confidence.

However, this study is not without limitations. The reliance on self-reported experiences introduces the possibility of social desirability bias, where participants may have presented their experiences in a way that aligns with perceived social expectations rather than actual practices. Additionally, the geographical scope of the study was limited to a single region, which may restrict the generalizability of the findings to other parts of Namibia or beyond. Furthermore, children's perspectives were not included, limiting the study's ability to capture the full range of experiences and emotional responses to disclosure. Future research should incorporate children's voices, allowing for a more holistic understanding of the emotional, psychological, and behavioral outcomes of disclosure.

Future research should also focus on evaluating the long-term effects of HIV disclosure on children's mental health, social integration, and adherence to ART. Investigating structured interventions that support caregivers throughout the disclosure process is essential, particularly in determining which approaches are most effective in mitigating stigma-related fears and enhancing caregiver confidence. Additionally, studies should explore healthcare providers' roles in assisting caregivers with disclosure, emphasizing the importance of specialized training in equipping professionals with the skills necessary to guide caregivers through this process sensitively and effectively. Expanding research in these areas will contribute to the development of evidence-based policies and interventions that support both caregivers and children, ensuring disclosure is approached in a manner that prioritizes psychological well-being.

Overall, this study highlights the critical need for culturally sensitive, structured, and well-supported disclosure strategies that address caregivers’ concerns while ensuring children receive the information necessary to manage their health and well-being. Strengthening community and healthcare support systems will be instrumental in improving disclosure experiences, reducing stigma, and promoting better health outcomes for children living with HIV. Moving forward, collaborative efforts among caregivers, healthcare providers, policymakers, and community organizations will be vital in ensuring disclosure practices evolve in a manner that prioritizes the best interests of HIV-positive children while empowering caregivers with the tools they need to navigate this challenging but necessary process.

5.3.1 RECOMMENDATIONS

Based on the findings of this study, it is evident that structured interventions, community support, and professional guidance are critical to improving HIV disclosure practices among caregivers in Namibia. The following specific and actionable recommendations are aligned with the study’s findings, ensuring that barriers to disclosure are effectively addressed while supporting both caregivers and children throughout the disclosure process.

5.3.1. Strengthening Structured HIV Disclosure Programs

The study revealed that many caregivers lack structured guidance on how to disclose a child’s HIV status, leading to delayed disclosure or uncertainty about the best approach.

To address this, the Ministry of Health and Social Services (MoHSS) should integrate HIV disclosure counseling into routine pediatric HIV care. This includes:

- Providing age-appropriate disclosure materials, such as storybooks, animated videos, and illustrated caregiver guides, which simplify HIV information for children in a developmentally appropriate manner.
- Expanding training programs for healthcare workers, including nurses, social workers, and community health workers, to ensure they have the skills to guide caregivers through the disclosure process.
- Establishing structured disclosure frameworks that outline step-by-step approaches caregivers can follow, reducing fear and uncertainty surrounding disclosure.

These measures if implemented. Ensures that caregivers will receive consistent and structured support, increasing their confidence and willingness to disclose in a manner that prioritizes the child’s well-being.

5.3.2. Addressing Stigma and Social Barriers through Community Awareness

Stigma emerged as a significant barrier to disclosure, with caregivers fearing social rejection, discrimination, and emotional distress for their children. To battle stigma and create a more supportive disclosure environment, the following actions should be taken:

- Community-based awareness campaigns should be implemented to challenge misconceptions surrounding HIV and promote positive HIV narratives. These campaigns should include radio programs, social media campaigns, and community dialogue sessions to ensure broad reach and engagement.

- Faith-based and traditional leaders should be actively engaged to normalize discussions around HIV within communities. Many caregivers hesitate to disclose due to cultural and religious beliefs, making it crucial to involve trusted community figures in promoting accurate HIV knowledge.
- School-based education programs should be integrated into life skills curricula, ensuring that children grow up in an environment where HIV is openly discussed, reducing bullying and discrimination against HIV-positive children.

Reducing stigma and promoting inclusivity, can make caregivers feel less fearful about disclosure, and children will experience greater social acceptance, improving their mental well-being and treatment adherence.

