UNIVERSITY OF ZULULAND

Title

Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal.

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DEDICATION

I dedicate this mini dissertation to:

My parents, **Mrs. T.H. and Mr. T.N. Myeni**. I am so grateful for your support and how you nurtured me to become the person I am today. Having not attended school yourselves, but you ensured that I get an education and today this is all your product.

Thank you!

STATEMENT OF AUTHENTICATION AND DECLARATION

This statement is to confirm that the research report contained in this manuscript is, to the best of my knowledge, original, except where I have acknowledged through citations in the text. Consequently, I hereby declare that this manuscript has not been submitted, either in full or in part, to the University of Zululand or any other university or institution of learning, for a degree.

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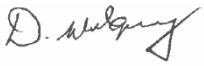
Signature:  **Date: 12 December 2025**

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> ***What, what would have become of me had I not believed that I would see the Lord's goodness in the land of the living! Psalm 27, p. 13 (AMP)***

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ABSTRACT

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Abstract

Background: The prevention of mother-to-child transmission (PMTCT) programmes globally has prevented expectant mothers from perinatally infecting their babies with the HIV. However, despite PMTCT programmes being available, a number of children between 0-14 years are living with HIV globally. As these children grow into adolescents, their parents or caregivers are faced with the responsibility of disclosing their HIV status to them. Disclosure to children living with HIV (CLHIV) is an essential process as it allows them to understand their HIV-infection, how their medicine works and protects the lives of people around them. However, there are several factors that influence and affect the

disclosure process. Caregivers' experiences (challenges and successes) pertaining to disclosing their children's HIV status to them vary and are not widely known. Hence, the pivotal role of disclosure in perinatally HIV-infected children's lives, and the low rates of disclosure, necessitated this study on caregivers' experiences of disclosing perinatally infected children's HIV status to them in the uMzinyathi District, KZN.

Methods: An explorative, interpretivist, qualitative approach was used to explore caregivers lived experiences of disclosing their children's perinatal HIV status to them. Twenty caregivers of CLHIV between the ages of 6 and 12 years who are enrolled on ART programmes in four primary health clinics in uMzinyathi District, KwaZulu-Natal, were conveniently and purposively sampled. They voluntarily participated in audio-recorded semi-structured interviews that were conducted between December 2023 and January 2024. The interviews were manually transcribed and thematically analysed by the primary investigator.

Results: The findings depict both the complexity of the challenges and the successes experienced by caregivers of CLHIV when disclosing their children's HIV status to them. Though most caregivers had disclosed to their children, they indicated that the lack of support, resources, disclosure skills, knowledge and vocabulary, fear of emotional and psychological impact on the child, stigma and social isolation were some of the challenges that they encountered during the disclosure process. Some emphasised that their pleasant disclosure experiences were facilitated by a positive caregiver-child relationship, the assistance and counselling support services they have received from healthcare workers, acknowledgement that disclosure improves ART adherence, prevents further transmissions and reduces parental stress.

Recommendations: Parents need to be capacitated with knowledge and the skills to facilitate comprehensive and holistic HIV disclosure. Healthcare workers should provide support to caregivers as they volunteered that they could not disclose on their own due to fear and concerns associated with HIV disclosure. Intervention strategies should address these concerns and fears to foster health-promoting and supportive HIV disclosure. This can enhance measures to combat further transmission of HIV, improve health literacy, promote open communication about HIV, and form peer support groups that can reduce and improve caregivers' disclosure experiences.

Conclusion: Caregivers and healthcare workers play a pivotal role in ensuring health promoting HIV disclosure to children and in preventing negative consequences that may result from delayed and accidental and nondisclosure. Preparation and education play a huge role in empowering caregivers with appropriate knowledge and skills to lead a successful health-promoting disclosure. The support of HCWs is also relevant in preparing caregivers for disclosure and during the disclosure process.

Keywords: Adherence, ART, Caregivers, Children, Disclosure, HIV, HIV status, Perinatal

IsiZulu

Abstract

Isizinda: Uhlelo lokuvikela ukudluliselwa kwegciwane ukusuka kumama kuya enganeni emhlabeni jikelele, luvikele omama abakhulayo ukuthi bangabi nezingane ezizalwa ne-HIV. Nokho, naphezu kokuthi izinhlelo zokuvimba ukudluliselwa kwegciwane ezinganeni zitholakala, kunezingane eziningi eziphakathi kweminyaka engu-0-14 eziphila ne-HIV emhlabeni jikelele. Njengoba lezingane zikhula zibe yintsha, abazali bazo noma abanakekeli bazo babhekene nomthwalo wokudalula isimo sabo se-HIV kubo. Ukudalula kubantwana abaphila ne-HIV kubalulekile njengoba kwenza ukuba baqonde ngokusuleleka nge-HIV, indlela imishanguzo yabo esebenza ngayo nokuvikela izimpilo zabantu abasondelene nabo. Nokho, kunezinto eziningi ezithinta futhi zenza umphumela yokudalula. Izinto abanakekeli bezingane ababhekana nazo (izinselelo neziphumelelo) mayelana nokudalula isimo se-HIV sezingane zabo zihlukahlukene. Lezi zinto ababhekana nazo azikaqondakali kahle ngokusobala. Ngakho, indima ebalulekile yokudalulwa empilweni yezingane ezizalwe ne-HIV, kanye nezinga eliphansi lokudalulwa, yikhona okwenza ukuba kwenziwe lolu cwaningo mayelana nezinto abanakekeli bazingane ababhekana nazo ekudaluleni isimo se-HIV sezingane kuzo izingane ezizelwe ne-HIV esi-Fundeni sase-uMzinyathi, KwaZulu-Natal.

Izindlela: Kusetshenziswe indlela yokuhlola, yokutolika, eyi-qualitative ukuthola izinto abanakekeli bezingane abahlangabezana nazo ekudaluleni isimo se-HIV sezingane zabo. Abanakekeli abangamashumi amabili (20) bezingane eziphila ne-HIV ezineminyaka ephakathi kuka-6 no-12 ubudala ezibhalise ezinhlelweni ze-ART emitholampilo emine yezempilo esiFundeni uMzinyathi, KwaZulu-Natal, bakhethwa kahle futhi bafakwa

ngokuzithandela ukuthi babambe iqhaza ngokuzithandela kulolu cwaningo.

Imiphumela: Imiphumela ikhombisa ubunzima kanye nempumelelo abanakekeli bezingane eziphila ne-HIV ababhekana nakho uma bedalulela izingane zabo nge-HIV. Nakuba iningi labanakekeli bezingane lidalulile ezinganeni zabo ngesimo sazo se-HIV, baphawulile ukuthi ukungabi nosizo, izinsiza, amakhono okudalula, ulwazi olwanele, ukwesaba umphumela wokudalula kanye nokuphazamiseka noma ukuphatheka kabi kwabantwana, ukwesaba ukuchwaswa umphakathi kube ezinye zezinkinga abahlangabezana nazo naqondana nokudalulela izingane zabo. Kanti abanye abanakekeli begcizelela ukuthi ubudlelwano babo obuhle nabantwana babo, usizo nezinsizakalo zokweluleka abaluthole kubasebenzi bezemplilo, ulwazi lokuthi ukudalula kuzothuthukisa indlela izingane zabo ezithatha ngayo imishanguzo yabo, ukunciphisa amathuba okudlulisela igciwane le-HIV kanye nokwehlisa ingcindezi kubazali yikhona okubaqhuqhuzele ukudalulela izingane zabo.

Izincomo: Abazali kumele bahlome ngolwazi nezindlela zokuqala ukuveza ngokupheleleyo nangokubanzi mayelana ne-HIV. Abazali abaningi bezingane badinga ukwesekwa kusukela kubasebenzi bezempilo ngoba abakwazi ukuveza ngokwabo ngenxa yokwesaba nezinkinga ezihambisana nokukhuluma nge-HIV. Izindlela zokungenelela kumele zixazulule lezi zinkinga nezokwesaba futhi zikhuthaze ukuvezwa kwe-HIV okupheleleyo nokusekekayo. Lokhu kungakhuphula izinyathelo zokulwa nokudluliselwa kwe-HIV, kuthuthukise ukuthola ulwazi lwezempilo, kuxhase ukuxhumana okuvulekile nge-HIV, futhi kwakhe amaqembu okukweseka okungathuthukisa nokunciphisa izinto

Isiphetho: Abazali kanye nabasebenzi bezempilo banendima ebalulekile ekuqinisekiseni ukudalulwa kwe-HIV okukhuthazayo kumntwana nokuqeda imiphumela emibi engase ivele ngenxa yokudalulwa sekudlule isikhathi nokungaqondile kanye nokungadaluli kumntwana. Ukuhlela nokuqeqesha kungaba nendima enkulu ekuthuthukiseni abazali ngolwazi olufanele namakhono okuqala ukudalulwa okuphumelelayo nokukhuthazayo. Ukusekela kwabasebenzi bezempilo kubalulekile ekuhlinzekeni abazali ngokuqeqeshwa kokudalulwa kwe-HIV ezinganeni.

Amagama angukhiye: I-HIV, Ukudalulwa, isimo se-HIV, izingane, Abanakekeli, imishanguzo

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ACRONYMS

AHD	Advanced HIV Disease
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
ARVs	Antiretrovirals
AT	Attachment Theory
CALHIV	Children and Adolescents Living with HIV
CLHIV	Children Living with HIV
CPAH	Children with Perinatally Acquired HIV
CT	Cultural Theory
DoH	Department of Health
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
EST	Ecological Systems Theory
FST	Family Systems Theory
HAART	Highly Active Antiretroviral Treatment
HBM	Health Belief Model
HCT	HIV Counselling and Testing
HCP	Health Care Professionals
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
KZN	KwaZulu-Natal
KZN DoH	KwaZulu-Natal's Department of Health
MDT	Multidisciplinary Team
MSM	Men who have Sex with Men
NDOH	National Department of Health
NPO	Non-profit Organisation
OVC	Orphans and Vulnerable Children

PCC	Patient-Centred Care
PHC	Primary Health Clinic
PI	Principal Investigator
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
RLS	Resource Limited Settings
SA	South Africa
SAHCS	Southern African HIV Clinicians Society
SCT	Social Cognitive Theory
SLT	Social Learning Theory
SSA	Sub-Saharan Africa
SSM	Social Stigma Models
STI	Sexually Transmitted Infection
TA	Thematic Analysis
TPB	Theory of Planned Behaviour
UNAIDS	United Nations AIDS Programme
UNCRS	United Nations Convention on the Rights of Children
UNIZULU	University of Zululand
USAID	United States Agency for International Development
UZREC	University of Zululand Research Ethics Committee
WHO	World Health Organization
YPHIV	Youth with perinatally acquired HIV infection
YPHEU	Youth who were perinatally HIV-exposed but uninfected

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CHAPTER ONE
INTRODUCTION

1.1 INTRODUCTION

This exploratory qualitative study explores caregivers' experiences of disclosing their children's perinatally transmitted human immunodeficiency virus (HIV) status to them. The study was achieved by conducting semi-structured interviews with 20 caregivers who access antiretroviral treatment (ART) for their children at four (4) primary health clinics (PHC) in uMzinyathi District Municipality in KwaZulu-Natal (KZN). The ultimate aim was to yield further knowledge on caregivers' experiences (successes and challenges), to share best practices and make recommendations to improve disclosure techniques, adherence to ART and improve the health and wellbeing of caregivers' and their children living with HIV (CLHIV).

The study's background, a preliminary review of literature, theoretical framework, the problem statement, aim, objectives and research questions, significance of the study, intended contribution to the current body of knowledge, research methodology and researcher's position are contained in this chapter. The structure of all chapters in this dissertation, and a summary conclude this initial section of the dissertation.

1.2 BACKGROUND OF THE STUDY

The prevention of mother-to-child transmission (PMTCT) programmes globally, has prevented expectant mothers from perinatally transmitting HIV to their babies (Burton et al., 2015; Dong et al., 2020). Perinatal HIV-infections refer to mothers transmitting HIV to their baby during pregnancy, childbirth, or breastfeeding (Kung et al., 2016; Njom Nlend, 2022), while HIV-seropositive refers to HIV antibodies being detected in a person's serum which indicates an HIV-infection (White, 2013). Highly active antiretroviral therapy (HAART) in South Africa is freely available to mothers to prevent their children from perinatally acquiring HIV (Naidoo et al., 2015). However, despite PMTCT programmes being available, an estimated 1.7 million children between 0-14 years are living with HIV globally and 122 000, live in sub-Saharan Africa (SSA)

(UNAIDS, 2024). Of that number, only 52% have access to ART (The Joint United Nations Programme on HIV/AIDS [UNAIDS], 2022). In cases where babies are born HIV-seropositive, ART is freely available to children from public hospitals and clinics to improve their growth, development, health, and wellbeing. Antiretroviral treatment is also available in the private health sector (Long et al., 2023).

The disclosure of an HIV diagnosis, adherence on ART, healthy eating, avoidance of stress, timeous attendance of medical check-ups and regular routine blood tests and counselling are pivotal to the lives and wellbeing of the people living with HIV (PLHIV). Human immunodeficiency virus disclosure refers to the process whereby a person is informed about their HIV-seropositive status (Thapa et al., 2018). The disclosure process includes the PLHIV or third parties informing others about the diagnosis with or without the PLHIV's consent. However, despite guidelines and processes in place, HIV disclosure to perinatally HIV-infected children and adolescents, especially in resource limited settings (RLS) poses a challenge (Beima-Sofie et al., 2017; Bulali et al., 2018; Hayfron-Benjamin et al., 2018; Madiba & Diko, 2021; Sornillo et al., 2023). This is due to the hesitancy of caregivers, guardians, and parents to disclose their and/or their children's HIV status to them, out of fear of negative reactions and consequences, feelings of guilt on pediatric HIV transmission to them, and a lack of adequate knowledge, skills, and confidence to initiate the disclosure process (Beima-Sofie et al., 2017; NDOH, 2016).

Caregivers in this study refer to paid or unpaid individuals who may be biologically (parent/s, grandparents, relatives), or non-biologically (guardians, neighbours, custodians) related to CLHIV and who provide care and support to them (Li et al., 2022). Other stakeholders who play an integral role in the HIV-seropositive child's disclosure are healthcare workers, social workers, medical practitioners, and counsellors, including HIV counsellors (Madiba, 2016; Odiachi, 2017). Studies have shown that HIV disclosure reduces stress levels, improves, and increases patient's adherence to ART, facilitates robust support systems, reduces risky behaviour and practices, improves longevity, and fosters transparent relationships (Buckley et al., 2022; Joyce et al., 2022; Ramsammy et al., 2022). Due to the young age of perinatally HIV-infected children, this vital process is surrendered to their caregivers (Mandalazi et al., 2014).

The pivotal role of disclosure in CLHIV's lives, and the low rates of disclosure, necessitated this study on caregivers' experiences of disclosing perinatally infected children's HIV status to them in the uMzinyathi District, KZN.

1.3 PROBLEM STATEMENT

Though there are established guidelines for the disclosure of HIV to children and evidence that pediatric HIV disclosure enhances adherence to ART and improves PLHIV's self-esteem, health, and wellbeing, low levels of disclosure are still reported in most RLS (Damulak et al., 2021; Mutambo et al., 2021) including KZN, with negative consequences. The disadvantages of nondisclosure are clinical and psychological challenges which threaten children's health and quality of life (Hayfron-Benjamin et al., 2018). Madiba and Diko (2021) argue that the delay of pediatric HIV disclosure can hinder accessing much needed ART and contribute to children's refusal to take their antiretrovirals (ARVs). In addition, it could result in unplanned or forced disclosure of their status, resentment, and anger towards their caregivers, and an increase in the risk of secondary transmission of HIV that could result in advanced HIV disease (AHD). Withholding information from CLHIV, results in them feeling excluded from participating in important aspects of their health and deprives them of opportunities to actively develop their agency (Rost & Mihailov, 2021). Assigning children, their agency in their treatment promotes their cooperation, involvement in therapeutic goals and aids in their decision-making capacity (Kling, 2022). More importantly, children's non-adherence to ART hinders virological suppression, treatment success and can result in cross-resistance to similar drugs, multi-drug resistance, poor health outcomes, psychological distress, or morbidity (Amankwah-Poku et al., 2021; van Elsland et al., 2019). These outcomes negatively affect the child, family, and community while further burdening an already challenged public health care system. Lastly, children and teenagers are our country's future and all threats to their health and wellbeing are worth investigating.

1.4 RESEARCH AIM, OBJECTIVES AND QUESTIONS

The study's aim and objectives are found in Table 1, below:

RESEARCH AIM: To explore caregivers' experiences of disclosing an HIV-seropositive status to perinatally infected children in uMzinyathi District, KwaZulu-Natal.	
OBJECTIVES	**RESEARCH QUESTIONS**
A. To explore caregivers' experiences of disclosing perinatally infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal.	A. What are caregivers' experiences of disclosing perinatally infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal?
B. To explore factors affecting caregivers' disclosing perinatally HIV-infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal.	B. What are the factors affecting caregivers' disclosing perinatally HIV-infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal?
C. To make recommendations to improve caregivers' disclosure techniques to perinatally HIV-infected children in uMzinyathi District, KwaZulu-Natal.	C. What recommendations can be made to caregivers to improve HIV disclosure to perinatally HIV-infected children in uMzinyathi District, KwaZulu-Natal

Table 1: Research Aim, Objectives and Questions

1.5 INTENDED CONTRIBUTION TO THE BODY OF KNOWLEDGE

The study intended to expand the current body of knowledge on caregivers' experiences (successes and challenges) of disclosing their CLHIV status to them. The findings will contribute to a comprehensive approach to the management of CLHIV with a special focus on the disclosure of their HIV-seropositive status. The awareness and understanding of caregivers' experiences will further assist in designing and improving current strategies to address, facilitate and improve disclosure.

1.6 LITERATURE REVIEW

Local and internationally relevant literature focusing on caregivers' experiences of pediatric HIV disclosure was systematically reviewed by the researcher to ensure a robust and comprehensive study. The pivotal role of disclosure in CLHIV lives, and the low rates of disclosure, necessitated this study exploring caregivers' experiences of disclosing perinatally HIV-infected children's HIV status to them, in uMzinyathi District, KZN. The literature review is broadly and comprehensively discussed in chapter two of this dissertation.

1.7 THEORETICAL FRAMEWORK

Bronfenbrenner's Ecological Systems Theory (EST) grounds this study that aimed to explore caregivers' experiences of informing their HIV-positive children about their HIV status. The researcher found that Bronfenbrenner's EST befits this study as it presented the negative and positive factors affecting the pediatric HIV disclosure process to better understand caregivers' experiences (Manyam et al., 2019; Sokhela, 2016). The theoretical framework is discussed in detail in chapter three.

1.8 RESEARCH METHODOLOGY

This study employed an exploratory, qualitative research approach to facilitate the attainment of in-depth information and insight to better understand caregivers' experiences of disclosing children's perinatal HIV status to them and it assisted the researcher to obtain extensive data from the semi-structured interviews. Non-probability sampling in the form of purposive and convenient sampling were used to sample twenty (20) participants of all races and genders. This process is unpacked in chapter four.

1.9 RESEARCHER'S RATIONALE FOR CONDUCTING THIS STUDY AND HIS POSITIONALITY

The researcher works as a social worker in the uMzinyathi District and supports 54 clinics with HIV disclosure and adherence for children and adolescents on ART in the district and has observed that most HIV-seropositive children and adolescents on ART were unaware of their HIV status. The researcher is an outsider in this study, as he is not a caregiver of perinatally HIV-infected children and is not HIV-positive. In addition, the researcher observed that the caregivers of children and adolescents with perinatal HIV infections are hesitant and resistant to inform their children of their HIV diagnosis. This situation contributes to poor adherence and viral suppression. These observations propelled and encouraged the researcher to explore caregivers' experiences of disclosing children in their care's HIV status to them to empirically contribute to the body of knowledge and also afford an opportunity to further postgraduate studies. The researcher's positionality will be further discussed in the methodology section.

1.10 STRUCTURE OF THE DISSERTATION

This dissertation is divided into seven chapters:

Chapter 1 – Introduction

This chapter introduces the study and relevant background information, outlines a preliminary literature review, the theoretical framework, problem statement, aim, objectives and research questions, significance of the study, intended contribution to the current body of knowledge, research methodology and the researcher's position. A summary of all the chapters in this dissertation concludes this chapter.

Chapter 2 – Literature Review

Both local and international literature on caregivers' experiences of disclosing to their perinatally HIV-infected children is reviewed in this chapter.

Chapter 3 – Theoretical Framework

The theory that frames this study is discussed in-depth in this chapter.

Chapter 4 - Research Methodology

This chapter outlines the study's research design, methodology, paradigm, study sites and population, types of sampling, methods and analysis employed in this study.

Chapter 5 – Data Analysis and Interpretation

This chapter presents and discusses the findings of the study according to the main and the subthemes that emerged from the interviews and an analysis and interpretation.

Chapter 6 – Conclusions, Recommendations, Implications and Limitations

The study's analysed findings, conclusions and recommendations are presented and discussed and the implications and limitations.

Chapter 7 – Reflections and Contributions of the Study

Reflections on the study and the contributions of the study are discussed here and conclude the dissertation.

1.11 SUMMARY

This chapter summarised the entire study by commencing with an introduction of the study topic: Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KZN. Thereafter, the study's background, problem statement, research questions, aim and objectives and the intended contribution were discussed. The literature review, theoretical framework, research methodology and the researcher's positionality were briefly highlighted and will be dealt with in more detail in the following chapters. The structure of the dissertation concludes this section. The next chapter reviews relevant literature on the topic to provide a strong basis for the analysis of the data collected.

CHAPTER TWO
LITERATURE REVIEW

2.1 INTRODUCTION

South Africa has a sizeable adult HIV-seropositive population and a significant child and adolescents living with HIV (CALHIV) populace (Mabaso et al., 2021; Simbayi et al., 2019). However, more research focuses on the adult HIV populace than on CALHIV (Morales et al., 2022). Compared to adults, CALHIV continue to have an alarmingly higher mortality rate and poorer results in the HIV care cascade (Nyandiko et al., 2024). Hence, this study's focus is on CLHIV as ART and its management has resulted in children who are perinatally infected with HIV, living longer lives. Disclosure of their HIV status plays a prominent role in their longevity, quality of life, health, development, wellbeing, and future and is an important component of their HIV management. The aim of such a disclosure is for them to be informed, improve their knowledge of their illness, and to gain a complete understanding of their health diagnosis and prognosis. Early and age-appropriate HIV disclosure is reported as being paramount to improving long-term management of the disease, to provide relevant psychosocial support, assist with treatment adherence, and minimise caregivers' stress and burden and the inhibition of further transmissions of the virus (Baker et al., 2018). However, despite its importance and relevance to CLHIV, disclosure still constitutes a challenge to caregivers and health care workers in RLS (Adella et al., 2023).

In this comprehensive and critical review of current and relevant literature on the topic, the researcher commences with key concepts and terms used throughout the literature review and dissertation, and discusses caregiving, types of caregivers and orphaned children, and the frameworks, policies, guidelines and processes that support pediatric HIV disclosure in South Africa. The chapter continues with the prevalence of disclosure, the factors affecting disclosure, and the advantages and disadvantages of disclosure. In addition, the phases of HIV disclosure to children, the appropriate stakeholders who are involved in the disclosure process, the consequences thereof, and recommendations that enhance disclosure are also discussed. A summary concludes this chapter.

2.2 KEY CONCEPTS AND TERMS

The focus of the study is on caregivers' experiences of disclosing perinatally HIV-infected children's status to them; hence the key concepts and terms are presented in this chapter to provide context to the literature used in this review and throughout the dissertation.

Caregiver

A caregiver is someone who assumes the responsibility of caring for someone else who is incapable of taking care of themselves because of a disease or injury, disability, or the loss of loved ones (Ntuli et al., 2020). Caregivers, in this study refer to qualified, and/or unqualified, and formally and informally trained individuals, who are devoted to the care and wellbeing of HIV-positive children in the uMzinyathi District Municipality, KZN. Formally trained caregivers have undergone recognised training in preparation for their roles as caregivers and the quality of their care is positioned within structured social or health service systems for which they are remunerated (Kok et al., 2015; Moosa-Tayob & Risenga, 2022). In addition, they possess knowledge and skills to manage medical and psychosocial needs, including adherence to HIV treatment protocols (Mokwele & Strydom, 2017). Informally trained caregivers are usually family members, relatives, friends, or community volunteers who provide care without formal health qualifications or standardised training (Futado et al., 2024; Usai et al., 2025). Informal caregivers play a crucial role in sustaining HIV-positive children in resource-limited settings (RSL) but often lack sufficient knowledge and institutional support (Morton et al., 2018). The coexistence of formally and informally trained caregivers reflects the hybrid nature of caregiving systems in many rural South African communities such as uMzinyathi District, KZN (Brear et al., 2024; Lentoor, 2017).

Caregiving

It includes caring for individuals in an institutional setting, the home of the care recipient, or the home of the caregiver (Plöthner et al., 2019). Hermanns and Mastel-Smith, (2012, p.5) view caregiving as "…actions one does on behalf of another individual who is unable to do those actions for himself or herself".

Disclosure of pediatric/perinatally acquired HIV infections

This type of disclosure involves an age, developmental, emotional and cognitive-appropriate systematic process of informing a child of their HIV-seropositive status (Elizabeth Glaser Pediatric AIDS Foundation [EGPAF], 2018). In this study, it indicates the process whereby caregivers inform the children who are in their care about their HIV diagnosis. The words *pediatric* and *perinatal* are interchangeably used throughout the dissertation to describe health care and caregiving related to newborns, infants, and children, as the continuum of care from pregnancy through early childhood is central to the focus of this research. Pediatric includes care and medicine that focuses on adolescents, children and infants (0-18) development, diagnosis, health and treatment (Hockenberry & Wilson, 2019; WHO, 2022). Pediatric care inludes childhood illnesses (HIV), their development, growth, long-term wellbeing of children. Perinatal, specifically refers to the period before (22 weeks of gestation) and between 7 to 28 days after birth (Lowe et al., 2019; WHO, 2016). Perinatal care primarily focuses on maternal health, fetal wellbeing, childbirth, and immediate neonatal outcomes. Thus, *pediatric* relates broadly to childrens health across infancy, childhood, and adolescence, whereas *perinatal* is restricted to the critical time around birth involving both mother and newborn.

Experiences

Experiences refer to all the interactions between human beings and the world they live in (Hohr, 2013). In the context of this study, experiences refer to all caregivers' engagements (negative, pleasant, positive, and unpleasant) while disclosing an HIV-positive status to perinatally infected children in the uMzinyathi District Municipality in KZN.

Healthcare Provider

In the context of this study, a healthcare provider is any trained healthcare worker or practitioner (nurse, doctor, counselor, social worker or psychologist) who provides services relating to disclosure and the management of PLHIV within healthcare facilities or communities (Madiba & Mokgatle, 2015).

HIV-infected Minors/Perinatally Acquired HIV

HIV-infected, or HIV sero-positive, minors with perinatally acquired HIV or perinatally infected minors are CLHIV who are under 18 years of age and require a carer to take care of them. In the context of this study, they are between the ages of 0 to 12 years and the terms mentioned earlier are used interchangeably (Blencowe et al., 2025).

2.3 CAREGIVING, TYPES OF CAREGIVERS AND ORPHANED CHILDREN

2.3.1 Caregivers and caregiving

Caregiving is performed by caregivers who are individuals of all sexes, ages, genders, races, religions, creeds, and educational standing who assist other people who are not psychologically, mentally, financially, developmentally, or physically able and independent (Bainbridge et al., 2020; Xiong et al., 2020). Though caregiving is a global phenomenon, it does not submit to a universal definition as it is used and defined differently by researchers, contexts, professions and disciplines, carers, and care recipients (Kokorelias et al., 2019). The position or role is viewed as a vocation, thereby embracing financial gain and formal skills with the informal and nurturing aspect being secondary (Moalosi, 2019). In response, it can be argued that people create synergy by utilising their nurturing manner to render an income, based on making a meaningful difference in orphaned or vulnerable children's (OVCs) lives while being paid or unpaid for such services.

Kent et al. (2016) claim that the use of various definitions and the lack of a single definition influence the criteria for inclusion and exclusion of research studies that are conducted on caregiving and caregivers. These criteria can vary in terms of the hours that caregivers work, their roles and tasks and the number of care recipients they take care of, which can influence the number of study participants. Despite the absence of a global definition for caregiving, it remains an essential and a much-required service for OVCs in communities, and this has been highlighted and stressed by governments, civil society, researchers and religious bodies worldwide (Makosi, 2019; Shawar & Shiffman, 2023).

2.3.2 Types of Caregivers

Caregivers are formal, informal, primary, secondary or professional carers of children, adults, and the elderly (Li & Song, 2019; Oh et al., 2024). Formal caregivers are individuals who have studied or received some training on caregiving, belong to a carer body or work in caring homes, hospitals, and health care settings with formalised employment contracts (Plöthner et al., 2019). Moreover, they are individuals who take care of others and in most cases receive financial rewards, stipends or support from the state, family, friends, or community members (Bainbridge et al., 2021). Some health-care professionals (HCPs) are recognised as caregivers and are paid to offer support and care for their clients or patients (Diameta et al., 2018).

Informal and/or primary caregivers are family, relatives, friends, or neighbours who provide support regularly or on a rotation basis (Lethin et al., 2016; Shiba et al., 2016). The immediate family members, community caregivers or volunteers may commute between homes to care for children (Topp et al., 2015). These caregivers are responsible for providing physical, emotional and, where necessary, financial support of their care recipients who are incapable of taking care of themselves because of a sickness or injury, unemployment or disability (Muller-Kluits & Slabbert, 2018; Sherman, 2019). The recipients of care could be children, family members, life partners or acquaintances.

2.4 THE CONSTRUCTION OF CAREGIVERS, CAREGIVING AND THEIR ROLES

2.4.1 The construction of caregivers and caregiving

Studies have shown that males and females are caregivers (Hatch & Posel, 2018; Lopez-Anuarbe & Kohli, 2019; Pacheco Barzallo et al., 2024; van Polanen et al., 2017). In terms of the study setting, the researcher had also observed this. However, caregiving is still constructed as a feminine role, position, job, and duty, due to the patriarchal nature of many communities and gender stereotypes (Friedemann & Buckwalter, 2014; Sharma et al., 2016). This is based on how human beings construct their reality based on their upbringing, observations, experiences and interactions. Moreover, women being constructed as caregivers is ingrained in patriarchal

communities and cultures and demonstrates gender stereotypes and systemic gender inequalities that are still prevalent (Hatch & Posel, 2018; Ramírez-Perdomo et al., 2024). One can argue that the perception and the construction of women as caregivers is primarily due to them birthing children and being their primary carers from birth. However, Pacheco Barzallo et al. (2024) and Ramírez-Perdomo et al. (2024) argue that male caregivers are on the increase thereby narrowing the male-female divide.

In the context of many African and South African families and homes, older women perform caregiving roles including caring for their daughters, sons or mothers of children, while they go to work, hence elders are considered as valuable and financial capital in homes and communities (Gumede et al., 2022; Schatz & Seeley, 2015). Grandmothers and older women are both providers and receivers of informal care due to their dual role of being mothers to their children and carers to their grandchildren. Such roles render them respected, valuable, needed, and important (Hatch & Posel, 2018). Hence, their caregiving role is not constructed as a burden but as a human asset (Xaba, 2021). The researcher argues that the Fourth Industrial Revolution (4IR), is upon us and entails improvements in technology and adjustments in lifestyles and trends and questions whether older people will be able to keep abreast of the technological and communication skills required during this era. Moreover, providing care can be stressful and affect elderly caregivers' health and wellness, which in turn affects their ability to meet the needs of the people they are caring for (Gumede et al., 2022).

Due to caregiving transitions brought on by parental illness or death, many CALHIV have experienced both loss and sadness. Some of these children are consequently forced to live with friends, grandparents, foster parents, or other family members (Lentoor, 2019; Louthrenoo et al., 2018). One can argue that two people participated in the sexual act that resulted in the CLHIV, yet most of the responsibilities and caregiving tend to lie with one parent, their family and friends. The absence of biological fathers or mothers and many households being led by single parents have been discussed in several studies with many reasons being provided for this (Hatch & Posel, 2018; Zharima et., 2025). Some of the reasons are that fathers are providers and engage in migrant work to provide and this means migrating away from the family, relationships being irretrievably broken down, and challenges around paternity, and the person who transferred the

virus (Manyatshe & Nduna, 2014). However, one study conducted by Mwangala et al. (2022) found that more caregivers of CLHIV were biological mothers, than grandparents and other relatives.

2.4.2. Caregivers' Roles

Caregivers' roles in the lives of children vary across the trajectory of their caregiving mandates and their work settings. This can involve a variety of tasks such as attending to their educational, psychosocial, emotional, transportation, medical, special, and financial needs, and to orphans who require special attention based on their unique health needs. All of these, intensify demands on caregivers (Kidman & Thurman, 2014; Magidigidi-Mathiso et al., 2025). Many caregivers play an education and training role in children's lives, yet do so in small and often under-resourced, and financially challenged homes (Ayob et al., 2021; Vorster et al., 2016). Many carers have not completed their own formal education, yet they must check, mentor, and assist recipients of their care with their health, diet, medication, homework, projects, and assignments (An et al., 2022; Klein-Cox et al., 2023). A caregiving role can be challenging for many, due to their age, mobility, mental capacity, education levels, and health challenges (Muller-Kluits & Slabbert, 2020; Muller-Kluits & Slabbert, 2018).

Caregivers also play a psychosocial role by supporting recipients of their care to confront and address their psychological and social needs (Andrews et al., 2024; George et al., 2020). Such needs include the children's feelings, emotional and internal thought processes, and their actions and reactions to various stimuli (Celjalvo et al., 2021). On the other hand, they address, nurture, interact with and confront school, family and community networks, cultural practices and traditions, social values, and relationships. They also provide basic physical care, assist with mobility, maintaining personal hygiene, ensuring adequate ventilation, offering support and guidance, and ensuring their carers have adequate food (Kadungure, 2017). Providing, maintaining, and ensuring the emotional wellbeing or physical health of care recipients also form part of caregivers' roles and work (Akpunne, 2015). Their work may also involve continuous caregiving for people living with chronic diseases or physical and mental challenges and disabilities. Govender et al. (2015) reported that due to the high unemployment rate and elevated poverty in South Africa, social assistance, like disability grants, is extended to unemployed

adults living with HIV. Caregivers also take care of adult PLHIV who are unable to take care of themselves (Holmes & Lekganyane, 2025; Lekganyane & Manganyi, 2023).
The medical aspect that caregivers are confronted with includes taking care of children who have acute and chronic illnesses such as HIV, influenza, and cancer treatment, those on ART, and those having special needs (Bélard et al., 2015; Kuo et al., 2014; Piran et al., 2017). They may provide palliative care too.

In this study's context, caregivers not only assist children in their care with HIV treatment, but in disclosing their status to them. A qualitative study that was conducted at a few ART facilities in Vhembe district, Limpopo province, reported that the disclosure process to CLHIV were challenging due to caregivers' inability to comprehensively navigate the process due to a lack of information and skills and fear of the unknown (Muditambi et al., 2024). An HIV diagnosis is linked to ART initiation, adherence and non-adherence and is demonstrated in a qualitative study conducted in Tanzania that engaged 17 HIV-infected AIDS orphans in in-depth interviews. The study highlighted the important role that caregivers play in ensuring that children and youths adhere to their ART. This study and others recommended that they be included in interventions aimed at promoting adherence to their ART medication (Attigah et al., 2025; Gichane et al., 2018; Mokwele & Strydom, 2017). Moreover, a qualitative study conducted on caregivers caring for children with cancer highlighted that they play a pivotal role in delivering invasive and complex treatments with side effects (Melesse et al., 2023). Hence, literacy skills are important in ensuring that caregivers understand the medication, dosages, and side effects that individuals in their care require to avoid contraindications, overdosing or inadequate dosages with further complications (Chew et al., 2021).

Caregivers engage in play and recreational activities with children in their care to promote and stimulate socialisation, learning, interaction, and their emotional, physical and mental wellbeing. Such activities could include participating in and watching sport, dancing, listening to music, singing, and mimicking. Engaging in these activities plays an important role within various South African cultures and assists in children understanding their heritage (Balton et al., 2019). Caregivers also play a mediatory role between health, social, and education practitioners and

oversee the development and growth of their care recipients, thus rendering a key service in the care recipients' environments (Kidman & Thurman, 2014).

In conclusion, caregivers play a pivotal role in care recipients' lives, as their roles influence their care recipients in various ways. Open and honest communication, quality of care, and interaction between the caregiver and the care recipients can adequately address the latters' care, and hence it is important that they have ongoing assistance, counselling and training. This can include the caregivers receiving training and education and skills that would improve their handling of emotional, psychological, educational and academic development of the children.

2.5 POLICIES, FRAMEWORKS AND GUIDELINES THAT SUPPORT PEDIATRIC HIV DISCLOSURE IN SOUTH AFRICA

South Africa is committed to ensuring that age-appropriate sharing of one's HIV status, is a fundamental component of the care, treatment, and support services offered in the HIV management of children with perinatally acquired HIV (CPAH), hence several guidelines, policies and frameworks support this process. These include Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-communicable disease (2016), 2023 ART Clinical Guidelines for the Management of HIV in Adults, Pregnancy and Breastfeeding, Adolescents, Children, Infants and Neonates, Disclosure Toolkit, National Strategic Plan for HIV, TB, STIs (2023 – 2028), Children's Act (Act No.38 of 2005), and The United Nations Convention on the Rights of Children (UNCRC) (Article 12 of 1989) (NDOH, 2016; Children's Act, 2005; EGPAF, 2018, NDOH, 2015, NDOH, 2016).

Children's HIV disclosure is rooted in children's rights, meaning that rendering the decision to keep their HIV serostatus a secret is a violation of their rights (NDOH, 2016). The Children's Act (Act No. 38 of 2005) factors in the age of the child, their level of maturity and developmental stage, physical and emotional security, development of the child's intellect, emotions, social skills and culture, the effect of disclosure or nondisclosure on the child and their circumstances to determine whether it is in the child's best interest. Providing appropriate

developmental and age-appropriate HIV disclosure to CPAH protects their rights whereas nondisclosure violates their rights.

The UNCRC (Article 12 of 1989) highlights that children should participate in all decision-making processes pertaining to their health, treatment, and care, and that disclosing their HIV diagnosis to them should be mandatory and in their best interest. The World Health Organization (WHO, 2011) concurs with the UNCRC and has published guidelines on children's HIV diagnosis and disclosure that recommend an age-appropriate and stepped approach to disclosure.

These guidelines include partial disclosure to the child by six (6) years of age and full disclosure at 12 years (WHO, 2011). Similarly, the South African National Department of Health recommends that HIV disclosure follows a planned process that incorporates different levels of disclosure (NDOH, 2015). Moreover, the disclosure process should be ongoing due to the emergence of new information, and the implementation of policies and guidelines. Such information should be shared with the affected children, mindful of their age and development stage (NDOH, 2015).

2.6 PHASES OF HIV DISCLOSURE TO CLHIV

As CLHIV transition into adolescence and thereafter adulthood, HIV disclosure is a crucial psychosocial and public health concern (Odiachi, 2017). Disclosure to CPAH is not a once-off event but an iterative process that occurs over time and should be repeated to ensure that the child understands all the information shared with them during all the stages of the process (Madiba & Diko, 2021). This process can progress from nondisclosure to partial and then full disclosure. It also includes post disclosure and ongoing support (NDOH, 2023). Nondisclosure, partial and full disclosure are discussed below.

2.6.1 Nondisclosure

Nondisclosure, in this context, refers to secrecy and/or silence around the HIV diagnosis; not being honest or withholding any information pertaining to the child's HIV diagnosis (Elizabeth

Glaser Pediatric Foundation [EGPAF], 2018). Children under five (5) years, are considered too young for information on their diagnosis and are ineligible for HIV disclosure, hence information and explanations about how HIV affects the child, is provided to the caregiver (NDOH, 2016).

2.6.2 Partial Disclosure

During partial disclosure, the caregiver should be mentally and emotionally prepared to initiate the process of informing the child about their HIV diagnosis when they are developmentally ready to consume such information. This phase of disclosure can commence when the child is at the age of six (6) years old and is able to comprehend the information. This process entails caregivers or HCWs providing CLHIV with information about their illness without utilising the words *HIV* or *AIDS*. Instead of *HIV* or *AIDS*, their illness is described as a *germ* that can cause harm if medicine is not taken to put the germ to sleep or to kill it, and the white blood cells are described as soldiers in the body that fight germs and protect the body (Turner, 2021). This disclosure stage involves sharing the reasons for the CLHIV regularly attending the clinic, having their blood drawn, describing how their body works, the importance of nutrition, hygiene and them adhering to their treatment (Tapscott, 2016).

2.6.3 Full Disclosure

During this stage, HCWs and caregivers should provide the child with comprehensive and accurate information and knowledge about HIV, and the word *HIV* can be used (EGPAF, 2016). Healthcare workers or caregivers should dispel all the myths that the child may have about HIV. These myths are often acquired from their familial, community and social circles that include that HIV kills, people get HIV because of promiscuous behaviour, and that PLHIV cannot live normal lives (NDOH, 2023). This phase should begin when the child is 12 years of age and is able to comprehensively understand information about HIV (WHO, 2011).

2.6.4 Ongoing Support for Disclosure

Ongoing support is vital for successful disclosure to ensure the process occurs at the appropriate age or cognitive developmental stage and that the discloser/s are not ill-prepared, or the process does not occur prematurely, accidentally, or age-inappropriately, and results in resistance from the primary caregiver/s. Like rehabilitation, it acts as a buffer throughout the disclosure process

to ensure there is support for the caregiver and child to be confident that someone is available should assistance or interventions be required. Hence the importance of HCWs and caregivers systematically planning the disclosure process in a private, confidential and enabling environment and ensuring that the children have access to ongoing support and guidance.

Madiba and Diko (2021) argue that HCWs should provide continuous disclosure support to caregivers and their children, to monitor their progress on treatment adherence and their emotional wellbeing. Furthermore, other stakeholders such as psychologists, social workers, counselors and medical practitioners should be involved to guide, encourage and facilitate the health and wellness of the children on ART and continuity of care.

2.7 ROLEPLAYERS IN PERINATAL HIV DISCLOSURE

As CPAH grow into adolescents, caregivers and HCWs are faced with the critical decision about *how, when, why* and *who* should disclose the child's HIV-seropositive status to them. Conflicting views between caregivers and HCWs often delay or affect disclosure (Madiba & Diko, 2021; Sabharwal et al., 2018). The NDOH (2016) suggests that the child's caregiver should initiate and lead the disclosure process but does recognise that caregivers could partner with HCWs or request HCWs to facilitate the process.

Some caregivers are reluctant to initiate the disclosure process due to their discomfort about discussing HIV transmission and sex with their children, lacking the skills and adequate and relevant information to disclose, and their inability to respond to questions in an age-appropriate manner (DeSilva et al., 2017). This is demonstrated in studies (Madiba, 2016; Mashile & Maake, 2024; Sabharwal et al., 2018; Turner, 2021) that show that caregivers may want to disclose on their own but are unable to, due to lack of proper skills and knowledge, and would therefore need support from HCWs to provide more accurate information, answer questions that may arise from CPAH and provide psychosocial support and counselling that caregivers may not be able to provide. Even though caregivers indicate that they require the support of HCWs in disclosing to their children, they are conflicted as they see themselves as being primarily responsible for disclosing to their children (Madiba, 2016). A study conducted in China found that most caregivers preferred and requested the assistance of HCWs to lead the disclosure process as the

topic was too sensitive for them to do on their own. The participants cited feelings of guilt, condemnation and irresponsibility in their inability to protect their children from an HIV-infection (DeSilva et al., 2017).

Other stakeholders who may play an integral role in the HIV-infected child's disclosure are healthcare workers, social workers, medical practitioners, psychologists, counsellors, and HIV counsellors as many of them have been trained in HIV counselling and testing (HCT), disclosure and ART (Madiba, 2016; Odiachi, 2017; SAHCS, 2017).

2.8 PREVALENCE OF PEDIATRIC HIV DISCLOSURE IN SOUTH AFRICA

Statistics for pediatric HIV disclosure are not easily available on statistical websites; however, some studies have assessed the prevalence of pediatric HIV disclosure (Hayfron-Benjamin et al., 2018; Madiba & Diko, 2021; Turner, 2021). An example is a study conducted in the Western Cape of South Africa, which reported that 145 (76.3%) of 190 interviewed caregivers of CLHIV stated that they had not informed the children of their status. In addition, 28 children (14.7%) had been partially disclosed to, while only 17 children (8.9%) had been fully disclosed to (van Elsland et al., 2019). The HIV disclosure guidelines for children and adolescents in South Africa has reported that in a study on the demographic characteristics and trends of HIV disclosure in children, only 59 of 149 children (39.6%) had been fully informed of their HIV diagnosis. Of the 59 children who had been fully disclosed to, 30 (50.85%) were aged between 11- 17 years when they first learned of their diagnosis, 26 (44.1%) were between 6 to 10 years of age, and 3 (5.1%) were below the age of 6 years (NDOH, 2016). Furthermore, a cross-sectional survey of 406 caregivers of CLHIV conducted in Mpumalanga province, South Africa, found that only 27% of CPAH knew their HIV-seropositive status (Madiba & Mokgatle, 2017).

From the literature, it is evident that pediatric HIV disclosure is an important process with many factors influencing it and these are discussed below.

2.9 FACTORS AFFECTING DISCLOSURE TO PERINATALS

Disclosure of CPAH's status is a multifaceted and complex process that is affected by the caregivers' perceptions of disclosure, their knowledge and skills on disclosure, stigma, fear, concerns regarding the CPAH's emotional maturity to accept, understand and deal with their diagnosis, and the impact of religious and cultural beliefs (Makworo & Odero, 2019). Notwithstanding all these factors, research has indicated that disclosing children's HIV-seropositive status has more benefits than psychological and emotional harm (Buckley et al., 2022; Mpofu & Jacobs, 2017; Sokhela, 2016).

2.9.1 Caregivers' Roles and Perceptions on Disclosure

Caregivers are perceived as the primary source of care by the children in their care and key stakeholders within the patient's social networks, including family members, relatives, friends, and volunteers. Other stakeholders involved in the HIV-seropositive child's disclosure are parents, grandparents, guardians, healthcare workers, social workers, medical practitioners, counsellors, and HIV counsellors (Madiba, 2016; Odiachi, 2017). Some caregivers are trained while others are not. Their roles are to provide companionship, health education, medical support, and nutrition assistance for people under their charge, and some accompany their minders on their visits to hospitals and clinics (Kalembo et al., 2018). Caregivers may decide not to disclose or postpone the disclosure process due to the guilt and shame attached to watching their children grow up with HIV, being afraid of what their children may ask during the disclosure process and them having little or no support from their spouses, partners and others (Evangeli & Kajee, 2016). It is also reported that due to many fathers' tendency to shift the responsibility to raise their children to their mothers, many refrain from disclosing to their CPAH and surrender this task to the mothers (Wariri et al., 2020).

2.9.2 Inadequate Knowledge and Skills

Doat et al. (2019) reported that caregivers with low literacy levels and insufficient knowledge of disclosure often resist telling their children about their HIV diagnosis, while Tucho et al. (2021) reported that caregivers with high levels of education are likely to inform their CPAH of their HIV status. These findings are similar to those revealed in research carried out in Ethiopia on the elements that contribute to HIV disclosure to CPAH, where it was found that caregivers' level of

education had a significant impact, either positive or negative, on disclosure. Caregivers with primary education are usually more willing to disclose compared to caregivers who are not fully informed (Abegaz et al., 2019). Furthermore, a study conducted in Ghana on caregiver's experiences of HIV disclosure to CLHIV, found that caregivers lacked disclosure skills and were uncomfortable and uncertain of children's reaction to disclosure, and therefore opted not to disclose to them (Klutsey et al., 2021).

2.9.3 Stigma

Stigma in most rural communities constitutes one of the major barriers to caregivers disclosing their children's HIV diagnosis, (WHO, 2011). The WHO (2011, p.11) acknowledges that stigma is a barrier to HIV disclosure and states that "… reducing stigma should make disclosure easier and thus increase the uptake of treatment, adherence to medication, and coping with HIV-related symptoms and the side effects of treatment." However, many caregivers are reluctant to expose their children to any form of stigma and discrimination. This reluctance is born out of fear of any adverse repercussions on their lives, wellbeing, and mental health (Wariri et al., 2020). This is borne out of caregivers' responsibility of protecting their children from stigma and discrimination by shielding them from interactions and information that may psychologically harm them. Moreover, biological caregivers fear that their children may inquire about their role in transmitting the virus to their children and them being pressured to disclose their own HIV status (Nabunya et al., 2020).

Fear of stigma results in poor social connections, caregivers not accessing resources and services that are beneficial to CLHIV and their caregivers and not engaging in supportive community structures such as adherence clubs and support groups (Kontomanolis et al., 2017).

2.9.4 Fear of negative outcome

Caregivers fear initiating HIV disclosure dialogues as they regard their children as minors who are too immature to comprehend their HIV-positive diagnosis, the mode of transmission and infection, the outcomes of such disclosure, the impact of internal and external stigma, and their relationship with their care recipients post the disclosure (Joyce et al., 2017; Li, et al., 2015).

They are also concerned with their children's reasoning capabilities, their capacity to manage the pressures of their HIV-infection, and the fear that the children will accuse them of transmitting the infection to them (Okolo-Francis et al., 2021). They also fear that their children may ask questions that they will not be adequately able to respond to or feel uncomfortable answering. Another fear of caregivers is that children's awareness of their HIV serostatus may result in them experiencing depression, anxiety or contemplating committing suicide. Previous studies (Kreniske et al, 2019; Rukundo et al., 2020) have reported an increase of suicide risks among youth living with HIV and those receiving ART. The relationship between an HIV diagnosis and suicide is due to diagnosed people feeling hopeless, depressed, having low self-esteem, and poor social support. In most cases, young people living with HIV hide their suicidal ideations due to fear of being stigmatised and negatively judged by others. For fear of them committing suicide, caregivers prefer to conceal their children's HIV status to them.

Some caregivers fear their children disclosing their HIV status to their friends/schoolmates or to other family members, may result in them, or their caregivers being rejected and discriminated against (Doat et al., 2019). Others fear that their children would worry about their prognosis and not fully enjoy their lives or successfully complete their education, due to other children's or adults' perceptions and attitudes about their diagnosis and prognosis (Mandalazi et al., 2014). This could be worsened due to caregivers still struggling with their own feelings of guilt and shame (Tapscott, 2016). Caregivers have reported hiding their children's diagnosis out of fear of depriving them of a happy and fulfilled life (Joyce et al., 2020).

2.9.5 Attitudes and Behaviour of Healthcare Workers and Service Providers

In South Africa, pediatric HIV disclosure is often affected by the conflicting opinions between HCWs and caregivers on when and whose responsibility it is to disclose to CLHIV (Madiba & Diko, 2021). Moreover, some HCWs report that they have not been adequately trained in pediatric HIV disclosure, some feel uncomfortable doing so, while others disclose without referencing specific guidelines (Namasopo-Oleja et al., 2015). Some HCWs are ill-prepared to disclose to children, hence they find this process complex, emotionally draining and time consuming and rather choose to distance themselves from the process. Lack of clear documentation about the levels of disclosure in clinical charts as well as poor communication

amongst staff members within the same healthcare facilities are also contributing factors for HCWs feeling uncomfortable about facilitating the disclosure process. Dahourou et al. (2018) recommend that the progression of the disclosure process should be clearly recorded in clinical charts to allow other HCWs involved in managing the child to be well informed to avoid accidental disclosure or to avoid providing information that is above the child's reasoning capacity.

A study conducted in Gombe, Northeast Nigeria, found that most caregivers shifted the responsibility of disclosure to HCWs, believing that they are trained and know more about HIV, and they should either facilitate or provide support during disclosure (Wariri et al., 2020).

2.9.6 Cultural and Religious Beliefs and Alternative Medicines

Cultural sensitivity, especially in rural areas, affects HIV disclosure to CPAH as caregivers in these areas, avoid discussing issues relating to sex, sexuality, and sexually related illnesses (STIs) including HIV with their children (Marhefka et al., 2017; Wariri et al., 2020). Adegoke cited in Mpofu et al. (2020), argues that some religions perpetuate negative beliefs about HIV such as an HIV diagnosis being a result of sin, or due to immoral behaviour (Adegoke, 2015). This can result in CLHIV being negatively viewed due to their parents' sin and immorality. In addition, accepting the HIV diagnosis and choosing to initiate on ART is perceived as the caregivers and/or PLHIV having insufficient faith in their God to heal them (Mpofu et al., 2020). Such views and beliefs can influence non-adherence to their treatment and affect and influence the caregiver's decision to disclose or conceal their child's HIV seropositive status (Vreeman et al., 2015).

Doat et al. (2019) acknowledge that open and free discussion on sex is viewed as a taboo in most SSA countries, resulting in caregivers refraining from discussing this with their children. This has also been observed by Marhefka et al. (2017) that caregivers are not comfortable discussing sex, especially with their care recipients. Consequently, caregivers' silence or discomfort in discussing sex and sexual issues with their children and their fear of their children questioning them on the source of their infection, result in their decision to keep their child's HIV-positive serostatus a secret.

Within many traditional families, men are the heads of the households, the providers and defenders and are expected to procreate and have their own children and families (Cavaliere, 2020; van Zyl & Visser, 2015). Hence, many women and men choose to conceal their HIV diagnosis to their partners and procreate as they do not want to disturb their traditional and cultural roles. This could be attributed to them having insufficient understanding and awareness of sexual and reproductive health (SRH) in relation to PLHIV. Thus, the importance of discussions on SRH, morality, and sex is crucial.

2.9.7 Child's age and cognitive development

The perception that children are incapable of understanding their HIV diagnosis often hinders the disclosure process to CLHIV (Doat, 2019). A child's age is often coupled with cognitive immaturity and incapability to comprehend their HIV diagnosis and its implications (Kairania et al., 2023). Mphego et al. (2023) acknowledge that a child's age may negatively affect disclosure, but advocate for staged disclosure, as recommended by WHO, which encourages partial disclosure and then full disclosure to 12 years old children (WHO, 2011). Caregivers are more likely to tell their care recipients of their HIV diagnosis when they believe that their care recipients have a high-level of maturity and can understand their diagnosis. The reasons given by caregivers for hiding their children's HIV diagnosis from them, affects their adherence to ART as some children end up refusing to take their treatment. However, Joyce et al. (2022) argue that the perception that children are too young to understand that they have HIV reflects the caregiver's inability or refusal to disclose to their children, rather than children's inability to understand or accept their HIV status.

2.9.8 Caregiver-child relationship

The relationship between caregivers and their children is a contributory factor that affects disclosure (Madiba et al., 2013). Mandalazi et al. (2014) found that non-biological caregivers are more likely to tell children about their HIV-seropositive status than biological parents as the latter express fear, guilt and self-blame for infecting their children with HIV. The caregiver-child relationship can positively or negatively affect disclosure. The latter occurs when the caregiver's relationship with the child is poor, or the caregiver may decide not to disclose or to postpone disclosure if they perceive that tensions in their relationship may arise due to disclosure.