5.3.3. Enhancing Caregiver Support Networks

The study found that many caregivers feel isolated and emotionally burdened by the responsibility of disclosure, highlighting the need for stronger caregiver support systems. To improve caregiver resilience and readiness for disclosure, the following actions are recommended:

- Expand peer support groups where caregivers can share experiences, receive guidance, and learn best practices from others who have successfully navigated the disclosure process.
- Increase access to mental health counseling for caregivers, ensuring that those struggling with guilt, fear, or emotional distress receive professional psychological support.

- Extend disclosure training workshops to rural areas, where healthcare resources and support services are often limited. These workshops should equip caregivers with practical skills and culturally relevant disclosure strategies tailored to their specific contexts.

By empowering caregivers through social and psychological support, they will feel less alone in the disclosure process and be better prepared to navigate disclosure challenges effectively.

5.3.3. Tailoring Disclosure Approaches to Children's Developmental Stages

One of the study's key findings was that caregivers struggle with knowing when and how to disclose, with many delaying disclosures due to uncertainty about the child's ability to understand and cope. To ensure that disclosure is done in a way that minimizes emotional distress, the following recommendations should be adopted:

- Implement a phased disclosure approach, where basic health-related concepts are introduced early in childhood, gradually building up to full disclosure as the child matures. This ensures that children process information over time, making it less overwhelming.
- Train caregivers on age-appropriate language to ensure that they explain HIV in ways that children can understand, reducing fear and confusion.
- Develop culturally sensitive disclosure frameworks that consider Namibia's diverse social and family structures, ensuring that disclosure methods are adaptable to different cultural beliefs and traditions.

Customizing disclosure approaches to suit the child's cognitive and emotional development will equip children to be able to better understand and manage their HIV status, reducing psychological distress and improving ART adherence.

5.3.4. Strengthening the Role of Healthcare Providers in Disclosure Support

The study found that caregivers who received guidance from healthcare providers felt more confident in disclosing their child's HIV status. However, many caregivers lacked access to professional disclosure support, particularly in under-resourced settings. To ensure that healthcare workers effectively support disclosure, the following measures should be implemented:

- Standardize disclosure protocols in all pediatric HIV care facilities, ensuring that every healthcare provider follows a clear, evidence-based approach to supporting caregivers through disclosure.
- Provide continuous training for healthcare workers, equipping them with specialized skills in disclosure counseling, including how to support caregivers dealing with emotional distress and stigma-related fears.
- Integrate disclosure discussions into routine pediatric HIV care, ensuring that every healthcare visit provides caregivers with an opportunity to receive guidance on disclosure.

By strengthening the role of healthcare providers, caregivers will have more consistent access to professional guidance, leading to improved disclosure outcomes and better psychosocial support for children.

5.3.5. Policy and Research Integration

To sustain improvements in pediatric HIV disclosure, the study recommends that policymakers and researchers work collaboratively to:

- Evaluate the effectiveness of disclosure interventions and adapt them based on real-world caregiver experiences.
- Develop national disclosure guidelines that offer clear, step-by-step recommendations tailored to Namibia's healthcare infrastructure and socio-cultural landscape.
- Promote longitudinal research on the long-term psychosocial effects of disclosure, ensuring that policies are informed by evidence-based insights into children's mental health, ART adherence, and social integration post-disclosure.

Namibia can strengthen HIV disclosure practices by bridging policy, research, and practical interventions, ensuring that both caregivers and children receive the necessary support to navigate disclosure confidently and effectively.

These recommendations, if implemented adequately, will improve the disclosure experience for caregivers, improve health outcomes for children, and foster a more accepting and supportive society for those living with HIV.

REFERENCES

Abebe, W., & Teferra, S. (2012). Disclosure of diagnosis by parents and caregivers to children infected with HIV: Prevalence, associated factors, and perceived barriers in Addis Ababa, Ethiopia. *AIDS Care*, *24*(9), 1097-1102. https://doi.org/10.1080/09540121.2012.656565

Ashaba, S., Cooper-Vince, C., Vořechovská, D., Maling, S., Rukundo, G. Z., Akena, D., ... & Tsai, A. C. (2019). Development and validation of a culturally adapted depression screening instrument in rural Uganda: Comparison of locally-derived versus Western-derived factor structures. *PLoS One*, *14*(4), e0214840.