2.10 ADVANTAGES AND BENEFITS OF DISCLOSURE

Evidence from studies has shown that pediatric HIV disclosure has positive clinical and psychological outcomes (Abegaz et al., 2019; Hayfron-Benjamin et al., 2018). Children who have had their HIV-seropositive status disclosed to them are able to make informed health choices, actively participate in their care and treatment, improve their adherence, and are less likely to experience advanced HIV disease (AHD) and death (Sariah et al., 2016). Madiba and Diko (2021) concur that disclosing to CPAH is an essential milestone in the retention and continuation of their HIV management and care.

Social and psychological challenges affect CPAH's adherence to ART, and unawareness of their HIV status affects their pediatric development and outcomes. Advantages of disclosing their status to them prior to transitioning to adolescence can improve adherence to ART, their active involvement in their appointments, ongoing care and treatment, their ability to make good health choices and improve their psychosocial adjustment and self-esteem and reduce horizontal transmission due to unsafe sexual behaviour later (Wariri et al., 2020). Timely and supportive disclosure processes and age or developmentally appropriate information sharing can enhance their physical, emotional, and psychological wellbeing (Beima-Sofie, 2017). These processes can assist children to better understand their medical condition, act as motivation for them being more involved in medical care decision making, increase their adherence to ART, and facilitate closer child-parent-health provider relationships (EGPAF, 2018). Msoka et al. (2025) acknowledge that disclosure may reduce caregivers' burden as CLHIV may take their medication without being reminded by their caregivers. When caregivers disclose to their children it promotes respect and trust and improves their relationship. It could also be the catalyst for navigating difficult and sensitive conversations on death, bereavement, and health in the future by fostering mutual understandings. In addition, disclosure can facilitate CLHIV seeking relevant support or joining support groups thereby reducing secrecy, misinformation and stigma, promoting openness, improving their self-esteem and image, and addressing issues of shame or guilt, thus resulting in an improved and healthier mindset.

Disclosing to CPAH allows them to understand their HIV-infection, how their medicine works and protects the lives of people around them. This is due to them transitioning into adolescence,

when many adolescents involve themselves in unsafe sexual behaviours. Thus, being aware of their HIV status could encourage them to prevent transmitting the virus to others by practising safe sex (Sokhela, 2016).

Nevertheless, despite governmental guidelines and policies, awareness programmes, HIV counselling and non-profit organisations' (NPOs) interventions, several reports show that pediatric HIV disclosure rates are low in RLS (Hayfron-Benjamin et al., 2018; Madiba & Diko, 2021; NDOH, 2016). This can be attributed to barriers preventing caregivers from facilitating perinatal HIV disclosure which include their fear of disclosing the HIV diagnosis, lack of disclosure skills, and assumptions that children are too young to comprehend such a diagnosis and prognosis (Okolo-Francis et al., 2021). Furthermore, caregivers hide their children's HIV status because they are unsure of how their children will react to the disclosure (Bulali et al., 2018), or will share their status with their friends, family and community members with dire consequences. Due to these factors, they shift the responsibility of disclosure onto HCWs (Zanon et al., 2021).

2.11 DISADVANTAGES AND POTENTIAL RISKS OF DISCLOSURE

Very little evidence exists on mental, cognitive or emotional impairment of children due to perinatal HIV disclosure while evidence does exist on the absence of appropriate support and community acceptance, accidental or unintentional disclosure. The latter negatively affects the wellbeing of infected children and their families (WHO, 2011). Stigma and discrimination play a negative role in disclosing PLHIV's status in communities as it can cause shame, social isolation, unfair treatment and bullying or discrimination. Likewise, a child's HIV diagnosis becomes a family health issue that affects other family members and subsequently the entire family (Joyce et al., 2022). Lower disclosure rates are associated with the fear of stigma and discrimination from other family members who are unaware of the child's HIV status. Caregivers fear that their children's HIV status could become known by others who may accidentally or maliciously pass the information on to others, thus leading to stigma and undue family discrimination (Sariah et al., 2016). It has been recorded by Mukhtar-Yola and Kuczawski (2020) that the fear that children may disclose their HIV status and that of their parents to other children and family

members has also been reported in Nigeria, because most of the extended families live in one big compound and the children play together as a family. Therefore, there is a high possibility of them accidentally sharing their HIV diagnosis.

A study conducted in Lima, the capital city of Peru, found that CLHIV react differently when they are informed of their HIV status as some initially became depressed and angry with their caregivers, but psychological support assisted them to gain perspective and knowledge about HIV. Furthermore, HCWs and caregivers of CLHIV reported declining adherence to treatment immediately after disclosure but it improved as time progressed (Baker et al., 2018). Turner (2021) reaffirms that the risks of disclosing HIV diagnoses to CLHIV include internalised stigma and stigma from others, withdrawing from peers, escalating behavioural problems and rebellion, and children accusing their parents of purposefully infecting them with HIV. Caregivers also fear the backlash of disclosure.

Caregivers must confront and decide on the advantages and disadvantages of disclosure as it can improve relationships and adherence to ART, empower their children with information, but if not done correctly can have potential psychological implications.

2.12 CONSEQUENCES OF NONDISCLOSURE

Nondisclosure of children's HIV status in this context, refers to withholding complete information from the child about their HIV serostatus and not informing the child that they are living with HIV (EGPAF, 2018). The literature shows that nondisclosure presents HCWs with challenges especially during adherence counselling to CLHIV as they must avoid mentioning *HIV* or *AIDS* during their counselling session, and this results in unproductive adherence counselling (Madiba, 2016; Makworo & Odero, 2019). Moreover, children's non-adherence to ART hinders virological suppression and treatment success, and can result in cross-resistance to similar drugs, multi-drug resistance, poor health outcomes, psychological distress, or morbidity (Amankwah-Poku et al., 2021; van Elsland et al., 2019). These outcomes negatively affect the child, family, their educational trajectory and community while further burdening a challenged health care system.

As children transition to adolescence, they begin to engage in sexual activities, and nondisclosure of their HIV serostatus puts them at risk of transmitting the virus to others due to non-adherence to their treatment, (Dlamini & Matlakala, 2020; Mphego et al., 2023). Nondisclosure of a child's HIV serostatus may lead to unsatisfactory health-related outcomes in CLHIV such as poor adherence to ART, unsuppressed viral load, AHD and low self-esteem which have harmful consequences and negatively impact the health of the CLHIV. In SSA countries, poor health outcomes such as psychological distress, burden of keeping a child's HIV status secret and the fear that the child may accidentally discover their HIV status have been recorded from caregivers of CLHIV (Amankwah-Poku et al., 2021; Msoka et al.,2025; Nathaniel et al., 2024). As a result of a lack of open and transparent discussions regarding the child's illness within the family, some caregivers opine that nondisclosure breeds anxiety, stress and dysfunctional relationships within the family, (Amankwah-Poku et al., 2021; McHugh et al., 2018). Furthermore, HCWs have observed negative outcomes of nondisclosure to children on ART as some become rebellious, withdrawn, exhibit a lower self-esteem, and refuse to continue taking their HIV medication or attend health facilities. Hence, nondisclosure can be perceived as denying children their agency and the opportunity to make informed decisions and take responsibility for their own health and wellness (Madiba & Diko, 2021).

2.13 RECOMMENDATIONS FOR IMPROVING DISCLOSURE

The importance of disclosing a pediatric HIV diagnosis to CLHIV cannot be overstressed. However, the way it is conducted, the timing and the environment in which such disclosure is conducted, the emotional, cognitive, developmental and social status of the child and the stakeholders involved in the disclosure are important components of this process (Gomo et al., 2017; Hayfron-Benjamin et al., 2018). This is an emotional and sensitive intervention and a challenge for most caregivers with implications and consequences. These include children rebelling against them, becoming distant, having cognitive, mental health and behavioural challenges, non-adhering to ART, being stigmatised and discriminated against, having suicidal ideations and acting on those, hurting themselves and others hurting them (Nabunya et al., 2023; Ramsammy et al., 2022). Moreover, the children could disclose their status to others who may

not have their best interest at heart, and they may become traumatised or emotionally or psychologically affected. Incorporating all the above, the researcher sourced studies that highlighted recommendations aimed at improving this emotionally charged process and they include the caregivers, HCWs, families and communities.

2.13.1 The Timing of the Disclosure Process

Governments, health departments, humanitarian agencies, non-governmental and community organisations, HIV/AIDS activists, parents, caregivers, and healthcare workers have advocated for gradual and age appropriate and developmental HIV disclosure to CPAH (Mburu et al., 2014; Mugo et al., 2023; Sariah et al., 2016; WHO, 2011). More importantly, it is imperative that all stakeholders take this staging into account when disclosure is contemplated or taking place. The disclosure process should include rigorous planning that is age and developmentally appropriate and be linked to ongoing medical support and counselling (NDOH, 2016). Pediatric HIV disclosure should be an ongoing process entailing progress from non-disclosure to partial disclosure and then full disclosure.

2.13.2 Environment must be conducive to disclosure

Caregivers that participated in a study undertaken in the Vhembe district of Limpopo province, suggested that establishing caregivers' support groups has the potential to encourage disclosure as caregivers can learn from the experiences of others who have disclosed to their CPAH (Mphego et al., 2023; Muditambi et al., 2024). Aderomilehin et al. (2016) suggest that the setting should be an essential consideration in the disclosure process to ensure that both CLHIV and their caregivers feel safe and comfortable during the process. Healthcare facilities are preferable settings for the disclosure process as they afford an opportunity for caregiver support during the process.

2.13.3 Healthcare Workers and Caregiver Training and Knowledge Sharing

Caregivers who are uncomfortable disclosing children's HIV status to them should identify skilled and experienced individuals to do so. Health education that includes modes of HIV transmission, dealing with stigma, overcoming shame and guilt and initiating disclosure of HIV

status were also mentioned by caregivers as important for improving pediatric HIV disclosure (Mphego et al., 2023). A study conducted by Madiba and Diko (2021) found that HCWs had implemented different intervention strategies to assist caregivers to disclose to their children. These strategies included working with caregivers to identify their challenges and barriers to disclosure and trained and capacitated them with disclosure skills and how to deal with negative emotional reactions of their children during and after disclosure. The literature highlighted that HCWs lack relevant information on disclosure; hence the DOH should provide capacity building on the staged disclosure process and cultural sensitivity to ensure that they are trusted partners with caregivers navigating the complex disclosure process. Moreover, African and culturally appropriate disclosure materials should be developed and provided, given the influence of culture and tradition in KZN and other parts of South Africa. Health facilities should facilitate partnerships with religious and traditional leaders so that disclosure can be framed within the ambits of culture and religion. Community healthcare workers and community leaders should also form part of community healthcare outreaches to facilitate open dialogues on HIV, stigma, perinatal disclosure and adherence (Kalembo et al., 2018)

2.13.4 Resources and Tools to Facilitate the Disclosure Process

To encourage caregivers and HCWs to engage CALHIV in the disclosure process, Wright et al. (2017) recommend tools that can assist HCWs navigate this essential, yet sensitive process. A clear step-by-step guide that provides information and non-stigmatising words for HCWs during the disclosure process can boost their confidence and knowledge, thus leading to successful disclosure. Turner (2021) has suggested utilising the Mini Flipster Disclosure Method (MFDM) to assist HCWs and caregivers with the disclosure of CALHIV's status. The MFDM educates CLHIV about HIV and how the disclosure process can be conducted prior to disclosing children's HIV status. Consideration can be given to having mobile health clinic staff offer counselling on pediatric disclosure and since we are in a digital age information could be uploaded on social media platforms or using chatbots or WhatsApp messaging. This recommendation could aid in lowering information and logistical barriers.

2.13.5 Communication

Children require honest, relevant, and correct information that is age, developmentally, emotionally and cognitively appropriate to alleviate their fears and concerns regarding their HIV status (Okolo-Francis et al., 2021; Sariah et al., 2016; WHO, 2011). Responsible and skilled HCWs could lead the disclosure process in tandem with the parents/caregivers to help them learn, understand and explore all aspects of HIV, and how the disease affects them and their future life with HIV. Healthcare professionals and workers, HIV counsellors, and social workers could play a continuous role in assisting and educating caregivers to facilitate timely HIV disclosure in a sensitive and respectful manner that does no harm to their children and their lives (Li et al., 2015). The WHO (2011) suggests that HCWs and caregivers should use simple age-appropriate language that corresponds with the child's level of maturity. Age-appropriate messages will ensure that children understand the information about HIV and do not cause any harm.

2.13.6 Policies, Interventions and Guidelines

Mphego et al. (2023) suggest that it is essential for policies and strategies to empower and capacitate caregivers of CLHIV with the 'sadequate information, knowledge, and skills necessary to successfully initiate the HIV disclosure process with their children. Pediatric HIV disclosure interventions should aim at influencing HCWs and caregivers' disclosure decision-making, and interventions aiming at reducing stigma connected to HIV-infection in the community could greatly contribute to improving HIV related disclosure to CLHIV (Dahourou et al., 2018). Likewise, Mandalazi et al. (2014) concur that psychosocial support services that aim at assisting caregivers with disclosure process should be made available.

2.13.7 Embracing a right-based and child centred approach to disclosure

Patient-centred and child-centred care are advocated for globally; hence disclosure should embrace these approaches as these align with the UNCRC (UNICEF, 2025). The focus of these approaches is on the involvement of children in age-appropriate dialogue on matters (HIV disclosure) that affect them, facilitating pre, post and ongoing support that is contingent upon the needs of the caregivers and recipients of their care. The researcher argues that the staged

disclosure process can be perceived as a top-down, prescribed approach instead of a child-centred, developmental one where disclosure is customised to the emotional and cognitive readiness of the caregiver and their child.

Implementation of the recommendations can result in multidisciplinary, culturally sensitive, collaborative and empowering disclosure processes that encourage CLHIV and caregivers to thrive in informed, engaged, resilient homes, health facilities, relationships, care and treatment.

2.14 LITERATURE GAPS

Every endeavour was made to source as much literature on perinatal disclosure by caregivers, but literature gaps still exist. These gaps include more female than male caregivers' experiences, a lack of longitudinal studies that focus on monitoring the clinical and psychosocial impact of disclosure, experiences of caregivers living in cities rather than those living in rural settings, and the implementation and impact of social media and digital interventions on perinatal disclosure. Studies on the relationship between perinatal HIV infections and CLHIV's future sexual reproductive health and sexual desires are silent in the literature and the development of these could expand the knowledge bases on the topic. Moreover, studies on the impact of single-parent disclosure are absent. Additionally, studies on the reflexive lived experiences of adults who were perinatally infected with HIV are required as they have had time to reflect on what worked and what did not and provide input to improve the disclosure process. The dynamism of disclosure is not pronounced in studies, thereby highlighting the need for caregivers, their children and health professionals to engage in participatory research to manifest the co-creation and construction of knowledge on best disclosure practices that embrace culture, religion and tradition and are developmentally relevant.

2.15 THE RELATIONSHIP BETWEEN SOCIAL WORK AND PERINATAL HIV DISCLOSURE

In his book, *Introduction to Social Work and Social Welfare*, Zastrow (2017, p.41) maintains that "Social Work is a professional activity of helping individuals, groups, families, organizations

and communities to enhance or restore their capacity for social functioning and to create societal conditions favorable to their goals." He further argues that social workers possess the expertise to effectively address the challenges confronting individuals, groups, families, and societies. Social workers' tasks include rendering effective counselling and services as they possess the knowledge, values and skills to effectively intervene in the social, environmental and psychosocial aspects of individuals, groups and communities' social problems and in individuals personal and emotional problems.

Social workers have assumed a pivotal role since HIV/AIDS was first identified in the early 1980s by providing support, counselling, conducting home assessments for PLHIV, and support for medical practitioners who provide medical care for PLHIV (Lekganyane & Alpaslan, 2019; Mutluri, 2021; Shaari et al., 2024). Social work practitioners have also made a significant impact on educating communities regarding HIV/AIDS, upholding the rights of CLHIV, developing intervention strategies aiming at preventing the spread of HIV, facilitating group counselling, and providing emotional and psychosocial support to PLHIV, their friends, families and partners. They have the capabilities, knowledge and skills to address their clients' emotional needs, self-management skills, sexual and reproductive health, and internal and external stigma attached to an HIV diagnosis (Okonji et al., 2020).

Sesane and Geyer (2017) and Shaari et al. (2024) state that social work professionals have been utilising their psychological and clinical expertise to assist individuals, groups and families manage trauma associated with learning about their HIV diagnosis. Through their organisational skills, they have assisted with implementing community-based structures to train and educate societies and advocating on behalf of PLHIV. Involvement of social workers in pediatric HIV is intensive as they render multifaceted therapeutic and psychological support to CLHIV and their parents or caregivers. They ensure that essential services and resources are available and easily accessible for CLHIV, thereby equipping families with the relevant HIV knowledge and frequently acting as negotiators between medical and psychosocial care. Their expertise in rendering integrated and comprehensive care places them in a unique position to support disclosure decisions as they are often called upon to provide guidance and support in preparing CLHIV and parents or caregivers for full disclosure of HIV diagnosis.

Verma (2020) asserts that social work practice contributes to the management of HIV/AIDS as social workers provide counselling, treatment adherence support, disclosure counselling and social justice activities to PLHIV and those affected by HIV and AIDS. Such practice includes pediatric HIV disclosure. He further adds that social workers interact and are conversant with a diverse range of community structures and resources that include support groups, support grants, skills development and nutrition programmes that may be useful to CALHIV and their caregivers.

Social workers in health and medical settings also link caregivers and their CLHIV with resources through referrals, assessments, and render psychosocial support prior, during and after the disclosure of the perinatal HIV serostatus due to the complexities associated with HIV disclosure (Manganyi, 2021). Moreover, social workers form part of multidisciplinary teams (MDTs) at hospitals and clinics that provide management and services to CLHIV and their carers. The findings of this study will help social workers understand caregivers' experiences and to tailor make interventions and responses to best serve them.

2.16 SUMMARY

This section concludes the review of literature on caregivers' experiences and perspectives on disclosure to CPAH. The literature showed that the disclosure process is complex and multifaceted as it factors in cultural, social, psychological, financial and medical elements and implications. Also revealed through the literature was that perinatal HIV disclosure rates are low despite the benefits of disclosure outweighing any potential risks. The researcher also reviewed the factors affecting disclosure to CLHIV, the people responsible for initiating or facilitating disclosure, the different levels of disclosure, the consequences of nondisclosure, recommendations aimed at enhancing disclosure, and the relationship between the social work profession and pediatric HIV disclosure. The theoretical framework is discussed in the next chapter.

CHAPTER THREE
THEORETICAL FRAMEWORK

3.1 INTRODUCTION

This chapter presents the theoretical framework that undergirths this explorative qualitative study on the complexities of pediatric HIV disclosure. A theoretical framework is used to predict, investigate, understand and explain a phenomenon. It is the glue of the study as it links the topic, and encompasses the literature review, the research design, methodology and methods (Passey, 2020). Pediatric/perinatal HIV disclosure includes many roleplayers including the child, caregiver, community, and healthcare workers. In addition, there are health facilities, policies, guidelines and processes, interpersonal and social factors, strategies, processes, and challenges involved in the process, hence the importance of utilising a theoretical framework that is best suited to achieving the study's aims and objectives. Different theories that have been used in perinatal/pediatric HIV disclosure are now unpacked.

3.2 THEORETICAL FRAMEWORKS

Various conceptual frameworks and theories including the Attachment Theory (AT) (Ramsammy et al., 2022; Zeanah et al., 2011), Social Cognitive Theory (SCT), Social Learning Theory (SLT), Cultural Theory (CT), Family Systems Theory (FST), Social Stigma Models (STM), Theory of Planned Behaviour (TPB), Health Belief Model (HBM) and the Ecological Systems Theory (EST) have been used in studies to understand the complex process of disclosing pediatric HIV-seropositive status (Cantrell et al., 2013; Kidia et al., 2014, Madiba & Diko, 2021; Rochat et al., 2016). These theories are briefly explained below.

3.2.1 Attachment Theory (AT)

Bowlby's attachment theory has framed studies investigating the relationship/bond between caregivers and CPAH in their care, and the disclosure process between them (Ramsammy et al., 2022; Zeanah et al., 2011). The importance of the child-caregiver dynamic as influential in the

manner and time that the disclosure occurs is stressed in studies that use Bowlby's theory. A positive and strong dynamic/attachment enables confidence in the carer to facilitate the disclosure process whereas distrustful and toxic relationships hinder and delay the process. Ramsammy et al. (2022) highlighted the relevance of using the AT in their study on the perspectives of disclosure on recipients of care and showed how the AT was used in such a study. In this study, the caregivers' perspectives were accessed.

3.2.2 Social Learning Theory (SLT)

Bandura's Social Learning Theory (SLT), highlights modelling, observing and imitating as catalysts for learning behaviours (Bandura, 1977). Reproduction, attention, motivation and retention, are components of this theory that demonstrate how acquired or learned behaviour is modelled through social interactions with people and environments. In relation to pediatric or perinatal HIV disclosure, SLT is relevant as it highlights caregivers as role models guiding children in their care's sensitive journeys living with HIV and can articulate their disclosure journey to others and their children (Joyce et al., 2022). Demonstrations of positive reinforcement through encouragement and support are useful tools that enhance the disclosure process. Moreover, within the social circle (family, healthcare providers, and peers) it can shape their attitudes and behaviours towards HIV disclosure. Caregivers' observations of successful HIV disclosure can motivate them to pursue a positive attitude towards disclosure and if they observe discrimination or stigma, they could resist disclosing, thereby cementing the relevance of social learning in various social contexts. This highlights that caregivers' observations of outcomes of disclosure, influence their decision to disclose.

3.2.3 Social Cognitive Theory (SCT)

This theory was developed by Albert Bandura and emphasises observational learning, self-efficacy and social learning as components of people's behaviour change and the dynamic interaction and relationship between people, their environment and behaviour (Islam et al., 2023). It has been used in a study on disclosure among HIV-seropositive men who have sex with other men (MSM) (Brown et al., 2015), while Jia et al. (2022) used SCT in the context of disclosure, quality of life and self-efficacy among MSM. Relevant to this study is one conducted

by Sokhela (2016) on caregivers' experiences of disclosing children's HIV-positive status to them.

The difference between Bandura's SLT and SCT is that the latter places emphasis on how mental processes can shape an individual's behaviour, whereas the former emphasises the importance of observation and imitation.

3.2.4 Family Systems Theory (FST)

Bowen's Family Systems Theory positions the family as a cohesive emotional unit and a mode of differentiation that highlights the interdependence of family systems to enhance and facilitate healthy relationships and self-reflection, communication and growth (Papero, 1990). In the context of pediatric HIV disclosure, this theory assists in unpacking how immediate and extended family can influence and affect caregivers' decisions to disclose, the emotions associated with such disclosure and the consequences such as disrupting family harmony and caregivers' relationships with children in their care and family members (Jantarapakde et al., 2019; Khumalo et al., 2020).

3.2.5 Theory of Planned Behaviour (TPB)

Icek Ajzen's Theory of Planned Behaviour (TPB) serves as a predictor of human behaviour that incorporates perceived behavioural control, negative or positive attitudes and subjective norms as influencing people's decisions to behave in particular ways, and such decisions affect their execution of such behaviour (Tornikoski & Maalaoui, 2019). Within a study on caregivers' disclosure of pediatric HIV status, TPB can assist in understanding the complex barriers influencing their decision to inform the children in their care about their diagnosis (Jemmott III, 2014). The decision to inform children of their HIV seropositive status is complex, as caregivers' attitudes are influenced by their lives, beliefs and traditions, and their perceived benefits (improved relationships and trust relationship) and risks (stigma, mental illness and isolation). These subjective norms incorporate their expected or supported expectation of whether others will agree with their choice to disclose. Caregivers perceived behavioural control includes the available resources, support, and their emotional readiness to disclose. If their perceived barriers are numerous due to insufficient information and skills and stigma they may choose not to

disclose. These predictors of human behaviour can facilitate relevant interventions being developed that improve their attitudes, strengthen their support systems and significantly reduce all barriers prohibiting disclosure.

3.2.6 Health Belief Model (HBM)

The Health Belief Model (HBM) was developed in the 1950s and is popular in health behaviour and related studies (Orji et al., 2012). The six tenets of the HBM are: *perceived susceptibility* due to people viewing themselves or others as being at risk of a health challenge; *perceived severity* incorporates how serious they view the challenge and its consequences; *perceived benefits* of taking a particular stance such as disclosure; *perceived barriers* about any challenges associated with an action (stigma, fear); *cues to action* that incorporate the triggers (advice, support) that encourage such action; and *self-efficacy*, meaning their confidence in their ability and capacity to carry out the action (disclosure) successfully with positive outcomes. Relating to caregivers' disclosure, the HBM can align the six tenets to improve perinatal HIV disclosure rates (Aurpibul et al., 2023). This can be achieved through training programmes, provision of information and emotional support, and creating a nurturing environment that reduces perceived barriers and increases their confidence to disclose.

3.2.7 Bronfenbrenner's Ecological Systems Theory (EST)

Urie Bronfenbrenner's Ecological Systems Theory (EST) was developed in the 1970s and consists of socially organised subsystems that assist, support, and guide human development or growth to study the whole ecological system (Bronfenbrenner, 1994). It comprises nested systems that span from micro to macro levels and include microsystems, mesosystems, exosystems, macrosystems, and chronosystems that all shape and influence human development (Tong & An, 2024). Figure 1 below is an image of the EST.

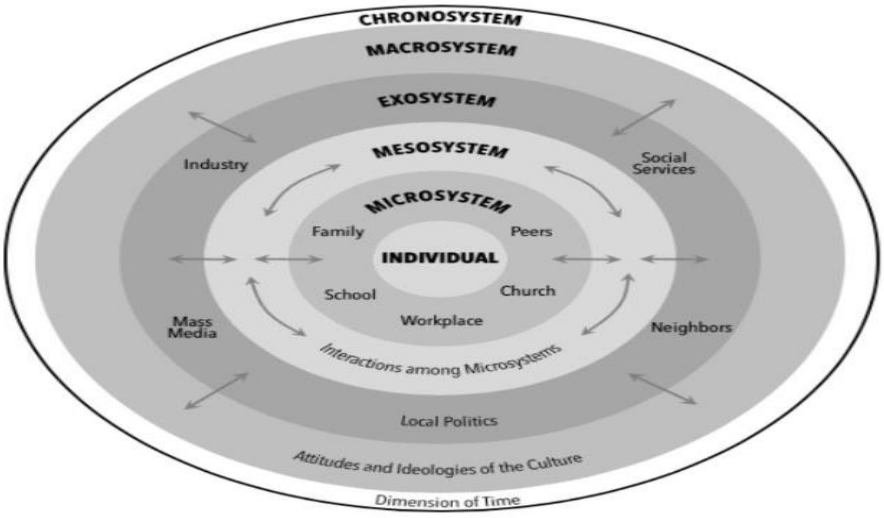

Figure 1: Ecological Systems Theory **Source:** Davis & Francis, (2023)

The systems are teased out below.

3.2.7.1 Microsystem

A microsystem refers to the direct or immediate environment that people interact with, which affects and influences their lives. This system comprises the individual's family, relatives, friends, colleagues, classmates, neighbours, and others who directly impact and have contact with them (Bronfenbrenner, 1979). In this study, the caregiver-child dynamic, healthcare providers and facilities constitute the microsystem as their interactions affect the disclosure process. Caregivers and CLHIV's relationships and interactions in the family setting can negatively or positively impact disclosure. The transparency and openness of caregivers and family members when discussing health and sensitive subjects like sex, HIV/AIDS, sexuality, sexual health and other chronic diseases also affect the disclosure process. Some caregivers choose to conceal their children's HIV-seropositive status if they, their family or the neighbourhood perceive discussing HIV, sexuality-related illnesses, or any other sensitive topic, as a taboo. This is backed by studies which show caregivers providing alternate illnesses or scenarios to the child to avoid telling them their HIV status (Jemmott et al., 2014; Nathaniel et al., 2024). On the other hand, disclosure of a child's status is more possible for caregivers who are open and flexible to discuss such topics with their child, their school or family.

3.2.7.2 Mesosystem

A mesosystem incorporates the interrelations of the settings that individuals participate in, including schools, neighbourhoods, families, peers, work, or social life (Bronfenbrenner, 1979). Within this system, caregivers' attitudes towards perinatal HIV disclosure are influenced by the family, neighbourhood, and societal and cultural perceptions on disclosure. For example, if a society is discriminatory and stigmatises PLHIV, caregivers may resist informing their children about their status. The interrelationship between the different beliefs and personalities of the mesosystem influences and shapes children's and caregivers' perspectives on disclosing the HIV status. This is due to caregivers and CLHIV forming part of the community and belonging to groups within society, such as family, religious, educational and cultural organisations, support groups and schools. Hence their perspectives on disclosure may affect and influence the caregiver's decision to disclose or cover up their child's HIV-seropositive status.

3.2.7.3 Exosystem

According to Bronfenbrenner (1979, p. 237), "… an exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by what happens in the setting containing the developing person". Larger systems (policies, access to healthcare, societal attitudes) that indirectly involve people and that influence their lives form part of this system. Community-based interventions, awareness and relevant information on HIV and perinatal HIV disclosure processes, supportive and patient-centred care (PCC) facilities and workers are examples of interventions in this system that facilitate disclosure. In an exosystem setting, caregivers may work in a stressful environment or experience exhaustion due to their workload which may result in them having insufficient time and energy to focus on or prepare for the disclosure process with their children. In cases where caregivers work outside the home, CLHIV are not active participants at their workplace, but can be affected by their caregiver's emotions, state of mind, responses, and actions when they return from work. Another example is health care professionals who are not adequately conversant with the pediatric HIV disclosure process and are unable to comprehensively train or guide caregivers on HIV disclosure.

3.2.7.4 Macrosystem

The macrosystem embraces societal structures and cultures by demonstrating the interaction and interrelationship between and among the microsystem, mesosystem and exosystem (Crawford, 2020). The laws, policies and overall culture of societies can affect how caregivers feel about disclosing their children's HIV diagnosis. Though South Africa has policies such as HIV Counselling and Testing Policy, Operational Plan for Comprehensive HIV and AIDS Management, and Treatment & Care and guidelines that support the disclosure of such a diagnosis to children, if caregivers are unaware of them or do not understand those guidelines, the disclosure to children may not be effectively carried out. In addition, the rural study setting is steeped in cultural beliefs and traditions that can act as barriers to caregivers disclosing as they may fear the response (discrimination, stigma, isolation) to their disclosure.

3.2.7.5 Chronosystem

The chronosystem incorporates the time in which an individual lives and develops (Crawford, 2020). This system includes the transformation of the diagnosis and societal beliefs and behaviours about HIV, improvements to treatment regimens, ARV efficacy, and decreases in child mortality rates. The WHO (2011) recommendations promote age, cognitive, and developmentally appropriate pediatric HIV disclosure to be effective and promote the health and wellbeing of the child. Hence, partial disclosure at six-years to improve the caregiver's knowledge base about ART and HIV and then engaging in full disclosure at 12 years and above is advocated for (NDOH, 2016). Some caregivers delay disclosing to their children if the disclosure takes place on significant dates such as exams, birthdays, outings or other important events (Madiba, 2016). However, delays can cause challenges and even result in nondisclosure.

3.3 RATIONALE FOR USING BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY (EST)

Though the lens of several theories and models has been expanded on to frame the complexities of caregivers disclosing perinatal HIV-infections to children, after carefully considering all, the researcher found Bronfenbrenner's EST the most suitable and relevant theory to frame the study. This theory places emphasis on the interconnectedness and interactions of the environment on

human behaviour and the multiple intersectional influences affecting the disclosure process. In this study, these systems influence how the caregivers of HIV-seropositive children view and experience pediatric HIV disclosure and the negative or positive influences on their perceptions and experiences on such disclosure (Manyam et al., 2019; Sokhela, 2016). Of importance is that caregivers do not live and operate in isolation and disclosure is not only focused on caregivers but is dependent on multiple stakeholders, variables and systems.

In conclusion, the EST provided a robust framework to navigate the multilayered systems that constitute the barriers affecting caregivers' disclosure of perinatal HIV-infections to children in the uMzinyathi District, KZN and offered multiple advantages. It had successfully been used in studies on perinatal disclosure and allowed for the interplay of the caregiver-child relationship, health care staff and facility, and cultural and societal influences (Lekganyane & Manganyi, 2023; Mohoje, 2021; Qiao et al., 2021). The contextual influence of the rural setting of uMzinyathi District, healthcare resources, traditional and cultural norms and societal stigma allowed for a broader understanding of the structural challenges, economic and healthcare systems that affect and influence caregivers' decisions to disclose. The mesosystem allowed for the inclusion of relationships, support systems and networks available to caregivers that shape their attitudes and decisions towards disclosure. The chronosystems focus on time and transformation and purport that disclosure is not an isolated, static occurrence but a dynamic, and evolving one that is dependent on changes to systems, policies, guidelines, frameworks and human beings. Lastly, this theory informs research and interventions that can improve disclosure practices and systems for caregivers in rural, peri-urban and urban settings.

3.4 SUMMARY

The study aimed to understand caregivers' strategies, challenges, and the factors influencing their disclosure decisions to CPAH in uMzinyathi District, KZN, hence a plethora of theories and theoretical frameworks that could underpin the study were presented and critically discussed herein. This section presented the ecological systems theory and the rationale for applying it to this study as it shapes our understanding of the complexities of pediatric HIV disclosure by situating the caregiver and the child in various systems and levels. It also structures the

interconnectedness of systems that affect the disclosure process. The research methodology follows in the next chapter.

CHAPTER FOUR
RESEARCH METHODOLOGY

4.1 INTRODUCTION

Research methodology refers to the processes, techniques and procedures used to ensure a rigorous and ethical study that meets the study aims and objectives and adequately responds to the research questions (Garg, 2016). This study aimed to explore caregivers' experiences of disclosing an HIV-seropositive status to CPAH; hence this chapter presents and discusses the research design, methodology and methods implemented to achieve this. These are summarised in Table 2 below and unpacked further in the chapter.

RESEARCH METHODOLOGICAL MAP	
Research Approach	Qualitative
Research Design	Exploratory
Research Paradigm	Interpretivism
Data Analysis	Thematic Analysis
Data Gathering Tool	Semi-structured interviews with a flexible interview guide
Study Population	20 Caregivers of Children with Perinatal Acquired HIV
Sampling	Purposive and convenience sampling

Table 2: Research Methodological Map

4.2 RESEARCH DESIGN

A research design refers to a "…masterplan, blueprint, and even as a sequence of research tasks and activities... used by researchers to collect and analyze the data needed" (Mbaka & Isiramen (2021, p. 27). Descriptive, explanatory, and exploratory designs are used in research (Creswell & Poth, 2018). A descriptive design outlines specific patterns, phenomena and characteristics but excludes unexpected or new and subjective experiences or patterns, and anomalies (Siedlecki, 2020). Hence, it may not manifest the depth of participants' experiences. Explanatory designs are more structured and test causal relationships (Casula et al., 2021). This may not generate new insights on the multifaceted dimensions of disclosure due to support rendered to caregivers, but an exploratory design is flexible and well suited to under-explored, context-specific, sensitive and multifaceted, complex phenomena that assist in unpacking and discovering new themes,

factors, perspectives and patterns that may emerge from participants' input. This design was deemed as having the potential to explore sensitive topics that include disclosure and incorporate interconnected factors that are linked to healthcare, stigma, participants' traditions, and cultures, and emotions which affect and impact on their decision making. Hence, an exploratory research design was implemented to facilitate the attainment of in-depth information that included the cultural, ethical, emotional, and social dimensions, and participants' insights to better understand caregivers' experiences of informing their children about their HIV status (Madiba, 2016; Van Manene, 2014).

4.3 RESEARCH PARADIGM

A research paradigm is the belief systems, principles and assumptions that researchers use to navigate their studies (Kivunja & Kuyini, 2017). Three predominant research paradigms, namely positivism, critical theory and interpretivism, are used (Rehman & Alharthi, 2016). Positivism attaches value to objectivity or disproving or approving a hypothesis, critical theory incorporates societal influences or oppressive political practices, while interpretivism values subjectivity (Blackwell, 2018). This study utilised interpretivism as this paradigm embraces how human beings (caregivers) socially construct their complex reality of events, beliefs, thoughts, perceptions, and experiences within the world they live and participate in. Interpretivism incorporates individuals' multiple subjective realities, and the researcher opines that there is no single or universal experience of caregivers disclosing to CPAH (Kivunja & Kuyini, 2017; Okesina, 2020). Hence, the primary means to source such information was wading through a plethora of participants' (caregivers) experiences to source knowledge from them and to improve the pediatric HIV disclosure process.

4.4 RESEARCH APPROACH

Quantitative, mixed methods and qualitative research are the approaches used in research studies (Taherdoost, 2022). Quantitative research generates numerical data from questionnaires, statistical reports, experiments and surveys using statistical tools to procure correlations and patterns to produce generalisable and objective outcomes to measure a phenomenon (Mohanjan, 2020). If this study had aimed to ascertain the percentage or number of caregivers who disclose

pediatric HIV diagnosis to children, then a quantitative study using surveys would have been suitable. A mixed-method approach unifies qualitative and quantitative approaches using narrative and numerical data and statistical and thematic analysis to triangulate the findings to procure a full understanding of a phenomenon or problem (Dawadi et al., 2022). A study that aims to quantify how many caregivers disclose perinatal HIV and the subjective realities or barriers to such disclosure through focus group discussions (FGDs), would assume a mixed-method approach. A qualitative approach utilises life experiences, case studies and stories to explore a phenomenon that individuals are confronted with or experience in their lives (Lim, 2024). This approach emphasises participants' in-depth meanings, perceptions, experiences and emotions that cannot be numerically defined (Taherdoost, 2022; Tenny et al., 2022). A qualitative approach was considered ideal for this study as it allowed the researcher to understand the challenges confronting caregivers living in uMzinyathi District of KZN when they are disclosing a sero-positive HIV status to their CLHIV. Adopting this method enabled a thorough and in-depth, context specific, exploration of the emotional, social, and cultural factors influencing their decisions. It enabled the researcher to understand not just the "what" but the "why" behind disclosure practices and provided valuable insights for designing interventions and support systems tailored to the specific challenges faced by caregivers in this region (Sutton & Austin, 2015).

4.5 STUDY SETTING

Figure 2: uMzinyathi District Map **Source:** COGTA, (2023)

This study was conducted in uMzinyathi District that is situated between Durban and Gauteng and provides infrastructure and services to mostly rural communities. This region prides itself on being an agricultural hub (uMzinyathi District Municipality, 2023). However, the diverse nature of its natural resources, and its cultural heritage, its mostly rural communities cite infrastructure, poverty and economic insecurity, low levels of education, droughts and transportation as challenges affecting the region (KwaZulu-Natal Department of Economic Development [KZNDED], 2021; Corporative Governance and Traditional Affairs [COGTA], 2023). Economic insecurity, high poverty and unemployment levels render many community members beneficiaries of government social grants. Within the district, Black Africans constitute the predominant population with most speaking isiZulu and the area constituting a strong cultural and tradition stronghold (uMzinyathi District Municipality, 2023).

This district municipality comprises of four (4) local municipalities (Ndumeni Local Municipality, Nqutu Local Municipality, Msinga Local Municipality and uMvoti Local Municipality) and has a population of +456 452 (COGTA, 2023). There is one (1) district hospital in each local municipality (uMzinyathi, 2023). The four municipalities account for 54 primary health clinics (PHCs). The Ndumeni local municipality has 6 PHCs, Nqutu local municipality has 15 PHCs, Msinga has 21 PHCs and uMvoti local municipality has 12 (KwaZulu-Natal Department of Health [KZN DoH], 2021). The clinics provide immunisation, reproductive, maternal and child healthcare, and the treatment of chronic diseases including HIV (KZN DoH, 2021). High HIV prevalence rates are recorded in the area (South African National AIDS Council [SANAC], 2020). Hence, one PHC with high volumes of children on ART was chosen from each local municipality to be a study setting. This ensured a large and diverse population to draw participants from and a means of eliminating any challenges associated with sourcing participants.

4.6 METHODS

4.6.1 Study Population

The study population consists of all the caregivers of CLHIV who are enrolled on ART programmes at the four (4) PHCs (Inkosi Thathezakhe Clinic, Glenridge Clinic, Pomeroy CHC and Pine Street Clinic) in uMzinyathi District Municipality. However, it is not feasible to

interview all the caregivers of CLHIV, therefore, 20 caregivers of CLHIV between the ages of 6 and 12 years (WHO, 2011) who are enrolled on ART programmes in the four PHCs in uMzinyathi District were invited and recruited to participate in this study. This age group was chosen as the study sample based on the WHO guidelines on disclosure (2011) that recommended that pediatric HIV disclosure should commence with partial disclosure from 6 years and then full disclosure by the age of 12.

4.6.2 Sampling

Bhardwaj (2019, p. 158) views sampling as the "…procedure to select a sample from individuals or from a large group of population for a certain kind of research purpose, while a sample is a group of people, objects, or items that are taken from a large population for measurement". As this is a qualitative study, non-probability sampling was applicable as it considers that all the members of a study population may not choose to participate in a study, hence a sample can be drawn from the entire population (Taherdoost, 2016). Within qualitative research, several sampling techniques are available for use, including purposive, convenience, snowball and theoretical. Purposive sampling refers to participants (in this case, caregivers) being intentionally recruited for their experiences, knowledge, and characteristics, (Campbell et al., 2020), while convenience sampling refers to participants being available and easy to access and recruit (Golzar et al., 2022). The researcher worked at several clinics in the area and was able to secure participants. However, to avoid any bias, only participants who met the inclusive criteria and voluntarily consented to be part of the study were included in the sample. Convenience sampling allowed for a diverse pool of participants as their clinic, backgrounds and demographics differed. Snowball sampling applies in instances of hard-to-reach research populations which was not the case in this study as all the clinics had large populations of CLHIV. Lastly, theoretical sampling allows researchers to improve on the research questions based on emerging data and can be resource and time intensive.

After reading up on all the sampling techniques and discussing with the researcher's supervisor, purposive and convenience sampling techniques were considered the best fit as caregivers' experiences of pediatric HIV disclosure could only be obtained from those who have robust knowledge and lived experiences of that process. In addition, the researcher had easy access to

the study sites due to the nature of his job, being a social worker supporting the uMzinyathi District with HIV disclosure and ART adherence.

The researcher conducted information sharing sessions over two weeks during December 2023 at all four participating clinics in uMzinyathi District, KZN. This was to inform all patients attending the clinics during that period about the purpose and the benefits of the study, the inclusion and exclusion criteria and to answer any queries patients/clients had. All caregivers present on each day were informed that they could find the researcher in an office allocated to him at each clinic. This was done for them to take the initiative to find the researcher and to safeguard their privacy and ensure they voluntarily discussed the study and voluntarily participated in a safe and private space.

Inclusion and Exclusion Criteria

Caregivers who were 18 years and older and caring for perinatally infected HIV-seropositive children between the ages of 6 and 12 for a minimum period of two years and longer were recruited to participate in the study. This age group and the period of two years was chosen because the caregivers would have the necessary experience and knowledge of the disclosure process, caring for CLHIV and considered or completed disclosing to their children. Caregivers who did not meet all the study's criteria and those who were not well enough to participate in the data collection process were excluded from participating. In this study, non-probability sampling in the form of purposive and convenient sampling resulted in twenty (20) participants (caregivers) being sampled.

4.7 DATA COLLECTION

Data collection is the process that researchers use to gather relevant information to adequately respond to the study's research questions and attain the research objectives. It involves a variety of data collection tools and techniques (Barrett & Twycross, 2018; Taherdoost, 2021).

4.7.1 Data Collection Instrument

Interviews, focus group discussions (FGDs), observations, ethnographies, visual analysis, autoethnographies, and document reviews are some of the data gathering tools used in qualitative

research (Busetto et al., 2020; Ugwu & Eze Val, 2023). To gather rich data, interviews were regarded as the best option. Qualitative interviews afford an interviewer an opportunity to understand and describe the meanings of dominant themes that govern the beliefs, feelings, life and experiences of the research participants (Moser & Korstjens, 2018). Primarily three forms of interviews are used in qualitative research, namely structured, unstructured and semi-structured and can be conducted telephonically, face to face or online. Structured interviews are considered a rigid type of interview. Unstructured interviews have questions (generally few in number) that are mainly used to build rapport. Semi-structured interviews are flexible and allow interviewers to probe further to unpack issues and get data with depth. The researcher chose semi-structured, in-person interviews using an interview guide to afford participants options and an opportunity to provide in-depth information that allowed the researcher to probe for additional information.

4.7.2 Data Collection

4.7.2.1 Pretesting the interview guide

The researcher decided to pretest the interview guide to ensure that all questions were simple, not ambiguous and would render broad and rich data (Bhalla et al., 2023). One caregiver from each clinic was asked to voluntarily participate in the pretesting after being informed that this process was to ensure that the guide was understandable, flexible and client/patient centred. However, they were made aware that they would not participate in the actual study. Four caregivers readily agreed, and the process resulted in one question being rephrased.

4.7.2.2 Data Gathering

All the conveniently and purposively sampled participants were recruited from the four participating clinics in uMzinyathi District with the assistance of a nurse while attending the clinic on their appointment dates. The interviews were conducted between December 2023 and January 2024. Before data was collected, the researcher ensured that the study was understood by all the participants and personally assisted them with the process of voluntarily signing informed consent forms to participate in recorded interviews using voice recording devices. All were made aware that there was no financial benefit attached to their participation and that they would be assigned pseudonyms to protect their personal information. Due to the delicate nature of the study, the researcher negotiated a consultation room with the clinic management at all the clinics

to collect data from the caregivers of their CLHIV. Moreover, they were informed that the delicate nature of the study, necessitated a social worker being available to address any psychosocial issues that may arise. Once all the operational issues were discussed and resolved, the in-person semi-structured interviews were conducted.

The researcher conducted all 20 in person interviews guided by a bilingual (isiZulu and English) interview guide with flexible, open-ended questions. These languages were used as they are the predominant languages spoken by people living in and around the study setting who attend the clinics. Although the bilingual researcher practiced inclusivity by having bilingual interview guides, all the participants preferred to express themselves in isiZulu as it was their home language. The interview schedule allowed the researcher to probe and ask follow-up questions, observe non-verbal language, ask participants to expand on and clarify responses and explore in detail caregivers' experiences disclosing to their CPAH. During the audio-recorded interviews, the researcher also took notes.

The private, safe interview space allowed the participants to freely share their experiences and answer the research questions in a relaxed environment that prevented them being seen by others. The bilingual researcher made the participants feel respected by allowing them to choose the language they wanted to be interviewed in. Moreover, the participants expressed gratitude that their names would not be used in the research output but rather pseudonyms were used. Their gratitude highlighted that HIV related stigma was still an issue, and this has been reported in studies globally (Davtyan et al., 2023; Dube & Harms-Smith, 2016; Kontomanolis et al., 2017; Madiba & Mokgatle, 2017).

4.8 DATA ANALYSIS

Data analysis involves raw information being examined for relevant, valuable data, to find similarities, make comparisons and conclusions, and support decision-making (Bhatia, 2017; Maguire & Delahunt, 2017). Once all the data was collected from the research participants, the researcher transcribed it verbatim, translated it into English and thematically analysed the transcripts. Thematic analysis (TA) according to Braun and Clarke (2006, p.6) is a "method for

identifying, analyzing, and reporting patterns (themes) within data". This type of analysis was used by the researcher as it afforded him the opportunity to familiarise himself with the collected data, generate initial codes, search for themes, identify and assign names to the themes and produce an analysis report. Braun and Clarke's (2006) analysis process is as follows.

4.8.1 Becoming Familiar with the Data

This stage entailed the researcher listening to the audio recordings several times, immersing himself in the transcripts and repeatedly perusing the transcripts to ensure every detail of the participants recorded responses, had been correctly transcribed and were fully understood. This was done as the researcher had recorded and transcribed the interviews and transcripts. Initial ideas that emerged from this iterative process, were written down in a notebook. This was done to procure an in-depth understanding and to be familiar with the collected and transcribed data.

4.8.2 Generating Initial Codes

Coding is achieved by dividing the data into small chunks and labelling that with a code (Creswell & Poth, 2018). This process involved collating similar themes emanating from the participants' exact words and organising them into small chunks of data that mirrored the text. The researcher used highlighters to code similar features of the data that were pertinent to the study questions and the topic.

4.8.3 Searching for themes

Themes are patterns or similar words, relationships or meanings which recur in a chunk of data (Naeem et al., 2023). The researcher systematically clustered similar items of data together to make it easy to understand. Themes, patterns and subthemes that emerged from the data were written down and codes assigned to each of them. The researcher manually conducted the analysis process.

4.8.4 Reviewing Themes

This step required the researcher to review and refine the identified themes from the previous step to scrutinise if they related to the coded data, and all the data that was relevant to each

theme, was then categorised together. To ensure the transcripts were accurate and relevant, they were reviewed multiple times.

4.8.5 Defining the Themes

In this step, the researcher did the final refining of the themes to ascertain what each theme meant, if and how they related to each other and to ensure that they correctly reflected the participants' responses to the questions. These are further unpacked in chapter five.

4.8.6 Production of the Report

The final step of the analysis involved integrating all the emerging themes from the data into a report. The researcher took advantage of the verbatim responses of the research participants and used them in the report to strengthen and enhance the quality and authenticity of the study. The final report is the product of the researcher deeply immersing himself in the data, and of thoughtfulness and reflection (Braun & Clarke, 2006; 2019).

Thematic analysis assisted as it simplified the process and made it easier for the researcher to peruse all the collected data to classify caregivers' common experiences of disclosure to their children according to themes and subthemes.

4.9 ETHICAL CONSIDERATIONS

The University of Zululand's Research Ethics Policy formed the basis of the processes followed to ensure an ethical and compliant study. The steps pursued were as follows:

4.9.1 Ethical Clearance and Gatekeepers Permission

Prior to collecting data, ethical clearance (UZ-REC 0691-008 PGM 2023/35) to conduct this study was obtained from the University of Zululand Research Ethics Committee (UZREC), and permission was received from the KZN Department of Health, uMzinyathi Health's District Office and the four clinics that participated in the study. Other ethical practices adhered to, are as follows.

4.9.2 Confidentiality

Confidentiality was achieved by conducting the interviews in negotiated safe spaces. Furthermore, the researcher informed all participants that their information would not be shared with others, except the researcher's university supervisor.

4.9.3 Privacy

The interviews took place in secure and private consultation rooms at the clinics to protect participants from any harm such as stigma or violence. All research participants were assigned pseudonyms to protect their identities and ensure privacy and confidentiality of all the information they provided to the researcher.

4.9.4 Autonomy

All the participants were assigned, their agency on whether to participate in the study. In addition, the researcher assured the participants that they could withdraw from participating in the study at any time should they no longer want to and that their withdrawal would not affect the services that they receive from their healthcare facilities.

4.9.5 Informed Consent and Voluntary Participation

To ensure their voluntary participation, the researcher thoroughly explained the study and its objectives to the participants and gave them the opportunity to ask questions and seek clarity on all aspects of the study and their participation. Thereafter, all the participants voluntarily signed informed consent forms and provided permission for their interviews to be recorded. The interviews only commenced after they expressed comfort in the process, voluntarily consented to take part in this study and gave the go ahead for the researcher to proceed with the interviews.

4.9.6 Doing no harm

The researcher considered all the possible sources of harm (lack of privacy, use of their names and ensuring they could not be seen during the interviews) and made every endeavour to protect all the participants. A social worker was available and on call to attend to any negative emotions and psychological harm that was triggered due to the delicate nature of pediatric HIV disclosure. After the interviews, two participants were referred to a social worker for psychosocial assessment and counselling, one to a psychologist for review and one to an occupational therapist for assessment. The researcher informed them that due to the sensitive nature of their

challenge he would not follow up with the service providers, and that they were free to contact the clinic social workers and counsellors should they require further guidance.

4.9.7 Anonymity

Anonymity was guaranteed to participants as pseudonyms and codes were assigned to their responses. No photos or videos were taken of any participant and all their identifying details were removed from the dissertation and will not be contained in future publications or dialogues.

4.10 TRUSTWORTHINESS

Trustworthiness in qualitative research refers to the level of fidelity of the collected data, interpretation of the data, findings and patterns followed to ensure quality and authenticity of the research (Connelly, 2016). The trustworthiness of the study's findings was ensured by following the four criteria of confirmability, credibility, dependability, and transferability, which Guba and Lincoln (1994) have endorsed.

4.10.1 Confirmability

Confirmability implies that the collected data is well aligned to the study's findings, conclusions and recommendations (Stahl & King, 2020). The researcher made sure that each step of the sampling, data gathering, and analysing processes was clearly documented to guarantee confirmability of the findings. The researcher's university supervisor reviewed the field notes, transcripts and audio recordings during debriefing and supervision sessions, and guidance was provided accordingly. In addition, all the audio recordings, field notes, and the participants' voluntarily signed consent forms will be kept in a lockable safe in the researcher's office for five years, in case a third party wants to review them.

4.10.2 Credibility

Credibility refers to the degree to which the collected data and their interpretations are accurate and believable (Nguyen et al, 2021). The researcher assigned adequate time to explain the objectives, benefits and process of the study to the participants to build rapport and create an atmosphere that enabled the participants to openly and freely express their emotions and experiences. Credibility was ensured by involving the research participants in the verification of

primary investigator's (PI) interpretations of what they had said to ensure that he understood their responses and had correctly captured and interpreted them. Review sessions with the research supervisor ensured that the findings were accurately analysed (Kakar et al., 2023).

4.10.3 Dependability

To ensure dependability and trustworthiness, the researcher's unique ideas and understanding of the phenomenon had to be bracketed to allow the participants experiences to be accurately captured (Habibullah et al., 2023). The researcher clearly explained the research topic, objectives and the whole research process to the participants to ensure that they understood what was required of them prior to the interviews commencing. This concretised trust between the researcher and participants and ensured that the participants would provide similar responses to the questions, if asked years later, and that the findings would still be similar. The audio recorded interviews, the PI translating and transcribing them, notes being taken and compared with transcripts, and participants verifying that the analysis aptly captured their words were ways to ensure the data was correctly analysed. Lastly, the supervisor perused the interview guide, transcripts and provided ongoing support to the PI to ensure that all information was correctly captured and analysed.

4.10.4 Transferability

Although replication is not the main goal of qualitative research, researchers opine that patterns, trends and descriptions from one setting can be applied to another (Stahl & King, 2020). The researcher applied an appropriate and relevant theoretical framework, used recent and relevant literature, and ensured that the methods of collecting data and the duration of the field work were clearly articulated and followed. Thick and comprehensive descriptions of the research findings, including the participants' responses, make it possible for other researchers who may want to replicate the study to do so. The literature review demonstrated that studies had already been conducted on the topic, and these can be compared to this study's findings.