Beauchamp, T. L. (2008). The Belmont report. In *The Oxford textbook of clinical research ethics* (pp. 149-155). Oxford University Press.

Beima-Sofie, K. M., Brandt, L., Hamunime, N., Shepard, M., Uusiku, J., John-Stewart, G. C., & O'Malley, G. (2017). Pediatric HIV disclosure intervention improves knowledge and clinical outcomes in HIV-infected children in Namibia. *Journal of Acquired Immune Deficiency Syndromes*, *75*(1), 18-26. https://doi.org/10.1097/QAI.0000000000001290

Biadgilign, S., Deribew, A., Amberbir, A., & Deribe, K. (2016). Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: A qualitative study. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *13*(1), 148-154.

Brandt, L., Beima-Sofie, K., Hamunime, N., Shepard, M., Ferris, L., Ingo, P., & O'Malley, G. (2015). Growing up just like everyone else: Key components of a successful pediatric

HIV disclosure intervention in Namibia. *AIDS*, *29*(S1), S81-S89. https://doi.org/10.1097/QAD.0000000000000667

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Brittain, K., Mellins, C. A., Remien, R. H., Phillips, T., Zerbe, A., Abrams, E. J., ... & Myer, L. (2019). Patterns and predictors of HIV status disclosure among pregnant women in South Africa. *AIDS Care*, *31*(10), 1264-1272.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Casale, M., Boyes, M., Pantelic, M., Toska, E., & Cluver, L. (2019). Suicidal thoughts and behaviour among South African adolescents living with HIV: Can social support buffer the impact of stigma? *Journal of Affective Disorders*, *245*, 82-90.

Centers for Disease Control and Prevention. (2020). Applying the Social Ecological Model to Explore HIV-Related Stigma in Florida. https://pmc.ncbi.nlm.nih.gov/articles/PMC11936510/

Centeno, K. (2022). What is a literature review? *ODU Libraries*. https://guides.lib.odu/literaturereview

Cluver, L. D., Meinck, F., Toska, E., Orkin, F. M., Hodes, R., Sherr, L., & Yakubovich, A. R. (2018). Multitype violence exposures and adolescent antiretroviral nonadherence in South Africa. *AIDS*, *32*(8), 975-983.

Coetzee, B., Kagee, A., & Vermeulen, N. (2014). Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: The perspectives of health care providers. *AIDS Care*, *26*(2), 146-154.

Collings, S. J., Penning, S. L., Msimango, A., & Kuo, C. (2018). The intersection of trauma, mental health symptoms, and HIV risk among young men who have sex with men in South Africa. *Traumatology*, *24*(3), 189-198.

Creswell, J. W. (2014). *Research design* (4th ed.). SAGE Publications Ltd.

Damoyi, N., Mwaba, K., & Boulton, L. (2019). Predictors of medication adherence among children and adolescents living with HIV/AIDS in sub-Saharan Africa: A systematic review. *International Journal of Environmental Research and Public Health*, *16*(18), 3477.

Delve. (n.d.). What is Phenomenological Research Design? *Delve*. https://delvetool.com/blog/phenomenology

Dlamini, P. S., Makoae, L. N., Chirwa, M., Kohi, T. W., Greeff, M., Naidoo, J., ... & Uys, L. R. (2017). HIV stigma and missed medications in HIV-positive people in five African countries. *AIDS Patient Care and STDs*, *21*(7), 479-487.

Doat, A. R., Negarandeh, A. R., & Hasanpour, M. (2019). Disclosure of HIV status to children in Sub-Saharan Africa: A systematic review. https://dx.doi.org

Fentie, S., & Gedlu, E. (2021). Practices, perspectives, and barriers of HIV disclosure to children and adolescents by health care providers in Addis Ababa health facilities, Ethiopia. *Ethiopian Journal of Pediatrics and Child Health*, (1). https://ejpch.net/index.php/ejpch/article/view/82

Fetzer, B. C., Mupenda, B., Lusiama, J., Kitetele, F., Golin, C., & Behets, F. (2015). Barriers to and facilitators of adherence to pediatric antiretroviral therapy in a sub-Saharan setting: Insights from a qualitative study. *AIDS Patient Care and STDs*, *25*(10), 611-621.