4.11 RESEARCHER'S POSITIONALITY

A researcher's positionality is acknowledgment of their subjective positioning and how that can influence and affect their study (Jamieson et al., 2022; Mulqueeny, 2018). Positionality includes reflexivity which entails self-reflection of a researcher's biases and subjectivity which could

positively or negatively affect the research process (Mthombeni, 2024; Olmos-Vega et al., 2022). Positionality reveals a researcher's beliefs and knowledge, while reflexivity relates to the use and execution of such knowledge and beliefs through critically thinking, questioning and addressing the researcher's positionality and the impact thereof (Mulqueeny, 2022; Mulqueeny & Taylor, 2019). Insider/outsider positionality and reflexivity are important considerations in qualitative research (Yip, 2023). Within this study, the researcher admits that he assumed fluid positionality. He was an outsider as he was not a caregiver nor a friend or relative of any participant, was not HIV-seropositive, did not have children who had perinatally acquired HIV and did not form part of the participant cohort. He was an insider in terms of his knowledge and experience working in several clinics in the research area and of the topic under study. In addition, he shared race, age, language and cultural beliefs with some of the participants and was knowledgeable on HIV related disclosure, guidelines and policies, and the vocabulary used in HIV related research, and by the healthcare workers and caregivers. Reflexive bracketing was a tool he used to bracket out his personal perceptions, experiences and information on disclosure that could prejudice the study as ethical considerations were of prime importance. This technique is commonly used in qualitative studies (Habibullah et al., 2023).

4.12 DATA STORAGE AND MANAGEMENT

Data storage and management are important components of quality assurance and ensure ethical and reproducible studies (Kanza & Knight, 2022). In keeping with the University's policy, the interview transcripts and recordings will be saved to the iCloud for a period of five years with only the researcher and his supervisor having access to them. The physical transcripts, consent forms and recordings will be kept in a lockable safe in the researcher's office for a similar period. Thereafter, these will be permanently deleted.

4.13 SUMMARY

This research methodology chapter presented the process of achieving an explorative, qualitative study with data collected from semi-structured interviews with 20 caregivers of children with perinatal HIV-infections who lived and accessed health facilities in the uMzinyathi District and how the data was thematically analysed. In addition, the ethical considerations employed, and the

researcher's positionality were presented to ensure a principled and ethical study was thoroughly discussed. Lastly, the trustworthiness of the study and the data storage and management were discussed. The presentation of the analysed and interpreted data will be discussed in the next chapter.

CHAPTER FIVE
DATA ANALYSIS AND INTERPRETATION

5.1 INTRODUCTION

This chapter incorporates information and literature from the previous chapters as they form the foundation for the presentation and discussion of the analysis and interpretation of the collected data. The demographic details of all the participants, and the thematic analysis of their responses are categorised according to a key that is explained later, and a summary of the contents of this chapter is provided.

5.2 PARTICIPANTS' DEMOGRAPHIC DETAILS

The study sample consisted of 20 female caregivers who took care of CPAH receiving their ART from the four PHCs in uMzinyathi District. Table 3 below shows the key for the codes of participants' responses.

Clinic No	Clinic Code	Number of each Participant	Participant Code
Clinic 1	C1	P1-5	C1P1-5
Clinic 2	C2	P1-5	C2P1-5
Clinic 3	C3	P1-5	C3P1-5
Clinic 4	C4	P1-5	C4P1-5

Table 3: Key for Participants Responses

Participants' demographic details include the code assigned to them based on the key in Table 3, their relationship to the child in their care, age, the source of income, educational level, the gender and age of the child in their care and the status of the disclosure process. These details are summarised in Table 4 below:

CLINIC 1 (C1) – 5 PARTICIPANTS							
PARTICIPANT CODE	**RELATIONSHIP TO THE CHILD**	**AGE**	**SOURCE OF INCOME**	**EDUCATIONAL LEVEL**	**CHILD'S GENDER**	**CHILD'S AGE**	**LEVEL OF DISCLOSURE**
C1P1	Mother	36	Casually Employed	Secondary	Male	06	None
C1P2	Aunt	45	Casually Employed	Secondary	Male	11	Full Disclosure
C1P3	Mother	33	Social Grant	Secondary	Male	09	Full Disclosure
C1P4	Mother	38	Social Grant	Secondary	Male	12	Full Disclosure
C1P5	Mother	28	Employed	Secondary	Female	09	Partial Disclosure

CLINIC 2 (C2) – 5 PARTICIPANTS							
PARTICIPANT CODE	**RELATIONSHIP TO THE CHILD**	**AGE**	**SOURCE OF INCOME**	**EDUCATIONAL LEVEL**	**CHILD'S GENDER**	**CHILD'S AGE**	**LEVEL OF DISCLOSURE**
C2P1	Grandmother	55	Social Grant	Never been to school	Male	09	None
C2P2	Mother	48	Family Members	Secondary	Male	12	Full Disclosure
C2P3	Mother	32	Social Grant	Secondary	Male	06	Partial Disclosure
C2P4	Mother	28	Social Grant	Secondary	Male	06	None
C2P5	Mother	34	Social Grant	Primary	Male	10	Partial Disclosure

CLINIC 3 (C3) – 5 PARTICIPANTS							
PARTICIPANT CODE	**RELATIONSHIP TO THE CHILD**	**AGE**	**SOURCE OF INCOME**	**EDUCATIONAL LEVEL**	**CHILD'S GENDER**	**CHILD'S AGE**	**LEVEL OF DISCLOSURE**
C3P1	Mother	28	Casually Employed	Secondary	Female	10	Partial Disclosure
C3P2	Grandmother	55	Family Members	Secondary	Female	12	None
C3P3	Aunt	47	Social Grant	Never been to school	Male	08	None
C3P4	Aunt	25	Casually Employed	Secondary	Female	12	Full Disclosure
C3P5	Mother	45	Social Grant	Secondary	Female	12	Partial Disclosure

CLINIC 4 (C4) – 5 PARTICIPANTS							
PARTICIPANT CODE	**RELATIONSHIP TO THE CHILD**	**AGE**	**SOURCE OF INCOME**	**EDUCATIONAL LEVEL**	**CHILD'S GENDER**	**CHILD'S AGE**	**LEVEL OF DISCLOSURE**
C4P1	Aunt	29	Casually Employed	Secondary	Male	10	Full Disclosure
C4P2	Mother	38	Family Member	Secondary	Female	12	Full Disclosure
C4P3	Mother	34	Family Member	Secondary	Female	10	Full Disclosure
C4P4	Mother	45	Social Grant	Secondary	Female	12	Full Disclosure
C4P5	Mother	32	Social Grant	Secondary	Female	12	Partial Disclosure

Table 4: Participant's Demographic Details

5.2.1 Gender Representation of the Participants

The participation in this study was open to all genders, and the researcher approached male and female caregivers but only 20 females agreed to participate. According to Sharma et al. (2016) caregiving is primarily constructed as a feminine role. The researcher's view is that despite men and women being caregivers, women are primarily caregivers because they play a primary role

in nurturing and administering medication to their children. However, the findings of Pacheco Barzallo et al. (2024) differ by highlighting that this *female caregiving dynamic* is changing, as more males are playing a prominent caregiving role. The gender dynamics of the participants reflect that the majority (14) were biological mothers (females) of the CLHIV and involved in the disclosure process, which has been similarly reported in a study on disclosure in Kenya (Vreeman et al., 2015).

5.2.2 Caregivers' Relationship to the Child on ART

Most (14) of the participants were the biological mothers of CLHIV, with four biological aunts and two maternal grandmothers. These demographics are like those of Mwangala et al. (2022) but differ with other studies that have reported caregivers being grandparents, foster parents, relatives and friends (Lentoor, 2019; Louthrenoo et al., 2018). Interestingly, all were maternal females, which aligns with arguments from Sharma et al. (2016) above. Probing for more on these dynamics, rendered responses that showed that culturally, the responsibility of caregiving lay with the biological unmarried mothers and their family members. Further probing on the involvement of the biological dads rendered silence and discomfort from participants. The researcher argues that their silence could mean that their fathers are not involved, or the relationships have been terminated or as indicated in the literature review, paternity could be under question.

5.2.3 Age Distribution of the Participants

All age categories were represented in this study. The study had five participants between the ages of 18 – 29, eight participants were between 30 – 40 years old, five participants were between 41 – 50 years old, and two were between the ages of 51 – 65. This aligns with the literature that individuals of all ages engage in caregiving. It is worth noting that the two participants that were above 51 years of age were grandmothers and neither of them had disclosed their grandchildren's HIV-positive status to them. However, their reasons for nondisclosure were not age nor maturity related but are explained in the themes.

5.2.4 Educational Level of Participants

The participants' educational levels were not a criterion for inclusion in the study; however, of the 20 participants, 17 had a secondary level of education. Only one participant had a primary education while two had never attended a school in their lives. Of the 17 participants that had received secondary education, 9 of them had fully disclosed to their children, 5 had partially disclosed and 3 had not disclosed. The caregivers who had never been to school did not disclose and the only one with a primary level education had partially disclosed to the child. This corresponds with other studies (Abegaz et al., 2019; Doat et al., 2019; Klutsey et al., 2021; Tucho et al., 2021) that reported that caregivers with secondary levels of education were more likely to disclose their children's HIV-positive status to them as compared to those who had never been to school or had lower levels of education. Lack of disclosure skills and insufficient knowledge about HIV and HIV disclosure has been found to contribute to low levels of disclosure (Doat et al., 2019; Hayfron-Benjamin et al., 2018; Nathaniel et al., 2018). However, to the best of the researcher's knowledge, a link between low education and disclosure has not been adequately established.

5.2.5 Participants' Employment Status

Half (10) of the participants depended on the government's social grants for survival, and six (6) participants shared that they depended on casual employment while four (4) participants' family members financially supported them. Maddocks and Chetty (2020) have highlighted that poor finances constitute a burden on the caregivers' role when caring for PLHIV. Similar results have been reported in the context of adult PLHIV in cases where there are high levels of unemployment and poverty. In these instances, government assistance, in the form of social grants, has alleviated some of the financial challenges (Govender et al., 2015; Williams et al., 2016).

5.2.6 Level of Disclosure

Of the 20 participants, 9 (45%) had fully informed their children of their HIV status, and 6 (30%) had partially disclosed to their children. Five (25%) had never shared any information on their children's HIV status with them or about them ingesting treatment daily. Most participants (95%) shared the benefits of disclosure to a child. Of the five participants who had not

disclosed, four of their children were male and one female. It can be argued that this is a coincidence, or an argument can be made that a gender dynamic exists. Moreover, clinic 4 had no participants that had not disclosed and only one partial disclosure. This only emerged during data analysis, so the researcher was unable to ascertain why participants from this clinic had higher disclosure rates. During the semi-structured interviews, participants volunteered that some nurses at the clinics had instructed them not to disclose. This raises a concern, as there are policies in place that document the ages and stages of disclosure. As nurses and HCWs were not participants in the study, the researcher cannot conclude if this was really the case. Worth noting is that just under half of this sample of 20 caregivers had fully disclosed within the prescribed ages, with some ignoring or being unaware of the stages/ages of disclosure.

5.3 DATA ANALYSIS

All the collected data was transcribed, and translated into English by the researcher, and read repeatedly for deep understanding. After the researcher thoroughly interrogated the transcripts and field notes, and coded the data, the following themes and subthemes emerged in line with the study's objectives:

OBJECTIVE A: Caregivers' experiences of disclosing perinatally infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal	
Theme 1: Negative Experiences	
Subthemes	• Lack of Support, Resources, Disclosure Skills, Knowledge and Vocabulary • Fear of Emotional and Psychological Impact on the Child • Fear of Stigmatisation and Social Isolation • Guilt, Poor Self-esteem and Self-Blame • Fear of Children Blaming Parents and Loss of Trust • Continuation of the Family Legacy and Future Generations • Forced Disclosure
Theme 2: Positive Experiences	
Subthemes	• Sourced and Received Assistance • Self-disclosure • Improvement in ART Adherence
OBJECTIVE B: The factors affecting caregivers' disclosing perinatally HIV-infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal	
Theme 3: Factors Positively Affecting the Disclosure Process	
Subthemes	• Caregiver-child Relationship • Counselling Support Services received from PHC

	• Belief that Disclosure will Prevent Further Transmissions • Belief that Disclosure will Reduce Parental Stress
Theme 4: Factors Negatively Affecting the Disclosure Process	
Subthemes	• Child's Age and Cognitive Development • Fear of Negative Outcomes of Disclosure • Belief that Disclosure will cause Anger/resentment • Fear of their Children Informing Others • Concerns that Children will not Accept the HIV diagnosis
OBJECTIVE C: Recommendations to improve caregivers' disclosure techniques to perinatally HIV-infected children in uMzinyathi District, KwaZulu-Natal.	
Subthemes	• Assistance of Healthcare Workers • Training Caregivers on Disclosure • Caregivers' Support Groups • Use of Child-friendly Language

Table 5: Themes and Subthemes

To protect all the caregivers' privacy, their pseudonyms contain an alphabet figure (C) for clinic, and then a number (C1, C2, C3 and C4) that represents the clinic that their children access ART from and their participant number (P1-P5) as there are five participants per clinic.

5.3.1 Data and Analysis Relating to Objective A: Caregivers' experiences of disclosing perinatally infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal

Caregivers of children with perinatal HIV-infections had a diverse array of experiences (positive and negative) relating to them disclosing their children's HIV status to them. Their anticipation, concerns, challenges and support structures or lack thereof shape their experiences of the disclosure process. Caregivers' negative experiences are documented first, followed by their positive experiences. However, it is worth noting that some participants initially expressed negative experiences which later translated to positive experiences as they ultimately achieved partial or full disclosure. However, participants C1P1, C2P1, C2P4, C3P2, and C3P3 had not disclosed to their children during the period of data collection, and they only shared the negative experiences that are found in this section.

5.3.1.1. Negative Experiences

Lack of Support, Resources, Disclosure Skills, Knowledge and Vocabulary

Most of the caregivers revealed that though they wanted to disclose, they were hindered by a lack of knowledge on HIV and disclosure skills and did not have easy access to or were afraid to approach skilled and knowledgeable people to guide them through the disclosure process. Another reason was forced disclosure due to pressure from their children, HCWs, their family and friends. This corresponds with reviewed literature on caregiver's experiences of HIV disclosure to CLHIV, which reported that caregivers lacked disclosure skills and were uncomfortable and uncertain of their children's reaction to the process and therefore opted not to disclose to them (Doat el al., 2019; Hayfron-Benjamin et al., 2018; Klutsey et al., 2021).

A caregiver, who later disclosed to her son, reported that HCWs at her clinic were unwilling to equip her with adequate disclosure skills and information, which she felt constituted a challenge.

> **C1P4**: *I was not trained nor taught how to disclose…that was a problem.*

Similarly, participant C4P1 shared that she lacked the relevant information on disclosure to share with her nephew.

> **C4P1:** *In the beginning, I did not have information on how to explain to him and did not know how to, because there is a right and wrong way… It is a fear of questions that the child might ask, like what HIV is and where it is coming from …*

Participant C4P1's response reveals the aunt's lack of information and the correct disclosure steps to follow while admitting that she feared disclosing the source of the infection. She did not volunteer the reasons for her fear but later articulated that with assistance, she attained full disclosure.

Participants C1P1 and C3P3, who had not informed their children of their HIV status, offered the following reasons:

> **C1P1**: *I do not know how to start telling him because I do not have the right information, but I think the time will come where I will explain to him. He sometimes asks me, 'mother how long am I going to drink this thing [medicine]?', [and] I would tell him that it helps him to drink this thing; it helps him to stay strong and healthy.*

> **C3P3:** *I once wanted to tell him, but I do not know how I can tell him in a way that will not hurt him because his mother abandoned him, and his father is deceased. So, I really don't know who can help me tell him in a right way, but I know I must tell him.*

The above caregivers' responses reflect a lack of knowledge and skills on disclosure, but of concern is that they attend a clinic (3) where counsellors, health professionals and social workers are available to assist them, yet they choose not to. Conversely, the role of health professionals in initiating dialogue on, and addressing and eliminating nondisclosure to assist caregivers and their children is questionable. This highlights a literature gap as health professionals were not included in the sample.

Fear of Emotional and Psychological Impact on the Child

Caregivers' fear that disclosure of an HIV-positive status may result in depression, anxiety or children attempting suicide is well documented (Kreniske et al., 2019; Wariri et al., 2020).

A caregiver of a 12-year-old daughter revealed that she could not disclose on her own because she feared that disclosure of an HIV diagnosis to her child would cause emotional harm. She further revealed that she also feared that her child would feel inferior and look down on herself. The caregiver then gave incorrect reasons to her child for taking ARVs, until she disclosed the child's status.

> **C4P2**: *I was afraid that she would feel inferior that she is not like other children, even her siblings, because even while she did not know her HIV status, she used to ask why she is the only one taking these pills, and while she was young I would tell her that she had pneumonia. I told her that so she would stop asking why she must go to the clinic and have her blood taken. So, when I wanted to tell her, I would look at her and end up changing the topic because I did not want her to feel inferior to others.*

The above response highlights that due to her fearing disclosure, the caregiver was providing incorrect responses to her child's questions regarding her taking treatment to end further discussion, but after some time she ended up disclosing to the child. One could argue that the child's persistence pressurised her to later disclose her status to her. This has also been reported

by Nabunya et al. (2020), that some caregivers disclose CLHIV's diagnosis due to pressure from their children demanding to know the reason/s that they take ART.

Another participant shared that she feared the consequences and reactions to her disclosing to the child. She reported that she feared that her child could commit suicide.

> **C1P3**: *...this made it more difficult because I feared that maybe he could end up doing something like attempting suicide ....*

The response of participant C1P3 highlights a concern that her child may experience suicidal ideations or commit suicide. Such a response concurs with Kreniske et al. (2019) whose study compared youth's suicide attempts with perinatally acquired HIV-infection (YPHIV) and youth who were perinatally HIV-exposed but uninfected (YPHEU). The study found that YPHIV were more prone to suicidal ruminations than YPHEU during adolescence. Such thoughts are areas of concern and require attention and intervention from all stakeholders involved in the CLHIV journey.

Another participant narrated how disclosure had emotionally impacted the child and how challenging it was to talk to her so she could understand and accept the HIV diagnosis. Worth mentioning is that though the child had negative reactions at first, she gradually accepted her status and was more cooperative in terms of adherence to her treatment.

> **C3P4:** *...then you will find her sitting by herself... mood swing, doesn't want to be with other people... doesn't want to talk, she is emotional, and you don't understand how you will start talking to her...Yoh, it was a very big challenge...*

This agrees with the findings of Buckley et al. (2022) that reported that amongst caregivers' reasons for delayed disclosure or nondisclosure to CLHIV is their fear of the impact of disclosure on the child's emotional and psychological health, the child's bitterness and inability to accept the diagnosis and incorrect, and untimely disclosure of HIV status to children.

Both participants (C1P1 and C3P2), who had not disclosed at the time of data gathering, shared their responses that align to their fear of any psychological or emotional harm that may emerge

due to disclosure.

> **C2P1**: *I have not told him because I think telling him will upset him and maybe he ends up not doing well at school.*
>
> **C3P2:** *My granddaughter is a person that is very reserved, and by telling her now, I think it will cause her stress and maybe she ends up doing wrong things. I'm just afraid of that.*

Fear of Stigmatisation and Social Isolation

As a result of the fear of stigma, participant C1P3 had decided to risk her child's life and hers by not adhering to treatment, which had negative repercussions that led her to later disclose to her family and then to her child. She revealed that at first, she did not want any of her family to know that she and the child were HIV-positive because she did not know how they would treat her after disclosure. She further reported that her family was very supportive to them both after learning of their diagnosis.

> **C1P3:** *...and it was very hard for me to accept, and no one knew about it [at that time] in my family, it was not easy for me to tell them because I did not know how they would look at us, I was afraid to tell them. I ended up taking a decision that it's better for both of us not to take the medicine at all.*

As discussed in the theoretical framework underpinning this study, the family setting can negatively or positively impact disclosure. The above response of participant C1P3 confirms that her immediate surroundings, which is her family, negatively influenced her to hide her and her child's diagnosis, though she later disclosed when the child got sick.

Another participant shared her fear of her daughter being stigmatised due to her positive status. This is reflected in her response below:

> **C1P5:** *The other thing is the fear of stigma; I don't want my child to be mocked or laughed at because of being diagnosed with HIV.*

The above response reflects protection and love for her daughter which is admirable. However, she later volunteered, that her response reflected her own insecurity, low self-esteem and fear, rather than her concern for her daughter.

A mother of a 10-year-old child who had fully disclosed to her daughter, feared that she would tell her peers of her HIV status, but at the same time she felt that she had no choice but to disclose it to the child and to tell her to keep it secret.

> **C4P3**: *It was difficult to start [the disclosure process] but we had no choice, we had to tell her. There are many children in our family, and whenever I need to talk to her, I must take her in a private space because the other children would ask me why she [the child] is always taking pills. I had also told her not to tell anyone. But I had that fear that maybe she might tell them, and they may end up looking at us differently. I'm still asking myself if she will be able to continue keeping it a secret.*

Participant C4P3's response reflects that the child was sworn to secrecy regarding her HIV-positive status which could be perceived as imposing much pressure on a 10-year-old child. It can be argued that the child is being groomed in deception from a young age, which could have repercussions later as the child could normalise lies and deception. Moreover, the child could adopt antisocial tendencies to avoid answering questions about her medication routine to her relatives and friends.

The participant's response below, who had not disclosed to her grandson, shared her concern for her grandson's life, and future relationships, stigma and isolation.

> **C2P1: …** *Also, will women want to have a child with an HIV-positive man? They could be scared he will infect them and their child. So, if I tell him, and he tells women, they may avoid him, and he might not find a partner and be lonely without children.*

The grandmother's response can be perceived as lacking knowledge on discordant and cordant relationships couples, SRH and PLHIV's ability to have children. Moreover, she also does not factor in PMTCT or her grandson's choice to procreate or his ability to personally handle his status in the context of a relationship and regarding his SRH.

Guilt, Poor Self-esteem and Self-Blame

As in other studies (Tapscott, 2016; Wariri et al., 2020), participants mentioned guilt and shame as barriers that prevented them from disclosing their children's HIV diagnosis to them. Some reported postponing disclosure, due to the guilt and shame attached to watching their children

grow up with HIV and the questions that their children might ask during the disclosure process. One participant said she felt vulnerable and embarrassed to reveal a secret she had kept to herself for a long time.

> **C1P4**: *I was afraid to tell him, you see, when you know that you have a secret you have kept from someone and now you must reveal it. It was very hard because I knew that they [nurses] were the only ones, and my family knew about this.*

The above mother, C1P4, of the CLHIV knew her HIV-positive status and her nonadherence to ART was the primary reason for her son's HIV-infection. She exhibited guilt and self-blame which hindered her full disclosure. However, at 12 years, she had fully disclosed to her son. This finding concurs with other studies (DeSilva et al., 2017; Joyce et al., 2022; Sokhela, 2016) in the literature review that revealed guilt, condemnation and caregivers' irresponsibility in protecting their children from perinatally acquiring HIV, being often associated with nondisclosure of their status to them.

Another caregiver, who despite her fear of not having sufficient information relating to HIV, had disclosed to her nephew and stated that her fear was based on the source of his HIV and that he might ask questions that she was uncomfortable answering or explaining.

> **C4P1**: *It is a fear of questions that the child might ask, like what is HIV, where it comes from, and how the child got infected. It was the fear of explaining how he got infected with it.*

This response concurs with other researchers (Li, et al., 2015; Joyce et al., 2022) who alluded to caregivers having diverse fears when it comes to paediatric HIV disclosure, including them having to explain the mode of transmission and infection, the outcomes of such disclosure, the impact of internal and external stigma and their relationship with the children post the disclosure. Moreover, it can be argued that it aligns with HIV being a STI and many people's discomforts with discussing sex (Marhefka et al., 2017).

Another participant shared how she blamed herself and felt guilty when she disclosed to her son, recalling how she would throw her treatment away during her pregnancy. This response concurs with the findings of a study conducted by Sokhela (2016) that reported that many caregivers

were challenged regarding disclosing their child's HIV diagnosis due to self-blame for infecting their children with HIV and the feelings of guilt for non-adhering to their treatment.

> **C2P5:** … *he got infected because when they [nurses] were giving me treatment at the clinic to protect him, I would take them [tablets] and throw them away, I did not want my family to know I was taking them. I also did not believe I was HIV-positive and then I did not see any need to take the treatment to protect the child.*

> **C2P4:** *I will tell him, but I still need to counsel and forgive myself for passing AIDS to my child, it's just that it's not easy.*

These participants (biological mothers) expressed more feelings of guilt and self-blame in comparison to non-biological caregivers when it came to disclosing to their children, as the fact that they were the source of their children's infection made it more difficult to discuss the HIV diagnosis with them. Hence, C2P5, had only partially disclosed despite her son being 10 years old, while C2P4 had not said anything to the child regarding his treatment as she feels she still needs to forgive herself first before disclosing to her son. These findings concur with the findings of Joyce et al. (2022) who found that caregivers' lack of readiness to disclose was mostly influenced by their personal feelings of guilt and anxiety about disclosure.

Fear of Children Blaming Parents and Loss of Trust

Beside self-blame, caregivers have expressed their fear of being blamed by family and community members, and their children for infecting them with HIV, thus leading to a loss of trust.

> **C3P5:** *I was afraid that she would blame me and say that she [daughter] is like this [HIV-positive] because of me. I was also afraid that she would ask why she got infected, while her siblings were not infected. Since there is someone before her and another one after her, I thought to myself that she would just think that I did not protect her, or I only cared about her siblings because I did not love her. So, I was afraid to tell her, because she may not trust me afterwards.*

> **C1P3:** *It is that he will grow up maybe blaming his mother for infecting him with this virus and hating me and maybe end up committing suicide because he will think that it means that his mother never loved him. You find that sometimes you have more than two children but only one is HIV-positive, there will be that thing that, why is so and so not sick and I'm the only one who is sick and taking this medicine, then it means you did not love me… You love the other siblings, that is why they are fine,*

they are not on this treatment. So, I thought he would blame me, but I'm glad he did not.

On probing, it was revealed that the children had different biological fathers of which the latter were unaware. These responses reveal dual deception as their children are unaware of who their biological dads are and their HIV status. Moreover, their biological mothers maintaining secrets could have dire consequences later, when the truth is revealed. The children could become withdrawn, and isolate and dislike the parent.

One mother of a CLHIV, who was diagnosed HIV-positive at the age of 8, shared that she and her husband were both HIV-negative. Hence, she could not comprehend how she could explain or disclose to the child, something that she did not know nor understand. But after the nurses had explained to her the benefits of disclosure, she managed to disclose to the child.

C2P2: *I don't even want to lie. It was never easy to tell the child, because how do I start explaining what I do not know? I don't understand this, and I don't know what can be done to me to understand. It would be better if there was someone in the family who had HIV, but there is none. His father and I tested HIV-negative. So, it was really very hard for us to tell him. But after nurses advised us to tell him, I did. He knows [his status].*

The response above is consistent with Okolo-Francis and colleagues (2021) who argue that some caregivers, especially biological parents avoid sharing children's HIV status with them, due to fear of being blamed for infecting them. The researcher was concerned about confusion surrounding the source of infection and the mother's being silent on knowing but she saw disclosure as the answer.

Continuation of the Family Legacy and Future Generations

A grandmother, C2P1, shared that she feared that her nine-year old grandson would procreate, and expressed concern about how his HIV-positive status would affect his sexual and reproductive health and future.

C2P1: *Culturally he should carry on the family name. Boys must have children to continue our family. I'm afraid to tell him. He may get angry and infect others.*

The importance of males being protectors, providers and procreators has been discussed in cultural, traditional and health contexts and PLHIV reproductive desires (Cavaliere, 2020; van

Zyl & Visser, 2015). However, to the researcher's understanding, this has not been discussed in the context of pediatric HIV disclosure and presents a literature gap that was discussed in the literature review chapter.

Forced Disclosure

Participant, C1P4, felt compelled to disclose as she was tired of not addressing her child's disclosure. Moreover, she feared that he was becoming a teenager and knew that teenagers and adolescents rely heavily on information from friends and peers. Hence, she felt pressurised to disclose to him, rather than him being misinformed by others. Okolo-Francis et al. (2021) have acknowledged that some caregivers are driven to disclose due to concerns that their children could disclose their status to others who may not have their best interest at heart, resulting in them becoming traumatised or being emotionally or psychologically affected.

> ***C1P4***: *Explaining to my child the reason for him taking treatment was hard but it was my duty. My motivation for disclosure was that the child was supposed to know the truth about his status from a parent so he would not get incorrect information from friends and the community about HIV.*

Interestingly, most participants did not voluntarily choose to disclose to their children but circumstances, pressure from HCWs and their children and others questioning the need for their CLHIV taking medication daily. This is in sync with Bronfenbrenner's EST that an individual's decision is influenced and affected by the community they live in, and societal and cultural perceptions. Some caregivers disclose to their CLHIV to protect them from stigma, discrimination and misinformation from family, friends and the community they live in. In conclusion, though most disclosure was forced, they persevered and engaged in partial and full disclosure.

Despite all the challenges due to a lack of knowledge, technique and the correct process of disclosing, 15 caregivers managed partial or full disclosure, while five had not disclosed and they shared their reasons for the status quo. Emerging from the analysed data was that all five participants from the clinic (C4) had partially or fully disclosed compared to C1, C2 and C3. The reasons for the higher disclosure rate among participants from C4 are unclear as this rate of disclosure only emerged during the data analysis. A subsequent study could investigate input

from all stakeholders at these four clinics who are involved with paediatric HIV, to ascertain what their opinions are on the barriers to disclosure.

5.3.1.2 Caregivers' Positive Experiences

The responses of most caregivers reflect that disclosure is a reiterative process fraught with doubt about their children's responses and their own capabilities and skills, but despite these concerns and challenges, they managed partial or full disclosure.

Sourced and Received Assistance

A middle-aged caregiver stated that her initial fear was of her child questioning her about the source of her infection, the mode of transmission and why she was the only CLHIV among her siblings. Hence, she initially decided that she was not going to tell her why she had to take medication daily. This was due to her feeling uncomfortable explaining the source of infection to the child as it entailed explaining unprotected sexual practices and discussing her sexual behaviour and activities with the child.

> **C3P5:** *At first, I had the feeling that I should not tell her, I was always afraid of how I would explain to her. Also, we never spoke about sex or HIV before… … I was afraid that she would ask me how and why she got infected while her siblings are not infected.*

> **C4P1:** *It was difficult because I did not know whether he would understand and accept it as a child if I tell him, you see…*

This corresponds with other research studies (Doat et al. 2019; Amankwah-Poku et al., 2021) that acknowledged that the fear of the CLHIV response and open-sex discussions are viewed as a taboo in most SSA countries. This results in biological and non-biological caregivers refraining from discussing this with their children and may result in some caregivers being silent or uncomfortable to discuss HIV and sex issues with their children out of fear of their children questioning them on the source of their infection. The consequence of their discomfort is them hiding their children's HIV-seropositive status. However, regarding C3P5, she managed to disclose with the assistance of a HIV counsellor.

> **C3P5:** … *Then the counsellor started and explained it well to her.*

Participant C3P5's response highlights the dynamics of disclosure and fear confronting caregivers but participant C1P3 felt that co-opting an HCW, made the process easier.

> **C1P3**: *It was never easy [to disclose] because I ended up requesting the nurses at the clinic to help me disclose, because it was not easy for me to tell him.*

Participant C1P3, also highlights that without the support of nurses from her local clinic, she would not have disclosed it to her son on her own.

> **C1P4**: *... but we used to talk with a nurse, and she would tell me that I must tell the child. I even asked her [nurse] how I am going to start telling him, and she told me I will see how I tell him, but I will have to sit down with him and tell him.*

Like C1P3, the above participant also shares her interaction with a nurse who stressed the benefits of disclosing to the child. The response above reflects a lack of patient-centred care (PCC) and support from many HCWs, as the nurse was aware of the caregiver's concerns and shortcomings regarding disclosure, yet she encouraged her to disclose. This shows a lack of empathy and disregard for the importance of disclosure being a systematic and empathetic process that entails sharing correct, relevant and age-appropriate language. Worth noting is that both the participants were from clinic C1. There responses are congruent with other researchers (Mabida, 2016; Odiachi, 2017) who have mentioned that HCWs play an integral part in the disclosure of children's HIV diagnosis.

Another participant, who shared that she was counselled by a clinical social worker on how to disclose to the child, expressed that she felt challenged regarding whether the child would accept and understand his HIV status and what it meant for him to be living with HIV.

> **C4P1**: *I did not have information on how to explain to him, until I had a discussion with a social worker who supported me with information, and she advised me how I should tell him [the child]. However, I was scared he wouldn't understand what I was telling him and what his life was going to be like.*

Participant C4P1's nephew is 10-year-old, and her initial response demonstrates her lack of knowledge of age-appropriate disclosure. Moreover, the crucial role of social workers in the management of children who are on ART has been alluded to by several researchers (Manganyi, 2021; Sesane & Geyer, 2017; Verma, 2020) who mentioned that their involvement in paediatric

HIV is extensive. This is due to them rendering multifaceted therapeutic and psychological support to CLHIV and their parents or caregivers and preparing the latter with the necessary tools for HIV disclosure.

Self –disclosure

One participant also expressed fear of disclosure but relented and disclosed to her child on her own and her response depicts a favourable response.

> **C1P4**: *It was not easy to tell him, …but he was strong, he shocked me by just accepting it.*

The above-mentioned caregiver's response demonstrates how the carer is more fearful of the child's response, than the child. She had underestimated his level of understanding, as he had just accepted his diagnosis after disclosing his status to him.

> **C4P1**: *…he knows his status, I have told him…I am the one who told him…though it was difficult, but I sat him down and told him [that he has HIV]. When I told him, I noticed that he understood and accepted it.*

Participant C4P1, the aunt of the 10-year-old boy, reported that her nephew did not articulate any negativity with her disclosing his HIV status to him, instead he promised to adhere to his treatment. This was a relief to the aunt as she initially approached disclosure with doubts and fear. She further indicated that he attends a support group and receives counselling which she thinks is assisting him to cope with his status. The importance of support groups has also been mentioned by Mphego et al. (2023) as a positive intervention that assists PLHIV to stay engaged in care and treatment to enhance their quality of life and decision-making skills.

Improvement in ART Adherence

One caregiver stated that disclosure process was emotionally draining but rewarding and she was excited about the positive outcome of her disclosing to her 12-year-old daughter. She narrated how courageous and motivated her child was to take her treatment after being informed about her HIV status. Before disclosure, her child used to throw her ARVs in the dustbin because she saw herself as healthy and not sick, and therefore she did not understand the reason to take them. Turner (2021) concurs that the availability of ART makes convincing CLHIV that they live with

HIV very difficult because they appear strong and feel healthy compared to the past years when HIV treatment was not available.

> **C4P2:** *It is important [to disclose] as I have just explained that since she knows her status, she has become courageous to take her pills, now she knows why she is taking them. Before the disclosure, I had to push her to take treatment; most times she would take them and throw them in a bin. She was not adhering and always had a high [unsuppressed] viral load which showed that she wasn't taking them. Now, she doesn't even need to be reminded and has a viral load that is lower than the detectable amount.*

This response reveals that though there may be fears and challenges associated with an HIV disclosure, the benefits of disclosure outweigh them. This caregiver managed to face her fears and disclose so that her child would be encouraged to make good decisions and take responsibility for her own health and wellbeing. Literature review has shown that there are many benefits of disclosing to CLHIV, such as improving adherence to ART, improving their psychosocial adjustment and self-esteem, reducing horizontal transmission due to unsafe sexual behaviour later, suppressed viral load, and less chance of advanced HIV disease (Amankwah-Poku et al., 2021; Nathaniel et al., 2024; Sariah et al., 2016).

5.3.2 Data and Analysis Relating to Objective B: The factors affecting caregivers' disclosing perinatally HIV-infected children's HIV status to them in uMzinyathi District, KwaZulu-Natal

This theme focuses on the factors that promote or hinder the process of disclosing an HIV status to children. Caregivers revealed different factors that facilitated disclosure with their CLHIV. Some revealed the factors that they felt negatively affected the disclosure process, such as the age of the child, perceived negative outcomes, concerns about children informing others of their status, concerns that children may not accept the status, and beliefs that disclosure may cause anger and resentment that may impair their relationships with their CLHIV.

5.3.2.1 Factors positively affecting the disclosure process

Caregiver-child Relationship

Caregivers have highlighted that their positive relationships with their children posed strong bases for discussions about their diagnosis to take place. This has also been affirmed by Madiba et al. (2013) and Mandalazi et al. (2014) that the caregiver-child relationship can either promote or serve as a hindrance to HIV disclosure. In this study, caregivers shared that it served as a positive factor in the disclosure process.

> **C3P5:** *It's nice to have a good relationship with your child because you will know when she or he is happy or sad, and then you can postpone telling him/her when you see that it is not the right time to disclose. As for me, I had a very good relationship with her, I had to make her my friend so she would trust me, though it was hard to tell her as I feared that I might lose her trust, and that she might blame me, but I was confident that our relationship would not be impaired for a long time.*

> **C4P1:** *I did not want someone else like nurses or social workers to tell him, but I only required information and guidance on how to tell him because he is like my child now and I know how to make him feel comfortable. There is this connection between us because even after I told him, he promised to take his treatment accordingly.*

The responses above show the importance of building and maintaining good relationships with CLHIV. Participants indicated that their relationships did not become volatile or break down after disclosure, instead it was strengthened. This aligns with EGPAF (2018) who acknowledged that disclosure could aid and improve caregiver-child relationships. Contrarily, Joyce et al. (2017) and Li, et al. (2015) had reported that some caregivers postpone or are reluctant to disclose, due to fear that their relationships with their CLHIV will be negatively affected. However, some caregivers in this study emphasised the necessity of enjoying good, honest and transparent relationships with their children to easily facilitate disclosure and continuing their positive relationship.

Counselling Support Services from PHC

Some caregivers mentioned that the counselling support they received from the clinics made them overcome any concerns and internal fears they had regarding disclosure. They mentioned

that supportive counselling was key to assisting them and their children to take an active role in HIV management.

> **C4P1:** *They assured me that they will freely explain to the child the importance of this treatment when I disclose it to him and that the disclosure will help the child understand why he must take his medication as ordered. The information from that social worker was very helpful.*

> **C1P3:** *...if it wasn't for the help of the nurses from the clinic, I think the child would not have known his status. They had to counsel me first to accept that I needed to tell him the truth, because even when I tried to tell him on my own I couldn't, but they [nurses] were there and helped me.*

This concurs with other researchers (Manganyi, 2021; Sesane & Geyer, 2017; Turner, 2021) who have indicated that caregivers need extensive supporting counselling to initiate the process of disclosing to their children as they are often faced with many psychosocial issues and fears regarding disclosure. This shows a crucial role played by HCWs, social workers and other stakeholders involved in pediatric HIV management including disclosure of their status.

Belief that Disclosure will Prevent Further Transmissions

Caregivers were motivated to disclose, to enjoy and experience the positive outcomes associated with HIV disclosure. Being cognisant that disclosure of an HIV status could prevent further transmissions of HIV was a factor that facilitated caregivers of CLHIV disclosing their status to them. Mandalazi et al. (2014) and Sokhela (2016) attest that children and adolescents who have been informed of their HIV-seropositive status will be encouraged to prevent transmitting the virus to others and practise safe sex and protect those around them. Caregivers who revealed that they do not regret confronting their fears of disclosure said they believed that their children had to be aware of their diagnosis to protect themselves and halt any further spread of HIV.

> **C2P2:** *After I have learnt that telling the child that he has this disease will protect him and not make him pass it on to another child or person, made me take a decision to disclose to him…*

> **C1P5**: *I think it is protecting them and protecting others from being infected and to inform their peers about HIV, you know, that's why it helps for a child to know their status…*

C1P3: *…So that he will grow up knowing that he has this disease and that if he wants to live long, he must take his medicine, take care of himself and protect himself so he cannot infect other people around him.*

The above responses indicate a humanitarian outlook as the caregivers' care about reinfections, new infections and the longevity and mortality of CLHIV. These caregivers were concerned that their children would get involved in unprotected sexual activities and therefore they hoped that disclosure would contribute to better health care and motivate their children to improve adherence to ART and thereby suppress the HI virus. The evidence suggests that HIV disclosure to CLHIV promotes adherence to ART, a better understanding of a CLHIV's status, and viral suppression (Beima-Sofie et al., 2017; Wright et al., 2017).

Belief that Disclosure will Reduce Parental Stress

As evidenced in the literature review, HIV disclosure reduces parents' and children's stress levels, increases patients' adherence to ART, and facilitates strong support systems, (Buckley et al., 2022; Joyce et al., 2022; Ramsammy et al., 2022), as participants cited similar contributing factors towards HIV disclosure. They further cited many benefits associated with disclosure, including opposing or being drained by keeping secrets, preferring transparent and open communication with their children, and increasing children's knowledge on HIV and related topics.

Another participant who had disclosed to her child and family said she felt peace in her heart after disclosure. She highlighted how stressed and burdened she was and how she previously did everything possible to ensure that her child did not find out what the treatment he was taking was for. By telling her child she overcame her concern as the disclosure assisted in improving his self-esteem as he now understood the role of ART, why he should adhere and the importance of taking care of himself.

C1P4: *It helped to tell him that he has HIV because now he knows how to behave, what he needs to do because he is growing… By telling him I removed from my shoulders a heavy burden that has been troubling me, because now I no longer have that heavy burden on my shoulders, a burden of always having to be behind him ensuring that he doesn't find out what the pills are for and that the other children do not find out as well. I always feared that if he could find out on his own it would be a*

problem because he could ask me why I did not tell him. I am happy that he knows now and at least he heard it from me, not from someone else.

C3P4: *It's better if she knows [her HIV status] because she is now aware of her [HIV] status, and I know that she is taking her medicine. It's no longer stressful for me as a parent.*

These responses reflect how disclosure relieves caregivers from keeping a secret from their children and fosters openness and strengthens their caregiver-carer relationships and affords them the opportunity to freely discuss HIV and sexual related issues with their CLHIV.

Studies on disclosure have recorded poor health outcomes associated with caregivers' reluctance to disclosure such as psychological distress, burden of keeping the child's HIV status secret and the fear that the child may accidentally discover their HIV status (Amankwah-Poku et al., 2021; Nathaniel et al., 2024). Due to nondisclosure, other caregivers of CLHIV revealed that nondisclosure breeds anxiety, stress and dysfunctional relationships within the family (Amankwah-Poku et al., 2021; McHugh et al., 2018).

Disclosing CLHIV's diagnosis to them, affords them an opportunity and responsibility to actively participate in preventing further HIV transmission, taking care of themselves and not engaging in risky behaviours that could put others at risk. Baker et al. (2018) mentioned that disclosure to children is crucial as it affords children and their caregivers an opportunity to receive relevant psychosocial support, assist with treatment adherence, and reduce caregivers' stress and burden. and inhibits further transmission of the HI virus.

5.3.2.2 Factors negatively affecting the disclosure process

Child's Age and Cognitive Development

Caregivers regarded the child's age as a barrier or hindrance to the disclosure of children's HIV diagnosis to them, stating that their children were too young and cognitively immature to process and understand discussions on HIV. However, this can be debated, since the WHO and other studies (EGPAF, 2018; Turner, 2021, & WHO, 2011) have recommended starting the disclosure

process with partial disclosure where the information surrounding HIV is shared with the child, taking into consideration their cognitive developmental level. Therefore, disclosure can be initiated but without mentioning the word *HIV* or *AIDS* to their CLHIV.

> **C1P1:** *It hasn't come to me to tell him yet because he is still young. Maybe when he is grown, I will tell him. But for now, I don't think he will understand what I will be talking about.*

> **C3P2**: *I think I can tell her when she is around 15 years old, then she will be able to handle it and know that she must take care of herself and not sleep with boys.*

Although caregivers agreed that disclosing to their CLHIV is important, some disagreed with the recommended ages for the different stages of disclosure. For them, 6 – 12 years was too young for children to be told their HIV status. Participant C3P2 is a grandmother of a 12-year-old child, who indicated that she felt that her granddaughter should be told her status when she is 15 years old as she would be more mature to handle the news. Such a response aligns with Okolo-Francis et al. (2021) who acknowledged that disclosure is often affected by caregivers' assumptions that children are too young to comprehend their diagnoses and prognoses. On the contrary, Joyce et al. (2022) have argued that caregivers who opine that their CLHIV are too young to accept and comprehend their HIV diagnoses, reflect their incapability or refusal to disclose to their children, rather than children's inability to understand or accept their HIV status. It is in such instances that social workers and HCWs trained in HIV disclosure should take a proactive role in educating and counselling caregivers on disclosing to their children.

Fear of Negative Outcomes of Disclosure

Caregivers have expressed that they were afraid that disclosure could make their children depressed and lose hope about their future, thus they refrained from disclosing to them. Other researchers (Kreniske et al., 2019; Msoka et al., 2025; Wariri et al., 2020) have acknowledged similarly that many caregivers are challenged when it comes to telling their children about their HIV status because it often associated with feelings of depression and hopelessness.

> **C2P1:** *It's the fear of causing depression to the child.*

> **C3P3:** *The child will be depressed and maybe lose hope about her future goals and dreams. Because she is still growing, she has dreams and maybe when she has been*

disclosed to, she will just lose hope and think that she will not be what she wants to be when grown up.

Participant C3P3 indicated that though she was aware that an HIV-positive status does not prevent one from achieving their dreams and becoming whoever, they want to be in life, she did not hold similar views regarding her niece. Disclosure to children significantly impacts on their longevity, quality of life, health, development, wellbeing, and future (Baker et al., 2028; Li et al., 2015). A health-promoting disclosure will not threaten children's quality of life and future.

Belief that HIV Disclosure will Cause Anger and Resentment

One participant highlighted that she first feared that the child would be angry at her for infecting him with HIV. She had a feeling that the child would not trust her anymore and that disclosure would negatively affect their relationship.

C1P4: *I feared that the child would grow up with anger, hate me and say that I infected him with this disease, and will end up not trusting me.*

Another participant stated that she did not want to disclose to her child because she assumed that the child would be rebellious and disrespectful toward her or assume that her parents did not love her, and therefore, they did nothing to protect her from getting infected with HIV.

C3P5: *Umm… you know, children in nowadays don't like to be hurt or to be told bad news, so I thought that she will just take it wrongly, maybe she will fight, maybe she won't respect me [as a parent] anymore, because she will say you got me infected because you did not love me from the beginning, that is why I'm sick, you treat others [siblings] well, you don't treat me well.*

This finding agrees with Kreniske et al. (2019) and Wariri et al. (2020) who have reported that most caregivers fear initiating HIV disclosure with their children as they fear that they will be angry toward them, and they also fear their children's perceptions of them and if their relationship will be affected after they have learned of their HIV diagnosis, thus deciding to keep their diagnosis secret. However, there is very little evidence of the negative emotional or psychological impact of disclosure in CLHIV's life. Other studies (Buckley et al., 2022; Joyce et al., 2022; Ramsammy et al., 2022) have shown that disclosure promotes trust and transparent

relationships between caregivers and the child. Hence, caregivers should be assisted and encouraged to conquer their fears and initiate the disclosure process.

Fear of Children Informing Others

Another barrier reported by caregivers that affected disclosure was their fear that their children would inform others of their HIV status, either at school, church, and family or in their community - subsequently disclosing their parents' status. Some participants had the following to say:

> **C4P5:** *We are staying in a big family and there are about 13 other children in the household, so what happens to any one of us will be known by everyone else. So, that made me hesitate and afraid to tell her, her HIV status because I knew that she is very open and can tell other children…*
>
> **C3P1:** *What I was worried about was what would happen if I told her the whole truth and she tells her friends. Therefore, I decided not to tell her everything, you see, in case she tells other people.*

This factor has been documented in other studies (Joyce et al., 2022; Mukhtar-Yola & Kuczawski, 2020; Sariah et al., 2016) where parents/caregivers refrained from informing their children of their HIV status due to fear that children will inform others of their status and therefore they may be discriminated against or ostracised. The district of uMzinyathi is predominantly a rural district with many extended families living together as one household, and therefore should a child disclose their HIV diagnosis to other children they automatically disclose their parents' HIV diagnosis to the rest of the family, which may to lead to gossip, discrimination and family conflict.

The Ecological systems theory attests that disclosure may be affected by family settings and community when caregivers are afraid of the family or community knowing their HIV status. These caregivers were more concerned that their children may accidentally disclose their status to other family members, friends or the community.

Concerns that Children Will Not Accept the HIV Diagnosis

One caregiver who had not disclosed to her child in full at the time of data gathering mentioned that her challenge was assessing if the child would accept or understand that she has HIV because her child had told her that she would stop taking her medication when she gets older.

> **C1P5**: *The first challenge was assessing if she would understand, especially with regards to the treatment which she must take every day and will never stop taking it, because this is what has been bothering her – asking for how long she is going to take it. [So], it is more of acceptance and understanding because this is bothering her. She started with syrup, now she is taking pills, she can see that she is not getting off this train; she just keeps taking this treatment. …she has been saying that she no longer wants to take the pills. So, it's about acceptance and will she be able to accept that and will she not stop taking them, once she knows? That's the challenge that I'm facing so far.*

Another participant who was advised by a clinical social worker to disclose her nephew's HIV status to him expressed a similar challenge regarding his acceptance and understanding of his HIV status and what it means for him to be a CLHIV.

> **C4P1**: *I had a discussion with a social worker before, and she advised me how I should tell him [the child]. It was difficult because I did not know how he would understand and accept it as a child if I told him, you see, but I noticed that he understood and accepted it. He also promised to take care of himself and adhere to the treatment because even now he adheres well to his treatment.*

Similarly, studies (Doat el al., 2019; Hayfron-Benjamin et al., 2018; Klutsey et al., 2021) have recorded caregivers' concerns regarding their children's' acceptance of their diagnosis and their reactions thereafter. The response above highlights the role social workers play in HIV disclosure.

5.3.3 Data and Analysis Relating to Objective C: Recommendations to improve caregivers' disclosure techniques to perinatally HIV-infected children in uMzinyathi District, KwaZulu-Natal.

This theme focuses on the final objective that relates to caregivers' recommendations to improve the disclosure process to children who had perinatally acquired HIV. Caregivers' recommendations and suggestions on the disclosure process are found below.

5.3.3.1 Assistance of Healthcare Workers

Studies reported that some caregivers prefer to disclose to their children themselves but due to a lack of proper skills and knowledge, require assistance from HCWs to provide more accurate information, respond to questions that CLHIV may have and to provide psychosocial support and counselling that caregivers may be unaware of or unable to provide (Madiba, 2016; Sabharwal et al., 2018; Turner, 2021). Madiba and Mokgatle's (2016) study found that participants in their study mostly received disclosure from their caregivers while other studies reported that HCW's primarily or in consultation with the caregiver, disclosed to CLHIV (Kalembo et al., 2018; Madiba & Diko, 2021; Mashile & Maake, 2024; Nathaniel et al., 2024).

When the participants were asked to share their recommendations to ease the disclosure process, participant C1P3 shared that nurses should disclose to their children because they have adequate, current and relevant information on HIV.

> **C1P3**: *It's better to find someone who will be able to talk to him, explain to him, like nurses because they are the ones who know about our health, so it is easier to ask them to disclose if you're not able to or if it is difficult for you, because it is difficult. ...really nurses should help us disclose.*

Another participant shared that the disclosure process is challenging for caregivers to do on their own. She, like C1P3, believed that nurses' assistance is required because they are trained to render counselling services to their patients. She revealed that she was unprepared to disclose to her child, but with the assistance of a nurse at the clinic, she was able to disclose her child's HIV status to her.

> **C4P2**: *I don't see how it would be easy to tell a child a condition like this; I just don't see how it could be easy… I don't see it. It can never be easy, but at least nurses should help us disclose because they are trained to give counselling to people.*

The above recommendation is based on experience, as this participant had fully disclosed to her 12-year-old daughter and in hindsight felt the assistance of adequately trained people makes the process easier. The literature review has presented that nurses, social workers, doctors, HIV counsellors and counsellors play a significant role in paediatric HIV disclosure (Kalembo et al., 2018; Madiba & Diko, 2021; SAHCS, 2017).

Participant C3P5, said it is much better for children to be told their HIV status by the HCWs because they know the correct and age-appropriate vocabulary to use so that the child understands them, as caregivers sometimes shout or respond to questions in anger. This is congruent with the findings of other studies (Okolo-Francis et al., 2021; Sariah et al., 2016) that suggested that children require honest, relevant and accurate information that is not detrimental to their mental health and wellbeing. Communicating accurate messages with CALHIV is paramount to ensure that the disclosure of their HIV status is successfully carried out.

> **C3P5**: *It is good for the child to start with their nurses or counsellors when a parent has already spoken with them about starting disclosure…because they have right words to say to the child, unlike me as a parent, who will just say to the child, "you see, you have HIV". If the child is informed by the counsellor, the counsellor will explain better, so the child will understand. Parents should be assisted by nurses [to disclose]. It helps to be assisted by nurses, because you might end up responding in anger or end-up shouting when the child asks you a lot of questions because you yourself didn't choose to be HIV-positive, so it is better if nurses help you.*

The role of HCWs in paediatric HIV disclosure has also been emphasised by the NDOH, that some caregivers in certain instances, could partner with HCWs or request HCWs to facilitate the process (NDOH, 2016). The responses mentioned above testify to the pivotal work done by HCWs in providing HIV disclosure information to both caregivers and their CLHIV.

5.3.3.2 Training Caregivers on Disclosure

Caregivers' lack of disclosure skills makes it difficult for them to initiate the disclosure process with their children as they are often uncomfortable and uncertain of their children's reaction to disclosure and therefore opt not to disclose to them (Klutsey et al., 2021). The study participants recommended that they be trained by professionals to initiate and facilitate the disclosure process. This is like the suggestions of Li et al. (2015) that healthcare professionals and workers, HIV counsellors, and social workers should play a role in assisting and educating caregivers to facilitate timely HIV disclosure in a sensitive and respectful manner that does not harm children and their lives.

One participant indicated that it is much better when a caregiver has been trained because they will have accurate information to share with their children.

C1P2: *As I have already explained, it is important to have knowledge. When someone has relevant or correct information, they can easily do disclosure to their child. I am really pleading with the Government [DoH] to educate/train us as caregivers. They can invite us all into a group and teach us. It becomes easy to explain to the child when you have knowledge, and you have been taught. When you know nothing [about HIV disclosure], especially you find that the children are staying with their granny who does not have knowledge, but when she has been taught by the nurses, she will then be able to properly explain to the child.*

Some caregivers recommended that they should be equipped with disclosure information immediately after the child tests positive for HIV, so they will be prepared to initiate the disclosure process with them. Emphasising the importance of education, they said:

C3P4: *Parents should quickly get information and be educated on how to disclose. They [parents] should be taught early while the child is still growing, you find that the mother is already taught how to tell the child, and maybe when the child is 7, then should be told. Once the child tests [HIV] positive, nurses should start preparing the parent/caregiver for disclosure.*

C4P1: *They [parents/caregivers] should be educated on how to disclose to their children, I think that can make disclosure easy.*

These recommendations align with Mphego et al. (2023) who recommended that health education should include the various modes of HIV transmission, dealing with stigma, overcoming shame and guilt, and that initiating HIV disclosure should be conducted with caregivers of children on ART, so they are able to initiate disclosure and discuss HIV related issues with confidence. Therefore, HCWs need to prioritise educating caregivers on how to initiate the disclosure process.