Frambach, J. M., van der Vleuten, C. P. M., & Durning, S. J. (2013). Quality criteria in qualitative and quantitative research. *Academic Medicine*, *88*(4).

Gachanja, G., & Burkholder, G. J. (2016). A model for HIV disclosure of a parent's and/or a child's illness. *PeerJ*, *4*, e1662.

Greyling, M., & Marais, D. L. (2020). Disclosure experiences of mothers living with HIV in South Africa: A systematic review and meta-synthesis of qualitative evidence. *Journal of the Association of Nurses in AIDS Care*, *31*(6), 692-710.

Gyamfi, E., Okyere, P., Enoch, A., & Appiah-Brempong, E. (2017). Prevalence of, and barriers to, the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC International Health and Human Rights*, *17*, 1-8. https://doi.org/10.1186/s12914-017-0114-6

Heeren, G. A., Jemmott, J. B., III, Sidloyi, L., & Ngwane, Z. (2012). Disclosure of HIV diagnosis to HIV-infected children in South Africa: Focus groups for intervention development. *Vulnerable Children and Youth Studies*, *7*(1), 47-54. https://pubmed.ncbi.nlm.nih.gov/22468145/

Hogwood, J., Campbell, T., & Butler, S. (2013). I wish I could tell you but I can't: Adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clinical Child Psychology and Psychiatry*, *18*(1), 44-60. https://doi.org/10.1177/1359104511433195

Hogwood, J., Campbell-Yeo, M., Ementil, B., Mitchell, A., Sherry, M., & Bishop, A. (2021). Paediatric HIV disclosure: A systematic review of quantitative and qualitative studies. *Journal of Advanced Nursing*, *77*(3), 1138-1158.

Jaspan, H. B., Li, D., Boulle, A., Bacon, M. C., Johnson, L. F., Carrara, H., ... & Van der Linde, S. (2018). Two-year outcomes of children receiving antiretroviral treatment enrolled in the IeDEA Southern Africa Collaboration. *PLoS One*, *13*(2), e0193133.

Kairania, R., Onyango-Ouma, W., & Ondicho, T. G. (2023). Socio-cultural influencers of disclosure of HIV status to children on antiretroviral therapy in the Masaka region, Uganda: A qualitative study. *Journal of the International Association of Providers of AIDS Care*, *22*, 23259582231163695. https://journals.sagepub.com/doi/10.1177/23259582231163695

Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS and Behavior*, *15*(7), 1392-1398.

Kawuma, R., Bernays, S., Siu, G., Rhodes, T., & Seeley, J. (2014). 'Children will always be children': Exploring perceptions and experiences of HIV testing and disclosure among children and young people living with HIV in Uganda. *PLoS One*, *9*(8), e105115.

Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives. *PLoS One*, *9*(1), e87322.

Kimera, E., Vindevogel, S., Reynaert, D., Justice, K. M., Rubaihayo, J., De Maeyer, J., ... & Engelbrecht, M. (2019). Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: A photovoice study. *PLoS One*, *14*(2), e0210626.

Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to disclosure to children with HIV. *Journal of Tropical Pediatrics*, *51*(5), 285-287. https://doi.org/10.1093/tropej/fmi014

Lorenz, R., Grant, E., Muyindike, W., Maling, S., Card, C., Henry, C., et al. (2016). Caregivers' attitudes towards HIV testing and disclosure of HIV status to at-risk children in rural Uganda. *PLoS ONE*, *11*(2). https://www.0148950.pmid:26881773

Lowenthal, E. D., Jibril, H. B., & Sechele, M. L. (2014). Disclosure of HIV status to HIV-infected children in a large African treatment center: Lessons learned in Botswana.

Lowenthal, E. D., Jibril, H. B., Sechele, M. L., Mathuba, K., Tshume, O., & Anabwani, G. (2016). Disclosure of HIV status to HIV-infected children in a large African treatment center: Lessons learned in Botswana. *Children and Youth Services Review*, *45*, 143-149.

Luo, Z., Li, Y., Liu, J., Liu, D., Liu, K., Huang, A., & Yang, X. (2022). Factors associated with HIV status disclosure and its effect on treatment outcomes among children living with HIV: A systematic review. *AIDS Care*, *34*(3), 271-281.