Worth noting from the caregivers' responses is that most refer to HCWs as nurses and put more emphasis on nurses assisting with disclosure, with very few including HIV counsellors, social workers, doctors, and psychologists in this pivotal role.

5.3.3.3 Caregivers' Support Groups

Support groups for caregivers are intervention strategies that participants felt could assist with disclosure and its challenges. One caregiver opined that support groups can help them gain

knowledge from the experiences of others who have initiated disclosure, or partially or fully disclosed. This aligns with Mphego et al.'s (2023) findings that encouraged the formation of caregivers' support groups to encourage disclosure and address any disclosure challenges that caregivers may encounter.

> **C1P2:** *It can help greatly to have a support group because one can share a challenge, she/he encountered when disclosing [HIV status] to the child and another one can come up with his/her experience of a similar challenge. A solution will emerge because everyone will come up with different ideas on how they handled a similar challenge. A support group is very beneficial.*

Another participant said that support groups can facilitate them participating in open discussions about HIV and HIV disclosure and they can be sources of comfort to one another. In addition, they could share experiences and form a caregiver buddy group. Moreover, CLHIV could also participate in support groups which facilitate upliftment, information sharing, and the sharing of experiences.

> **C2P2***: If, at least, there can be a counselling [support group] for mothers and caregivers of HIV-positive children to have an open discussion about this thing [HIV], maybe in the form of a support group. The children themselves need to have their own support groups to teach them how to take care of themselves and protect others from spreading the virus.*

One caregiver expressed keen interest in being part of a caregivers' support group stating that she would value assistance and information sharing to address challenges associated with disclosure.

> **C3P5***: ...I would like to be in the support group as well, so I would learn how others have disclosed to their children or how they disclose…because maybe there is a thing or a problem that I cannot see or know, so maybe they can advise me on how to deal with it.*

> **C4P4:** *I think if counsellors or social workers can facilitate support groups to empower us and our children with skills because they are trained to counsel people and can help us on how we can overcome stress and depression because children in these days commit suicide when you tell them something they are not happy about, and maybe they can help us with worries that we have about telling our children [their HIV status].*

Participant C4P4 mentions the role that counsellors and social workers can play in empowering the community with knowledge and skills to address any HIV related issues including stigma, HIV disclosure, mental health, and adherence to HIV treatment. The crucial role of social workers in pediatric disclosure has been alluded to by Verma (2020) who states that they have been contributing to the management of HIV/AIDS by providing counselling, treatment adherence support, disclosure counselling and social justice activities to PLHIV and those affected by HIV/AIDS.

Caregivers of CLHIV require safe spaces where they can safely and confidentially discuss issues and challenges, they have regarding disclosure of their children's HIV status. Consequently, the establishment of caregiver support groups as an intervention to address and overcome challenges and the barriers of paediatric HIV disclosure could render positive results. These groups can be platforms for HCWs and social workers to educate the caregivers and dispel any myths that they may have about HIV and empower them with the information and skills to successfully execute the disclosure process. Multidisciplinary teams that include nurses, doctors, pharmacists, social workers, psychologists and counsellors should unite and work together, and caregiver support groups should be formed to encourage responsible disclosure, share experiences of disclosure, improve caregivers' self-esteem and address their psychosocial needs and challenges. Earlier it was highlighted that caregivers are concerned about their children's suicidal ruminations and such a concern requires the attention and intervention of stakeholders involved in the CLHIV's journey.

Interestingly, though, Kontomanolis et al. (2017) revealed that people with chronic diseases, including HIV, often refuse to join support groups due to fear of stigma associated with the diagnosis. Conversely, this study's participants from all four clinics mentioned support groups as a strategy that can improve paediatric HIV disclosure and adherence to ART and view support groups as a safe place to learn and share their experiences with HIV disclosure.

5.3.3.4 Use of Child-friendly Language

The literature has highlighted that children need honest and age-appropriate language when discussing HIV related issues (Okolo-Francis et al., 2021; Sariah et al., 2016; WHO, 2011).

Caregivers' and HCWs' assurance that children and adolescents understand the concepts relating to HIV, in simple and age-appropriate terms, disclosure can yield positive results. One caregiver emphasised how crucial it is to provide HIV information to the child in stages using language that is comprehensible to the child.

> **C2P5:** *...so, at the time when the child is asking question, you need to tell her according to her understanding and not just tell her anyhow…*

Another participant revealed how HCWs and counsellors are better able to communicate with children, as they are trained to communicate using age-appropriate words that will not harm the child. This is congruent with WHO (2011) recommendations that disclosure to children should follow a planned process and that HCWs and caregivers should use simple age-appropriate language that corresponds with the child's level of maturity.

> **C3P5:** *It is good for the child to start with their nurses or a counsellor [for disclosure] ... because the counsellors can talk, they have right words to say to a child.*

Communicating children's HIV diagnoses to them requires much thought and planning, including the use of child-friendly language that they easily understand. Healthcare workers and caregivers need to be well versed with child-friendly language and knowledge on HIV disclosure to ensure that children understand the basics of HIV, HIV transmission, and medicines. Once they are well versed, it will be easy to transfer the information to the children and be able to respond to questions that they may have. The importance of multidisciplinary teams cannot be overemphasised as most participants stated they felt ill-prepared to disclose on their own. Moreover, the importance of health professionals and caregivers continuously upgrading their skills and knowledge cannot be overstated as this enables them to disclose in an ethical, compassionate, supportive and culturally-sensitive way that improves the psychological wellbeing and long-term health outcomes for CLHIV.

Though the study was conducted at four PHCs, this is not a comparative study. Except for the participants from the C4 who have partially or fully disclosed, most caregivers' experiences were similar across the clinics. Hence the researcher could not identify better practices from a particular clinic, but a subsequent study could assist in unpacking the practices that facilitated

more disclosure at one clinic and included the voices of other stakeholders involved in disclosure to CPAH.

5.4 BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY

Bronfenbrenner's Ecological Systems Theory (1979) provided a foundational framework as it demonstrated the links between caregivers and their interconnected systems (chronosystem, exosystem, macrosystem, microsystem, mesosystem) and how each system influenced the caregivers' thought patterns and decision-making processes.

The focus of the microsystem is on direct relationships and interactions between caregiver-CPAH and the HCWs as these individuals are the primary stakeholders involved with disclosure. Emerging from the analysed data was the emphasis on the caregiver and their recipient of care's relationship as disclosure could disrupt or fragment their relationship. Moreover, the concern about emotional readiness of caregivers and the CPAH was volunteered on several occasions, thereby stressing the quality of the relationship and both parties' emotional state and wellbeing. This was also evident in the responses from caregivers who had disclosed as they reported stronger and more trustworthy relationships and improved adherence to ART and their children taking ownership of their treatment, care and wellbeing. The recommendations to develop caregiver and CPAH support groups and the improvement of HCWs knowledge through continuous training all fall within the microsystem.

The mesosystem's focus is on interconnectedness between systems outside of the immediate environment, with emphasis on health and educational facilities and families. This was apparent in the healthcare workforce and the carers and CPAH (Vreeman et al., 2015). Caregivers shared that they valued the input from HCWs due to them having more knowledge and skills to appropriately disclose with age and developmentally appropriate HIV related vocabulary that they felt they lacked. Inasmuch as the school forms part of this system, caregivers did not include much about the school except for recommending a closer relationship and input for strengthened support systems for the CPAH.

The focus of the exosystem is on indirect environments that affect the caregivers and their children, such as religious and traditional organisations, workplaces, support structures and access to education or healthcare. This was evident in caregivers' responses on the discomfort attached to discussing the source of the HIV infection, sex and sexual acts and how community and family members view HIV and PLHIV and the stigma attached to a HIV diagnosis. They expressed fear on how people would treat their CPAH. Hence, the relevance of exposing how community-led stigma and/or socioeconomics affects whether caregivers disclose to their children (Sariah et al., 2016), hence, recommendations on interventions to improve community knowledge bases and reduce stigma.

The macrosystem's emphasis on cultural, traditions and societal norms and practices was evident throughout the data as culture and traditional norms and practices form part of KZN which is steeped in these. Hence the importance of policies, processes and guidelines aligning with these and factoring them in when being developed. In addition, caregivers' concern about their CLHIV's maturity levels were inhibiting factors in them disclosing.

The Chronosystem captures transformation, and change, hence the importance of developmental stages and age-appropriateness in the disclosure process. This was demonstrated by caregivers feeling that their children were too young and would not process the information correctly; they therefore delayed disclosure, despite studies showing positive consequences to timely disclosure. As argued earlier, rigid age stipulations for disclosure could have negative repercussions as children are unique and physically and emotionally develop differently.

In conclusion, the EST allowed the participants' responses to be analysed broadly to include the connectedness of the caregiver, family, relationships, and community and society in disclosure to CPAH as these systems all impact on caregivers and their children's readiness for the disclosure process.

5.5 SUMMARY

The findings demonstrate the complexity surrounding pediatric HIV disclosure. Caregivers of children who receive ART from the four clinics under uMzinyathi District Municipality encountered a diverse array of challenges such as lack of support, knowledge and disclosure skills to facilitate the disclosure process, fear that disclosure might have a negative emotional and psychological impact on children after learning of their HIV diagnosis, fear of stigma, and social isolation. Some caregivers mentioned that their children did not want to associate themselves with others after disclosure, and caregivers feared that their isolation might give birth to suicidal ideation. However, none of the caregivers reported any incidence of suicide or suicide attempt. As in other studies (DeSilva et al., 2017; Joyce et al., 2022; Sokhela, 2016) reporting feelings of guilt and blame, participants of this study were not immune to those feelings, and they reported that they felt ashamed and embarrassed for infecting their children with HIV and could not stand their children questioning them about the source of infection.

CHAPTER SIX
SUMMARY, CONCLUSIONS, RECOMMENDATIONS, IMPLICATIONS AND LIMITATIONS

6.1 INTRODUCTION

The presentation and discussion of the participants' interviews are contained in the previous chapter. This chapter summarises the study's findings, the participants' recommendations to improve pediatric HIV disclosure, and provides recommendations for policy development and community work practice. Ways of disseminating the knowledge, and the limitations of the study are also discussed, and the chapter concludes with final remarks.

6.2 CONCLUSIONS

This qualitative study explored caregivers in the uMzinyathi District of KwaZulu-Natal disclosing their children's perinatally acquired HIV status to them. The findings demonstrated the complex, multifaceted and emotionally charged process of HIV disclosure. They further highlighted how caregivers' emotional readiness, cultural expectations, knowledge, education, perceived stigma and their socioeconomic status influence and affect the disclosure process.

All the participants being female, re-enforce the literature on caregiving being largely feminised (Sharma et al., 2016), however, cognisance is taken of the shift in gender according to Pacheco Barzallo et al. (2024). The findings highlighted that disclosure is still a challenge as 45% of participants had fully disclosed their children's HIV status, 30% had partially disclosed and 25% had not disclosed at all. A lack of disclosure skills, resources, knowledge and support and the fear of their children's emotional and psychological reactions, self-blame, and fear of stigma were key barriers. In cases where caregivers had fully disclosed, much credit was assigned to the role of healthcare workers. Furthermore, those caregivers who had disclosed, reported that their children demonstrated improved adherence to ART and that their stress was reduced.

The findings highlight the fears and concerns of caregivers regarding loss of trust, stigma, their children's psychological wellbeing and how these should be addressed through policy,

community and health interventions. Most importantly, non-disclosure persists despite policy guidelines in the public health sector suggesting gaps and opportunities for the healthcare sector to further support caregivers. Disclosure of children's HIV status is not a once-off event but an ongoing, dynamic process that requires support. In the context of this study, healthcare workers, age-appropriate, culturally sensitive and reciprocal communication strategies and interventions that empower the caregiver and children in their care, are fundamental to the disclosure process.

6.3 PARTICIPANTS' RECOMMENDATIONS TO IMPROVE PEDIATRIC HIV DISCLOSURE

The recommendations below were raised by study participants to help improve pediatric HIV disclosure in society.

6.3.1 Assistance of Healthcare Workers

Most caregivers who had informed their children of their HIV status, mentioned that they could not or would not have disclosed without the assistance of HCWs as they perceived their role as crucial in ensuring that their children received the correct information and responses to questions that parents were uncomfortable answering. Although disclosure is an emotional process, the presence of the HCWs somehow comforted and assured the parents that they were not alone. They mentioned that multidisciplinary teams should prepare them for disclosure and educate them on the correct vocabulary and terminology they should use for their children to understand. This recommendation was to facilitate reciprocal learning as the caregiver's and their child's knowledge base would improve.

6.3.2 Training Caregivers on Disclosure

Participants who had disclosed their children's HIV status to them, reported that they were untrained and had insufficient knowledge about initiating the disclosure process with their children. Some had requested information from their local PHCs but had not been assisted and ended up disclosing to them on their own. Caregivers and HCWs required ongoing training, and some participants reported that some HCWS did not feel confident performing disclosure, and they suggested that they should be equipped with disclosure information immediately after their

children test HIV-positive, regardless of the child's age at the time. They felt that being prepared and educated in advance could play a huge role in their empowerment with appropriate knowledge and skills to lead successful health-promoting disclosure.

6.3.3 Caregivers' Support Groups

In addition to the abovementioned suggestions for improving disclosure of CLHIV's status to them, caregivers support groups were also advocated for as they could learn from other caregivers' experiences of disclosure, share best practices, fears or concerns and ask questions to improve their knowledge and build their confidence about the disclosure process. Some stated that they would also like their children to have their own confidential support groups where trained personnel could educate them on the importance of good adherence, safe sex, and fully understanding their diagnosis and how to navigate their lives in a positive way living with their illness.

6.3.4 Use of Child-friendly Language

Lastly, caregivers have indicated that they lack proper vocabulary appropriate for CLHIV when disclosure of their status is concerned. They indicated that young children need child-friendly language that will not harm them. They recommended that HCWs should be the ones who train caregivers and lead the disclosure process so they will be able to use the appropriate language.

6.4 RECOMMENDATIONS FOR COMMUNITY WORK AND SOCIAL WORK PRACTICE

The challenges and successes of disclosure to children who perinatally acquired HIV need to be fully understood for intervention strategies that aim at addressing this complex process and fostering health-promoting and supportive HIV disclosure to be developed. This can combat further transmission of HIV, improve health literacy, promote open dialogues about HIV between caregivers or parents and their children, and result in support groups formed that can reduce parents' challenges relating to disclosure to CLHIV.

Findings from this study, reveal caregivers' fear of stigma that indicates that more work needs to be done at the community level to address the challenges confronting caregivers of CLHIV and the larger community when it comes to understanding HIV and HIV disclosure. Social workers can play a more active role in empowering the community with knowledge and skills to address any HIV related issues including stigma, HIV disclosure, mental health, stress, depression, and adherence to HIV treatment. When these issues are left unaddressed they can hinder the programmes that aim to stop the spread of HIV in society.

Refresher training for HCWs on HIV disclosure, and guidelines and manuals are essential to facilitate health-promoting and a supportive HIV disclosure process. Social workers are proficient, so those working in the PHCs in communities can help form and facilitate support groups and community dialogues in easy-to-understand language that benefits parents and children and equips them with relevant knowledge and skills for disclosure. In addition, this can promote adherence to ART, and address stigma and any concerns and fears that parents or children may have, to benefit the caregiver and children.

6.5 RECOMMENDATIONS FOR POLICY DEVELOPMENT

As this study's findings will be shared with the KZN DoH and the uMzinyathi Health District Office, some of the findings and recommendations could be incorporated into amended and/or new policies. Based on the study's findings and the researcher's input, a recommendation is that policies aimed at addressing HIV stigma and equipping caregivers with disclosure skills be developed and implemented throughout the province of KZN, immediately after the child tests HIV-positive to empower, assist and address caregivers, their fears, concerns and challenges.

6.6 RECOMMENDATIONS FOR FUTURE RESEARCH

Since this study's findings are based only on mothers'/caregivers' experiences of disclosure, and not on their experiences and perspectives of the disclosure process, a study on children's experiences with HIV disclosure is essential to understand how they feel and how they would like the disclosure process to be done. Moreover, HCWs' perspectives on disclosure should be researched. Another recommendation is an evaluation of the effects of HIV disclosure on

CLHIV in terms of adherence to ART and viral suppression. Lastly, the researcher would like to write a reflexive research paper on his research journey based on this study.

6.7 IMPLICATIONS OF THE STUDY

6.7.1 Implications for the Advancement of Knowledge

This study presents profound and rich data on caregivers' experiences of pediatric HIV disclosure, which still constitutes a concern as disclosure levels are relatively low in most RLS. It has produced new knowledge of caregivers' experiences in uMzinyathi District and has expanded on the existing insights on the disclosure of perinatal HIV-infections. Understanding pediatric HIV disclosure will inform interventions aimed at addressing the low levels of disclosure, and caregivers' concerns, challenges and experiences, and address other pediatric HIV disclosure issues.

6.7.2 Implications for Practice

It is evidenced from the findings, that HCWs especially those involved in the management of CALHIV on ART, have a crucial role to play in the disclosure of their HIV status to them. Caregivers of CALHIV need to be supported and thoroughly prepared for the disclosure process. Healthcare workers need to promote HIV disclosure to CALHIV and clearly record levels of disclosure in the clinical charts of CALHIV who are on ART to avoid accidental disclosure or sharing of information that is beyond children's ability to comprehend. Social workers and psychologists should be included and involved when dealing with complex disclosure issues, such as children contemplating suicide or self-harm, or when they experience depression, anxiety or mental health issues because of the disclosure of their HIV diagnosis to them.

6.7.3 Implications for Policy

In the best interest of CALHIV, it is suggested that the disclosure of their HIV-positive status to them should be mandatory, and include all steps necessary for successful, health-promoting disclosure. Policies and legislation that inform pediatric HIV disclosure should be grounded in the Children's Act to ensure that their rights are not violated by disclosure or nondisclosure. It is also suggested that there should be clear documentation of the levels of disclosure in the clinical charts of children and adolescents on ART to let other healthcare cadres know the level of

disclosure of the patient. Lastly, it is recommended that a policy be developed to prepare caregivers of CLHIV in good time for disclosure to be prepared and confident to initiate the disclosure process starting from partial disclosure.

6.8 LIMITATIONS OF THE STUDY

The sample size was not large enough to represent all the caregivers of perinatally HIV-infected children, but the depth, richness and comprehensiveness of the findings can be generalised to the entire uMzinyathi District, and possibly, KZN province.

The views and experiences about HIV disclosure expressed in this study are from caregivers and do not include children's perceptions. Therefore, the lack of children's perspectives on perinatal HIV disclosure as well as the lack of social workers', teachers' and other stakeholders' perspectives who are involved in the management of CLHIV, could also be perceived as a limitation. However, this limitation provides an opportunity for further studies to get the viewpoints and experiences of other stakeholders involved in pediatric HIV disclosure. The participants' willingness to share information or the provision of acceptable responses could indicate sample bias due to them seeing the researcher in the clinics even though they had no previous interactions with him. A complete female sample being interviewed by a male interviewer and their data analysed by a male could be viewed as having gender bias. Worth noting is that the researcher did approach male caregivers, however they did not want to participate in the study.

In conclusion, limitations are inevitable in any study, yet despite this, the findings will contribute to literature on caregivers' experiences of perinatal HIV disclosure in a country with a large HIV population.

6.9 CONTRIBUTION TO THE BODY OF KNOWLEDGE

This study expands the current body of knowledge on caregivers' experiences (successes and challenges) on disclosing their CLHIV status to them. The findings contribute to a comprehensive approach for managing CLHIV with a special focus on the disclosure of their seropositive status. The awareness and understanding of caregivers' experiences can further

assist in designing and improving strategies to address and facilitate disclosure. To the best knowledge of the researcher, this is the first study to be conducted in uMzinyathi District Municipality that investigated caregivers' experiences of HIV disclosure to perinatally HIV-infected children and could be used to improve HIV disclosure practices and to develop and update HIV related policies in the district and beyond.

CHAPTER SEVEN
REFLECTIONS AND CONTRIBUTIONS OF THE STUDY

7.1 INTRODUCTION

A summary of the findings, recommendations, implications as well as limitations were discussed in the previous chapter. This chapter presents the reflections on the research journey, intended contribution of the study, dissemination of the findings and the conclusion.

7.2 REFLECTIONS

7.2.1 This research journey

On Sunday, July 10, 2022, I had a profound realisation that I wanted to pursue a master's degree. This decision stemmed from my desire to acquire the necessary skills and knowledge to effect meaningful change in society, extending beyond my local district, region, or province to a national and global scale. My professional background in the HIV sector had ignited a passion to explore the experiences of caregivers, particularly the barriers and facilitators they encounter in the disclosure process. This was prompted by my observation of children and adolescents receiving ART without a complete understanding of the nature of their illness and treatment, as their caregivers had not communicated this information to them. I wanted to understand caregivers' experiences so that intervention strategies could be developed and implemented to address these.

Determined to be intentional and avoid the procrastination challenge, I searched for master's programmes from various South African universities and decided on the programme offered by the University of Zululand (UNIZULU). This was due to me being familiar with their Department of Social Work, as I had successfully obtained my undergraduate degree from there, years earlier. I applied for admission and submitted a concept note and proposal. Speaking of writing a research proposal as part of application I honestly had no idea what I was doing on my first attempt, but fortunately I was accepted and invited for an oral presentation, and a few days later received an email notifying me that I had been admitted into the 2023 programme.

Interestingly, I had already identified my area of study as being HIV disclosure related. With a clear topic in mind, I embarked on my research journey.

My research journey was not easy, but enjoyable. I was constantly motivated by the words, *Kunqoba abaphikelelayo*, which when translated means, *those who persevere, win*. Perseverance is one of the virtues everyone requires, if they are to undertake a postgraduate journey.

7.2.2 Engaging with the caregivers

I had already anticipated that working with caregivers of CLHIV would be emotional as parents/caregivers would narrate their disclosure journey and how their children reacted to the disclosure. However, they expressed willingness to share their experiences to help other caregivers of CLHIV in uMzinyathi District and in the KZN province as I explained to them that the study findings would be shared in community dialogues, at conference presentations and published in articles.

7.2.3 Putting Theory into Practice

Another time-consuming component was choosing the right theoretical framework guiding my research work. I had looked at different theories including Attachment Theory, Social Cognitive Theory, Social Learning Theory, Cultural Theory, Family Systems Theory, Social Stigma Models, Theory of Planned Behaviour, and the Health Belief Model. However, I found Bronfenbrenner's Ecological Systems Theory most suited to my study as it would allow me to better understand the negative and positive factors that affect the pediatric disclosure process within a multifaceted framework. Employing the EST theory, deepened my understanding of the caregivers' experiences with disclosure to perinatally HIV-infected children and broadened my knowledge on the theory. Indeed, our surroundings and the people we live with or mostly associate ourselves with, have a great impact on how we view the world or certain things in life. I must be honest, without my supervisor's unwavering support and guidance, I would not have managed to put theory into practice with ease. Utilising this theory, I realised that caregivers are influenced by a myriad of factors on whether to disclose their children's HIV diagnosis to them. For example, from the findings we realised that many do not have the correct knowledge and

skills to lead the disclosure process, while others were supported by HCWs and social workers to disclose to their children.

7.2.4 Supervision

As I have previously mentioned in the *Acknowledgement* section, this dissertation would not have been completed without the guidance and support of a dedicated HIV-seropositive supervisor who provided invaluable mentorship, direction and expertise throughout my research journey. Besides being a hardworking supervisor, she has vast knowledge on my research topic due to her own HIV journey.

What made our relationship easier was that I knew what I wanted to research, and we discussed the topic together and the objectives of the study, and the timelines as well as the expected outcome. We had regular virtual and telephonic meetings where I sought clarity and guidance on certain aspects of the research process, like the methodology, selecting a relevant theory appropriate to analysing the collected data. The feedback sessions were productive. Supervision helped me conquer my fear of research and the challenges I encountered along the way.

7.2.5 Personal Growth

Conducting this research not only assisted me to get a deeper and broader understanding on the topic I was researching, but it also helped me develop some life, interpersonal and academic skills. These are provided below:

- I have developed critical thinking skills.
- My writing skills are still not perfect, but they have improved. When I reflect on my initial research proposal, in comparison to my current writing, I see growth and improvement with evidence of critical thinking.
- This master's journey has increased my confidence in pediatric disclosure, and I have a greater respect and empathy for caregivers.
- Organising and communicating with different stakeholders including the University of Zululand, Department of Health, primary healthcare clinics and the participants, has strengthened my communication skills.

- I also had to learn to plan and organise my time well, to strike a balance between home, family, exercise, work and my academic life. I made use of a reflexive diary to document my data collection journey. Not personalising events and information also assisted.

7.2.6 Future Research Aspirations

This has been the loneliest yet exciting journey, as I have developed a deeper passion for pediatric HIV. This journey has inspired me to consider registering for a PhD journey with a novel study that will produce new knowledge and insights by investigating pediatric HIV disclosure and mental health in CALHIV. Maybe even developing a disclosure model. I would like to pursue writing a minimum of three articles for publication, with one reflecting on this journey and my supervision relationship.

7.3 INTENDED CONTRIBUTION

7.3.1 Intended Contribution to Knowledge, Practice and Policy

The study intends to expand the current body of knowledge on caregivers' experiences (successes and challenges) of disclosing their CLHIV status to them. The findings will contribute to a holistic approach to the management of CLHIV with a special focus on the disclosure of their HIV-seropositive status. The awareness and understanding of caregivers' experiences will further assist in designing and improving strategies to address, facilitate and improve disclosure.

7.4 DISSEMINATION OF THE FINDINGS

Peer-reviewed and DHET-accredited journals dedicated to health and social work will be selected for the dissemination of the study's findings. These journals will include titles such as *AIDS Research and Therapy*, *Journal of Social Work and Social Development*, *African Journal of Primary Health Care and Medicine*, *Journal of Social Work Values & Ethics*, *Social Work/Maatskaplike Werk*, and South African Journal of HIV Medicine. Furthermore, the findings will be accessible through the library portal of the University of Zululand. Additionally, community-based dialogue sessions will be organised as forums for the dissemination of the study's findings and recommendations.

7.5 CONCLUDING REMARKS

Parents and caregivers must be psychologically and emotionally equipped for the disclosure of a perinatal HIV-infection, prior to the commencement of the disclosure process. The developmental stage of the child represents a significant factor that parents should consider when revealing the child's HIV status. While most caregivers expressed a willingness to disclose their children's HIV status, they faced obstacles that impeded their ability to independently initiate the process. The support of healthcare workers was imperative in assisting most caregivers with disclosing to their children at a formative stage, prior to them engaging in risky behaviours. An understanding of the challenges encountered by caregivers in disclosing an HIV status to their children is critical for the formulation of intervention strategies aimed at alleviating their apprehensions and concerns, thereby enhancing the child-parent relationship and facilitating an environment conducive to open dialogue regarding sexual and reproductive matters.