Madiba, S. (2013). Patterns and barriers to disclosure of HIV status to partners and parents of HIV-positive pregnant women in South Africa. *Health Care for Women International*, *34*(12), 1076-1094.

Madiba, S., & Mokwena, K. (2012). Caregivers' barriers to disclosing the HIV diagnosis to infected children on antiretroviral therapy in a resource-limited district in South Africa: A grounded theory study. *AIDS Research and Treatment*, *2012*, 402403. https://www.hindawi.com/journals/art/2012/402403/

Mahloko, J. M., & Madiba, S. (2012). Disclosing HIV diagnosis to children in Odi district, South Africa: Reasons for disclosure and non-disclosure. *African Journal of Primary Health Care & Family Medicine*, *4*(1), 345. https://phcfm.org/index.php/phcfm/article/view/345

Maman, S., van Rooyen, H., & Groves, A. K. (2014). HIV status disclosure to families for social support in South Africa (NIMH Project Accept/HPTN 043). *AIDS Care*, *26*(2), 226-232.

Manvwali, M. K. (2024). *The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, Namibia* [Doctoral dissertation, University of Namibia]. https://repository.unam.edu.na/server/api/core/bitstreams/a6ff4c36-0506-47ed-8723-ff5bbae5a066/content

Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D., & Ross, D. (2014). Adolescent HIV disclosure in Zambia: Barriers, facilitators, and outcomes. *Journal of the International AIDS Society*, *17*(1), 18866. https://doi.org/10.7448/IAS.17.1.18866

Mellins, C. A., Brackis-Cott, E., Dolezal, C., & Abrams, E. J. (2002). Patterns of HIV status disclosure to perinatally HIV-infected children and subsequent mental health outcomes. *Clinical Child Psychology and Psychiatry*, *7*(1), 101-114.

Mellins, C. A., Brackis-Cott, E., Dolezal, C., & Abrams, E. J. (2004). The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatric Infectious Disease Journal*, *23*(11), 1035-1041.

Ministry of Health and Social Services (MoHSS), Namibia. (2017). *National strategic framework for HIV and AIDS response in Namibia (2017/18 to 2021/22)*. Directorate of Special Programmes.

Ministry of Health and Social Services (MoHSS), Namibia. (2019a). *National Guidelines for Antiretroviral Therapy - Sixth Edition*. MoHSS.

Ministry of Health and Social Services (MoHSS), Namibia. (2019b). *Namibia Population-based HIV Impact Assessment (NAMPHIA) 2017: Final Report*. MoHSS.

Ministry of Health and Social Services (MoHSS), Namibia. (2019c). *Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations*. MoHSS.

Mukhtar-Yola, M., Kuczawski, M., & Oniyangi, O. O. (2020). Should children know their HIV status? Prevalence, caregivers' perspectives, and barriers to disclosure at the National Hospital Abuja, Nigeria. *Nigerian Journal of Clinical Practice*, *23*(10), 1419-1425. https://doi.org/10.4103/njcp.njcp_187_20

Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, M., & Cowan, F. M. (2014). "I don't feel shy because I will be among others who are just like me...": The role of support groups for children perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review*, *45*, 106-113.

Naigino, R., Makumbi, F., & Wanyenze, K. (2017). HIV status disclosure and associated outcomes among pregnant women enrolled in antiretroviral therapy in Uganda. *Reproductive Health*, *14*(1). https://reproductive-health-journal.biomedcentral.com

Namukwaya, S., Paparini, S., Seeley, J., & Bernays, S. (2017). "How Do We Start? And How Will They React?" Disclosing to Young People with Perinatally Acquired HIV in Uganda. *Frontiers in Public Health*, *5*, 343. https://www.frontiersin.org/articles/10.3389/fpubh.2017.00343/full

Nefungo, E. (2024). *An exploratory study of perceived barriers to antiretroviral therapy adherence amongst adolescents in Omuthiya district, Namibia* [Doctoral dissertation, University of Namibia]. https://repository.unam.edu.na/server/api/core/bitstreams/87d2a6e3-6932-4545-82b3-4d044c0722ec/content

Nel, E., Casale, M., Du Toit, S., & Toska, E. (2021). Mental health and resilience among young people living with HIV: Findings from a community-based study in South Africa. *Journal of HIV/AIDS & Social Services*, *20*(1), 59-77.

Ngeno, B. N., Waruru, A., Inwani, I., Nganga, L., Wangari, E. N., Katana, A., ... & Kim, A. A. (2019). Disclosure and clinical outcomes among young adolescents living with HIV in Kenya. *Journal of Adolescent Health*, *64*(2), 242-249.

Obermeyer, C. M., Baijal, P., & Pegurri, E. (2011). Facilitating HIV disclosure across diverse settings: A review. *American Journal of Public Health*, *101*(6), 1011-1023. https://doi.org/10.2105/AJPH.2010.300102

Odiachi, A. (2017). The impact of HIV status disclosure on health outcomes in children: A systematic review. *Journal of HIV and AIDS*, *3*(2), 1-7.

Osingada, C. P., Okuga, M., Nabirye, R. C., Sewankambo, N. K., & Nakanjako, D. (2016). Prevalence, barriers, and factors associated with parental disclosure of their HIV positive status to children: A cross-sectional study in an urban clinic in Kampala, Uganda. *BMC Public Health*, *16*, 1-7. https://doi.org/10.1186/s12889-016-3235-2

Paintsil, E., Renner, L., Antwi, S., Dame, J., Enimil, A., Ofori-Atta, A., ... & Lartey, M. (2015). HIV knowledge, stigma, and illness beliefs among pediatric caregivers in Ghana who have not disclosed their child's HIV status. *AIDS Care*, *27*(1), 18-27.

Pandey, P., & Pandey, M. M. (2021). *Research methodology: Tools and techniques*. Bridge Center.

Pinzón-Iregui, M. C., Beck-Sagué, C. M., & Malow, R. M. (2013). Disclosure of their HIV status to infected children: A review of the literature. *Journal of Tropical Pediatrics*, *59*(2), 84-89.

Qiao, S., Li, X., Zhou, Y., Shen, Z., Tang, Z., & Stanton, B. (2015). Factors influencing the decision-making of parental HIV disclosure: A socio-ecological approach. *AIDS*, *29*(Suppl 1), S25-S34. https://doi.org/10.1097/QAD.0000000000000613

Rochat, T. J., Arteche, A. X., Stein, A., Mitchell, J., & Bland, R. M. (2015). Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: The Amagugu intervention. *AIDS*, *29*(1), S67-S79.

Ssali, L., Kalibala, S., Abang, B., Kabugo, C., Bagenda, D., & Kaye, D. K. (2019). Factors associated with HIV disclosure to children by their HIV-positive mothers/caregivers in Kampala, Uganda. *AIDS Research and Treatment*, *2019*, 1-8.

Swarooprani, K. (2022). A study of Research Methodology. *International Journal of Scientific Research in Science, Engineering and Technology*, *9*(3), 537-543. https://www.researchgate.net/publication/361807570

Teasdale, C. A., Abrams, E. J., Coovadia, A., Strehlau, R., Martens, L., Kuhn, L., ... & Simonds, R. J. (2016). HIV testing for children in resource-limited settings: What are we waiting for? *PLoS Medicine*, *13*(7), e1002083.

Toska, E., Cluver, L. D., Hodes, R., & Kidia, K. K. (2015). Sex and secrecy: How HIV-status disclosure affects safe sex among HIV-positive adolescents. *AIDS Care*, *27*(sup1), 47-58.

UNAIDS. (2016). *AIDS by the numbers: AIDS is not over, but it can be*. UNAIDS.

UNAIDS. (2021). Namibia. https://www.unaids.org/en/regionscountries/countries/Namibia

UNAIDS. (2022). *Global AIDS Update 2022*. Joint United Nations Programme on HIV/AIDS.

UNICEF. (2021). *Children and HIV: Fourth stocktaking report*. United Nations Children's Fund.

Vale, B., Hodes, R., Cluver, L., & Toska, E. (2018). Symptoms of common mental health disorders and AIDS-defining illnesses among adolescents living with HIV in South Africa. *Journal of Acquired Immune Deficiency Syndromes*, *77*(5), 455-462.

Vreeman, R. C., Gramelspacher, A. M., Gisore, P. O., Scanlon, M. L., & Nyandiko, W. M. (2013). Disclosure of HIV status to children in resource-limited settings: A systematic review. *Journal of the International AIDS Society*, *16*(1), 18466. https://doi.org/10.7448/IAS.16.1.18466

Vreeman, R. C., & Scanlon, M. L., Inuis, T. S. (2015). "Why did you tell me?" Perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya.

Vreeman, R. C., Scanlon, M. L., Mwangi, A., Turissini, M., Ayaya, S. O., Tenge, C., & Nyandiko, W. M. (2014). A cross-sectional study of disclosure of HIV status to children and adolescents in Western Kenya. *PLoS One*, *9*(1), e86616.

World Health Organization. (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*. WHO. https://www.who.int/publications/i/item/9789241502863

World Health Organization. (2018a). *HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV*. World Health Organization.

World Health Organization. (2018b). Updated recommendations on first-line and second-line antiretroviral regimens and post-exposure prophylaxis and recommendations on early infant diagnosis of HIV. https://pesquisa.bvsalud.org/portal/resource/pt/biblio-994579

Xu, T., Wu, Z., Rou, K., Duan, S., & Wang, H. (2017). Quality of life of HIV-infected children and their caregivers in rural areas of Yunnan Province, China. *AIDS Care*, *29*(6), 769-774.

Zhao, J., Li, X., Fang, X., Hong, Y., Zhao, G., Lin, X., ... & Stanton, B. (2016). Stigma against children affected by AIDS (SACAA): Psychometric evaluation of a brief measurement scale. *AIDS and Behavior*, *20*(2), 323-333.

APPENDIX 1: ETHICAL CLEARANCE CERTIFICATE

UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: **DEC OSH 0116** **Date:** **16/04/ 2024**

This Ethical Clearance Certificate is issued by the University of Namibia Ethics Committee (REC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the ethics committee.

Title of Project: PERCEPTIONS AND BARRIERS TO DISCLOSURE OF HIV STATUS OF CHILDREN BY CAREGIVERS AT DONKERHOOK CLINIC, WINDHOEK, KHOMAS REGION, NAMIBIA

Principal researcher: NDINOMUKULILI NDAEDEELAO LOMBOLENI

Staff Number/ Student number: 201508300

Remarks: Low Risk and Approved with minor corrections

Centre for Research Services

Take note of the following:

1. Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the ethics committee. An application to make amendments may be necessary.
2. Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the ethics committee.
3. The Principal Researcher must report issues of ethical compliance to the ethics committee (through the Chairperson) at the end of the Project or as may be requested by the ethics committee.
4. The ethics committee retains the right to:
    i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
    ii) Request for an ethical compliance report at any point during the course of the research.

The ethics committee wishes you the best in your research.

Prof Hans J Amukugo (Oshakati Campus Chairperson Decentralized Ethics Committee)

Prof. Davis Mumbengegwi (Head, Multidisciplinary Research)

APPENDIX 2: RESEARCH PERMISSION LETTER

REPUBLIC OF NAMIBIA

MINISTRY OF HEALTH AND SOCIAL SERVICES

OFFICE OF THE EXECUTIVE DIRECTOR

Ministerial Building
Harvey Street
Private Bag 13198, Windhoek

Tel: No: 061 -203 2507
Fax No: 061-222 558
Andreas.Shipanga@mhss.gov.na

Ref: 22/4/2/3
Enquiries: Mr. A. Haufiku

Date: 14 June 2024

Ms. Ndinomukulili Lomboleni
PO Box 61126
Katutura
Windhoek

Dear Ms. Lomboleni

Re: Perceptions and barriers to disclosure of HIV status of children by caregivers at Donkerhook Clinic, Windhoek, Khomas Region, Namibia.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
   - 3.1 The data to be collected must only be used for academic purpose;
   - 3.2 No other data should be collected other than the data stated in the proposal;
   - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
   - 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
   - 3.5 Preliminary findings to be submitted upon completion of the study;
   - 3.6 Final report to be submitted upon completion of the study;
   - 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

Yours sincerely

BEN NANGOMBE
EXECUTIVE DIRECTOR