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ADDENDA

All the addenda pertaining to this study are contained in this section:

Addendum 1	Ethical Clearance from the University of Zululand's Research Ethics Committee (UZREC 0691-008 PGM 2023/35)
Addendum 2	Permission Letter from the Department of Health, Province of KwaZulu-Natal (NHRD Ref: KZ_202310_011)
Addendum 3	Letter of support from the District Director, Ms. J.Y. Dube, uMzinyathi Health District
Addendum 4	Permission letter from Clinic 1
Addendum 5	Permission letter from Clinic 2
Addendum 6	Permission letter from Clinic 3
Addendum 7	Permission letter from Clinic 4
Addendum 8a	Participants' Information Sheet (English)
Addendum 8b	Participants' Information Sheet (isiZulu)
Addendum 9a	Informed Consent Form (English)
Addendum 9b	Informed Consent Form (isiZulu)
Addendum 10a	Researcher's Declaration (English)
Addendum 10b	Researcher's Declaration (isiZulu)
Addendum 11a	Interview Guide Questions (English)
Addendum 11b	Interview Guide Questions (isiZulu)
Addendum 12a	Participants Demographic Details (English)
Addendum 12b	Participants Demographic Details (isiZulu)
Addendum 13	Example of Participant's Transcript
Addendum 14	Editor's Report
Addendum 15	Turnitin Report

Addendum 1: Ethical Clearance from the University of Zululand's Research Ethics Committee (UZREC NHRD Ref: KZ_202310_011_)

UNIVERSITY OF ZULULAND RESEARCH ETHICS COMMITTEE
(Reg No: UZ-REC 0691-008)

UNIVERSITY OF ZULULAND

ETHICAL CLEARANCE CERTIFICATE

Certificate Number	**UZ-REC 0691-008 PGM 2023/35**							
Project Title	**Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal**							
Principal Researcher/ Investigator	T.C Myeni							
Supervisor and Co-supervisor	Dr DM Mulqueeny							
Department	Social Work							
Faculty	Humanities and Social Sciences							
Type of Risk	Medium Risk – Data collection from people							
Nature of Project	Honours/4th Year		**Master's**	**X**	Doctoral		Departmental	

The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project. The Researcher may therefore commence with data collection from the date of this Certificate, using the certificate number indicated above.

SPECIAL CONDITIONS:

(1) This certificate is valid for 1 year from the date of issue.
(2) Principal researcher must provide an annual report to the UZREC in the prescribed format [due date- 24 November 2024]
(3) The UZREC must be informed immediately of any material change in the conditions or undertakings mentioned in the documents that were presented to the meeting.
(4) Under the Protection of Personal Information Act, 04 of 2013 ("POPIA"), researchers have a general legal duty to protect the information they process. They must ensure the security and protection of any personal information processed through the research and provide a compliant and consistent approach to data protection. The information collected via interviews must be for research purposes only. No personal information such as opinions, views, and academic background may be linked to the respondents' identity or shared with anyone for marketing purposes or otherwise.

The UZREC wishes the researcher well in conducting research.

Prof. Nokuthula Kunene
Chairperson: University Research Ethics Committee
Deputy Vice-Chancellor: Research & Innovation
24 November 2023

RESEARCH & INNOVATION OFFICE
Website: http://www.unizulu.ac.za
Private Bag X1001
KwaDlangezwa, 3886
Tel: 035 902 6374/6324
Email: MthembuN1@unizulu.ac.za/MangeleS@unizulu.ac.za

Addendum 2: Permission Letter from the Department of Health, Province of KwaZulu-Natal (DOH KZN) (NRD Ref KZ-202310_010)

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email:

Health Research & Knowledge Management

NHRD Ref: KZ_202310_011

Dear Mr TC Myeni
(UNIZULU)

Approval of research

1. The research proposal titled **'Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal.'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Inkosi Thathezakhe, Glenridge, Pine Street Clinic, and Pomeroy CHC.

2. You are requested to take note of the following:
   a. ***Kindly liaise with the facility manager BEFORE your research begins.***
      This is to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
   b. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to* ***HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200*** *and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Mr. X Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Provincial Health Research Committee
Date: 31/10/2023

GROWING KWAZULU-NATAL TOGETHER

Addendum 3: Letter of support from the District Director, Ms. J.Y. Dube, uMzinyathi Health District

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:
Private Bag X2062, Dundee, 3000
34 Wilson Street, Dundee, 300
Umzinyathi Health District Office
Tel: 034 299 8100 Fax: 034 212 4800 Email: charlotte.vanrose@kznhealth.gov.za

Enquiries: Ms. J. Dube
Date: 23rd October 2023

To: Mr. T. Myeni
University of Zululand

RE: RE: PERMISSION TO CONDUCT RESEARCH AT UMZINYATHI DISTRICT.

This letter serves to confirm that your application to conduct the research study titled " *Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal.*" has been approved.

Please also note the following:

1. This research project should only commence after final approval by the KwaZulu- Natal Health Research and Knowledge Unit, and full ethical approval has been granted,
2. That you adhere to all the policies, protocols and guidelines of the Department of Health with regards to this research.
3. All research activities must be conducted in a manner that does not interrupt clinical care at the health care facility,
4. Ensure that this office is informed before you commence your research,
5. The District Office / Facility will not provide any resources for this research
6. You will be expected to provide feedback on your findings to the District Office / Facility.

Thanking you.

Ms. J. Y. Dube
District Director
Umzinyathi District Office DC 24

Addendum 4: Permission Letter from Glenridge Clinic

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:

Dundee Hospital
Dundee Hospital, 121 Mackenzie Street
Private Bag X2011, Dundee, 3000
Tel 034 2121111 Fax: 034 2123245 Email: teresa.mkhize@kznhealth.gov.za

Nursing Service Manager

Enquiries: N.T. Mkhize

Date: 13/11/2023

Att: University of Zululand
P.O. Box X1001
KwaDlangezwa
3880

Dear Sir

RE- REQUEST FOR PERMISSION TO CONDUCT RESEARCH

Permission to conduct research in Glenridge Clinic is granted.

Thank you.

.....
Deputy Manager Nursing

Addendum 5: Permission Letter from Inkosi Thathezakhe Clinic

Addendum 6: Permission Letter from Pine Street Clinic

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

Postal Address: PRIVATE BAG X 5562, GREYTOWN, 3250
Physical Address: 100 PINE STREET, GREYTOWN,3250
Tel: 033 413 3010 Fax: 033 4132 809 Email address [redacted] www.kznhealth.gov.za

Enquiries : Mrs H.B Mdladla
Date : 14th November 2023

TO Mr T Myeni
University of Zululand

Re: Permission to conduct research at Pine Street Clinic.

This letter serves to confirm that your application to conduct the research study at Pine Street Clinic titled " Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in UMzinyathi District, Kwazulu- Natal" has been approved.

Thanks
HB MDLADLA (OPARATIONAL MANAGER)

Addendum 7: Permission Letter from Pomeroy Clinic

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE: POMEROY CHC

Physical Address: Pomeroy CHC, SHEPSTONE Rd, POMEROY, 3020
Tel: (034) 662 3300 Email: Thierry.kabwe@kznhealth.gov.za
www.kznhealth.gov.za

OFFICE OF THE ACTING
MEDICAL MANAGER

1st November 2023

TO: THEMBA MYENI

RE: PERMISSION TO CONDUCT RESEARCH AT: Msinga Sub-district

I have pleasure in informing you that permission has been granted to you by the management of Pomeroy CHC to conduct research on the study entitled: **"Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in UMzinyathi District, KwaZulu-Natal".**

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received approval of your study from the Provincial Health Research and Ethics Committee (PHREC) in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The District Office/Facility will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office/Facility.
6. You are required to contact this office regarding dates for providing feedback when the research has been completed.

Thanking you,

Dr. T Kabwe
Acting Chief Executive Officer
Pomeroy CHC
Date: 01 November 2023

Addendum 8a: Participants' Information Sheet (English)

My name is **Themba C. Myeni**, a master's student in the Faculty of Humanities and Social Sciences (Social Work) at the University of Zululand. I am conducting 20 semi-structured interviews with caregivers of children between 6 – 12 years who have been on antiretroviral therapy for two or more years as part of my research project. My intention is to source information on caregivers' experiences of disclosing perinatally HIV-seropositive children's status to them in uMzinyathi District, KwaZulu-Natal.

Purpose of the research:

If you decide to volunteer, you will be asked to participate in one interview. You will be asked several questions. Some of them are about your experiences of disclosing perinatally HIV-seropositive children's status to them. With your permission, I will tape record the interviews, so I don't have to make so many notes. You will not be asked to state your name on the recording.

Time required: The interview will take approximately between 45 and 60 minutes.

Risks: Some of the questions may cause discomfort or embarrassment. Hence, a social worker is available to you if you need their services.

Benefits: This is a chance for you to tell your story about your experiences concerning disclosing to perinatally HIV-infected children in uMzinyathi District, KwaZulu-Natal.

Compensation: You will **not** receive any money for participating in the study.

Confidentiality: Your responses to interview questions will be kept confidential. At no time will your actual identity be revealed. You will be assigned a random numerical code. Anyone who helps me transcribe responses will only know you by this code. The recording will be destroyed after my dissertation has been successfully examined. The transcript, without your name, will be kept until the research is complete.

The key code linking your name with your number will be kept in a locked file cabinet in a

locked office, and no one else will have access to it. It will be destroyed five years later. The data you give me will be used for my dissertation and as the basis for articles or presentations in the future. I won't use your name or information that would identify you in any publications or presentations.

Participation and withdrawal: Your participation in this study is completely voluntary, and you may refuse to participate or withdraw from the study without penalty or loss of benefits to which you may otherwise be entitled. You will receive no payment. You may withdraw by informing the researcher that you no longer wish to participate (no questions will be asked). You may skip any question during the interview but continue to participate in the rest of the study.

To Contact the Researcher: If you have questions or concerns about this research, please contact: [Mr T.C. Myeni, on thembamrhope@gmail.com and 0763812641]. You may also contact the faculty member supervising this work: [Dr Delarise Mulqueeny, PG Research Coordinator, 0839556755 and MulqueenyD@unizulu.ac.za].

Whom to contact about your rights in this research, for questions, concerns, suggestions, or complaints that are not being addressed by the researcher, or research-related harm:

University of Zululand Research Ethics Committee [UZREC], Research & Innovation Office: 035 902 6887 or the researcher's Department/supervisor.

Addendum 8b: Participants' interview schedule and information sheet (isiZulu)

Igama lami ngingu Mnu. T.C. Myeni ngenza izifundo ze Masters ngaphansi kwe Faculty of Humanities and Social Sciences emNyangweni wezeNhlalakhle eNyuvesi yase Zululand. Ngenza ucwaningo ngokusizwa ngabantu abangamashumi amabili (20) abanakekela izingane ezineminyaka ephakathi kweyi 6 kuya kweyi 12 eziseneminyaka engaphezulu kwemibili zisebenzisa amaphilisi e HIV. Inhloso yocwaningo ukuthola ukuthi yiziphi izinto abanakekeli bezingane abahlangabezana nazo ngokudalulela izingane zabo isimo sazo se-HIV esiFundeni uMzinyathi KwaZulu-Natal.

Inhloso yocwaningo:

Uma uthatha isinqumo ngokuzikhethela kwakho ukuba yinxenye yalolu cwaningo, uzocelwa ukuthi ubambe iqhaza ekuphenduleni imibuzo. Uzobuzwa imibuzo emininganа. Eminye yawo imayelana nezinto noma indlela yokudalulela izingane isimo sazo se-HIV. Ngemvume yakho, ngizoqopha izingxoxiswano lapho uphendula imibuzo, ngakho angeke ngibhale amanothi amaningi. Angeke ucelwe ukuthi usho igama lakho kusiqophamazwi.

Isikhathi esidingekayo: imibuzo nokuphendulwa kwayo kuzothatha imizuzu engamashuni amane nanhlalu (45) kuya ehoreni elilodwa.

Ubungozi: Eminye imibuzo kungenzeka ibangele ukungakhululeki nona ukuphoxela. Ingakho uSonhlalakahle ezobe ekhona ukukusiza lapho kufanele khona.

Imivuzo: Leli ithuba lokuthi uxoxe indaba yakho mayelana nezinto ozizwayo noma ngendlela ozizwa ngawo mayelana nokudalulela ingane ngesimo sayo se-HIV esiFundeni uMzinyathi, KwaZulu-Natal.

Isinxephezelo: Ayikho imali ozoyithola ngokuba yinxenye yalolu cwaningo.

Imfihlo: Izimpendulo zakho zemibuzo zizogcinwa ziyimfihlo. Angeke kwenzeke ukuthi kube khona lapho ubuwena buvezwa khona. Uzonikezwa ikhodi yezinombolo engahleliwe eqondene

nawe. Noma ngabe ubani ongisizayo ukubhala uzokwazi lekhodi kuphela. Okuqoshiwe kuzocekelwa phansi ngemuva kokuthi ucwaningo lwani luhlolwe ngokuphelele. Okulotshiwe, okungenalo igama lakho, kuzogcinwa kuze kuqedwe ucwaningo.

Ikhodi exhumanisa nenombulo yakho izogcinwa ehhovisi ekhabetheni elikhiywayo lamafayela, akekho omunye ozoba nemvume yokuwathola ngaphandle kwami. Izobe isidicilelwa phansi ngemuva kweminyaka emihlanu. Ulwazi onginika lona luzosetshenziselwa ucwaningo lwami nanjengesisekelo sama- articles noma izethulo esikhathini esizayo.

Ukubamba Iqhaza kanye nokuhoxa: Ukuhlanganyela kwakho kulolu cwaningo kungokuzithandela ngokuphelele futhi ngokwenqaba noma ngokuhoxa kwakho kulolu cwaningo angekho ujeziswe noma ulahlekelwe ngamalungelo akho onawo. Ayikho imali noma inkokhelo ozoyithola. Ungahoxa ngokutshela umcwaningi ukuthi angeke usaba ynxenye yocwaningo (ayikho imibuzo ozobuzwa yona). Ungayeqa eminye imiibuzo kodwa uqhubeke ube yinxenye yocwaningo

Ukuxhumana nomcwaningi: Uma unemibuzo ngalolu cwaningo, ungathint: [Mr TC Myeni, ku thembamrhope@gmail.com noma 076 381 2641]. Futhi ungaxhumalo nosebenza emNyangweni wezenhlalakahla nongumphathi walolucwaningo: [Dr Delarise Mulqueeny, PG Research Coordinator, 0839556755 noma MulqueenyD@unizulu.ac.za].

Ongaxhumana naye maqondana namalungelo akho mayelana nalolucwaningo, noma imibuzo, izincomo noma izikhalazo umcwaningi angabhekananga nakho, noma ubungozi obungavela ngalolu cwaningo: University of Zululand Research Ethics Committee [UZREC], Research & Innovation Office: 035 902 6887 noma umNyango womcwaningi/umphathi wakhe.

Addendum 9a: Participant's Informed Consent Form (English)

Project Title: **Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal**

Mr Themba C. Myeni, from the Department of Social Work at the University of Zululand has requested my permission to participate in the above-mentioned research project.

The nature and the purpose of the research project, and of this informed consent declaration have been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research project is to explore caregivers' experiences of disclosing a HIV-seropositive status to perinatally infected children in uMzinyathi District, KwaZulu-Natal.

2. The University of Zululand has given ethical clearance to this research project, and I have seen/ may request to see the clearance certificate.

3. By participating in this research project, I will be contributing towards the improvement of the disclosure process to perinatally infected children.

4. I will participate in the project by taking part in a semi-structured interview.

5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences.

6. I will not be compensated for participating in the research, but my out-of-pocket expenses will be reimbursed.
7. There may be risks associated with my participation in the project. I am aware that

    a. the following risks are associated with my participation: I could be emotionally affected while I share information on HIV disclosure.

b. the following steps have been taken to prevent the risks: A social worker is available to assist any participants with counselling.
c. there is a10% chance of the risk materialising.

8. The researcher intends to publish the research results in the form of: Research articles and having community dialogues. However, confidentiality and anonymity of records will be maintained, and my name and identity will not be revealed to anyone who has not been involved in the conduct of the research.

9. I will not receive feedback/**will receive feedback** in the form of participants' dialogues regarding the results obtained during the study.

10. Any further questions that I might have concerning the research, or my participation will be answered by: The researcher's supervisor: Dr D.M. Mulqueeny, on 0839556755 and via email: MulqueenyD@unizulu.ac.za or the senior administrator: Research Ethics & Postgraduate Studies on +27035 9026056.

11. By signing this informed consent declaration, I am not waiving any legal claims, rights, or remedies.

12. A copy of this informed consent declaration will be given to me, and the original will be kept on record.

I, …….. have read the above information / confirm that the above information has been explained to me in a language that I understand and I am aware of this document's contents. I have asked all questions that I wished to ask, and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

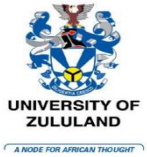
I have not been pressurised in any way, and I voluntarily agree to participate in the above-mentioned project.

……. …….

Participant's Signature **Date**

University of Zululand, Research Ethics Committee (UZREC)
Research & Innovation Office
Manager – Research Ethics & Postgraduate Studies: ManqeleS@unizulu.ac.za
t: +27 (0) 35 902 6324 or t: +27 (0) 35 902 6056
House 22, Next to Old VC House, 1 Main Road, KwaDlangezwa, 3886

Addendum 9b: Participant's Informed Consent Form (isiZulu)



<u>Isihloko socwaningo</u>: Ukudalulela izingane ezizelwe nesandulela ngculazi isimo sazo se HIV: Izinto abanakekeli bezingane abahlangabezana nazo ngaphansi kwesi-Funda uMzinyathi, KwaZulu-Natal.

uMnu. Themba C. Myeni, ovela emNyangweni wezeNhlalakahle, eNyuvesi YakwaZulu ube nesicelo semvume yokuzibandakanya kulolucwaningo olubhalwe ngenhla.

Imvelaphi kanye nenhloso yalolucwaningo kanye nemvume yokuzibophezela ngichazeliwe ngalo ngolimi engilwaziyo.

Ngiyakuqonda ukuthi:

1. Inhloso yalolucwaningo ukuthola izinto abanakekeli bezingane abahlangabezana nazo ngokudalulela izingane isimo sazo se-HIV esiFundeni uMzinyathi, KwaZulu-Natal.
2. INyuvesi yakwaZulu inikezele ngemvume kumenzi walolu cwaningo ukuba enze lolucwaningo futhi ngiyibonile leyomvume/ngingacela ukubona isitifiketi semvume.
3. Ngokubamba iqhaza kulolucwaningo ngizothuthukisa indlela ukudalulelwa kwezingane ezine-HIV okwenzeka ngayo.
4. Ngizobamba iqhaza kulolucwaningo ngokunikezela ngokuphendula imibuzo ehleliwe.
5. Ekuzibandakanyeni kwami angibheke nzuzo futhi ngingahoxa nanoma ngabe yisiphi isikhathi futhi ngaphandle kokujeziswa noma ukulahlelelwa ngamalungelo ami.
6. Mina angizukunxephezelwa ngokuzibandakanya kwami kulolucwaningo, kodwa izindleko eziphume kwelami iphakethe zizokhokhelwa.
7. Ngiyaqonda ukuthi kungaba nezimo ezibucayi nokho ezingengakanani ekuzibandakanyeni kwami kulolucwaningo, ngiyakuqonda ukuthi:
   a. Lobu bungozi obulandelayo kuxhumene nokuzimbandakanya kwami, ngingavukelwa imizwa ebuhlungu ngokuchaza kwami indlela yokudalulela ingane isimo sayo se-HIV.
   b. Lezi zitebhu ezilandelayo zithathiwe ukuvikela ubungozi: uSonhlalakahle ukhona ukusiza ngokweluleka.

c. Kukhona inxenye yokuyishumi (10%) yokuthi kungaba nobungozi.

8. Umcwaningi uhlose uzoshicilela imiphumela yalolucwaningo ngohlelo lokubhalwa kwama phepha kanye nenkulumo mpikiswano. Nokho igama lami lizofihlwa ngaso sonke isikhathi, futhi akekho ozokwazi ubumina noma igama lami kunanoma ngabe ubani ongesiyo inxenye yalolucwaningo.
9. Angeke ngiyithole imiphumela/ noma ngizoyithola imiphumela ngezinkulumo mpikiswano eziphathelene nemiphumela yalolucwaningo.
10. Eminye imibuzo ephathelene nalolucwaningo noma mayelana nokuzibandakanya kwami ingaphendulwa ngumphathi womcwaningi walolu cwaningo: Dr D.M. Mulqueeny, ku 0839556755 noma nge email: MulqueenyD@unizulu.ac.za noma umlawuli omkhulu: Research Ethics & Postgraduate Studies on +27035 9026056.
11. Ngokusayina lelifomu angiqubuli izimangalo zomthetho, noma amalungelo
12. Ikhophi yalemvume yokuzibophezela kwami ngizonikezwa, bese okungungqo kuyagcinwa.

Mina ……. ngikufundile lokhu okubhalwe ngenhla/ ngiyavuma ukuthi lolulwazi olungenhla ngichazelwe ngolimi lwami engiluqondayo futhi ngiyakuqonda okuqukethwe nokubhaliwe. Ngiyibuze yonke imibuzo engifunayo ukuyibuza, futhi yaphendulwa ngendlela engenelisayo. Ngikuqonda kahle okulindeleke kimi ngesikhathi salolu cwaningo.

Angiphoqwanga neze ukubamba iqhaza kulokhu kololucwaningo, ngiba yinxenye ngokuthanda kwami.

---------- ----------

ukusayina kobambe iqhaza **usuku**

Ukusayina kwami ngezansi kusho ukuvuma kwami ukuba yinxenye yocwaningo.

…….. **……..**

Isayini yoyinxenye yocwaningo **Isuku**

University of Zululand, Research Ethics Committee (UZREC)
Research and Innovation Office
Manager – Research Ethics & Postgraduate Studies: ManqeleS@unizulu.ac.za
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House 22, Next to Old VC House, 1 Main Road, KwaDlangezwa, 3886

Addendum 10a: Researcher's Declaration (English)

RESEARCHER'S DECLARATION

I, **Themba Cyprian Myeni**, declare that:

- I explained the information in this document to

  ……..……..……..

- requested him/her to ask questions if anything was unclear and I have answered them as best I can.
- I am satisfied that s/he sufficiently understands all aspects of the research so as to make an informed decision on whether to participate.
- The conversation took place in isiZulu / English.
- I used/did not use an interpreter.

…… ……

Researcher's Signature **Date**

Addendum 10b: Researcher's Declaration (Isizulu)

UKUZIBOPHEZELA KOMCWANINGI

Mina, **Themba Cyprian Myeni**, ngiyavuma ukuthi:

……

- Ngicelile ukuthi kubuzwe imibuzo uma kukhona la kungaqonakali khona futhi ngiyiphendulile ngalo lonke ulwazi lwami.
- Nganelisekile ukuthi uzwile indlela lolucwaningo oluzosebenza ngayo, lokhu kumenze wathatha isinqumo sokuthi alibambe yini iqhaza noma cha
- Ingxoxo yenziwa ngesiZulu / IsiNgisi
- Ngimsebenzisile noma/ angimsebenzisanga utolika

---------- ----------

ukusayina komcwaningi **usuku**

Addendum 11a: Interview Guide Questions (English)

A. WHAT ARE CAREGIVERS' EXPERIENCES (NEGATIVE AND POSITIVE) OF DISCLOSING PERINATALLY INFECTED CHILDREN'S HIV STATUS TO THEM IN UMZINYATHI DISTRICT, KWAZULU-NATAL?
• Describe your experience of disclosing your child's HIV diagnosis to them. • Explain your preparation for the disclosure process. Provide information on your sources of knowledge on disclosure. • Do you think you were well prepared or had sufficient knowledge/information to initiate the disclosure process with your child? Please explain. • If you have not disclosed to your child, what are your challenges with starting the disclosure process with your child? • Why do you think it is difficult for caregivers to initiate the disclosure process with their children?
B. WHAT ARE THE FACTORS AFFECTING CAREGIVERS' DISCLOSING PERINATALLY HIV-INFECTED CHILDREN'S HIV STATUS TO THEM IN UMZINYATHI DISTRICT, KWAZULU-NATAL?
• What are the factors that promote or that can facilitate disclosure of HIV status to children by their caregivers? • What are the factors that can hinder caregivers from disclosing to their perinatally HIV-infected children?
C. WHAT RECOMMENDATIONS CAN BE MADE TO CAREGIVERS TO IMPROVE HIV DISCLOSURE TO PERINATALLY HIV-INFECTED CHILDREN IN UMZINYATHI DISTRICT, KWAZULU-NATAL?
• What would make it easier for caregivers to disclose HIV diagnoses to children? • Who do you think should tell children about their HIV diagnosis and why? • Share an ideal disclosure process for children born with HIV.

Addendum 11b: Interview Guide Questions (IsiZulu)

• **YIZIPHI IZINTO ABANAKEKELI BEZINGANE ABAHLANGABEZANA NAZO NGOKUDALULELA IZINGANE ISIMO SAZO SE-HIV NGAPHANSI KWE-SIFUNDA UMZINYATHI, KWAZULU-NATAL?**
• Chaza indlela noma izinto owahlangabezana nazo ngesikhathi udalulela ingane yakho isimo sayo se-HIV. • Chaza kabanzi ngokuzilungiselela kwakho ukudalula isimo se-HIV enganeni. Chaza ngolwazi owawunalo. • Ucabanga ukuthi ubuzilungiselele kahle noma ubunolwazi olwanele lokuqala inqubo yokudalulela ingane yakho isimo sayo se-HIV? Ngicela uchaze kabanzi. • Uma ungakayitsheli ingane isimo sayo se-HIV, yiziphi izinselelo obhekene nazo ngokuqala inqubo yokudalulela ingane yakho isimo sayo se-HIV? • Kungani kube nzima ukuthi abanakekeli bezingane baqale inqubo yokudalulela izingane zabo ngesimo sazo se-HIV?
B. YIZIPHI IZINTO EZILEKELELA NOMA EZIVIMBA ABANAKEKELI BEZINGANE EZIZALWE NE-HIV UKUDALULA ISIMO SAZO SE-HIV NGAPHANSI KWE-SIFUNDA UMZINYATHI, KWAZULU-NATAL?
• Yiziphi izinto ezingasiza noma ezingalekelela abanakekeli bezingane ukudalula isimo se-HIV sazo izingane? • Yiziphi izinto ezingavimba abanakekeli bezingane ezizalwe ne-HIV ukuzidalulela isimo sazo se-HIV?
C. YIZIPHI IZINCOMO EZINGATHATHWA NGABANAKEKELI BEZINGANE UKUTHUTHUKISA UKUDALULWA KWESIMO SE-HIV EZINGANENI EZIPHILA NE-HIV ESIFUNDENI UMZINYATHI, KWAZULU-NATAL?
• Yini engenza kube lula kubanakekeli bezingane ukudalulela izingane isimo sazo se-HIV? • Ucabanga ukuthi ubani okufanele atshele izingane isimo sazo se-HIV, futhi kungani ucabanga kanjalo? • Iyiphi indlela engaba ngcono yokudalulela izingane ezizelwe ne-HIV isimo sazo se-HIV?

Addendum 12a: Participants Demographic Details (English)

Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal.

SECTION A: DEMOGRAPHIC DATA OF PARTICIPANTS

Caregiver's age group	**Tick √**	**Gender (Tick √)**		**How are you related to the child?**	**Tick √**
18-29 years		F	M	Biological mother	
30-40 years		F	M	Biological father	
41-50 years		F	M	Grandmother/grandfather	
51-65 years		F	M	Other (specify):	
66 and older		F	M		

Child's gender	**F**	**M**	**How old is the child**		**School grade**	

Caregiver's marital status (*Please tick* √)	Single	Married	Divorced	Separated
Caregiver's religion (*Please tick* √)	Christian	Muslim	Nazareth	Other:
Caregiver's level of education (*Please, tick* √)	Never been to school	Primary level	Secondary level	Tertiary level
Caregiver's source of income (*Please tick* √)	Employed	Self-employed	Social grant	Other (*specify*)

Level of disclosure to the child: (*please tick*)

No disclosure (*Please tick* √)		Partial disclosure (*Please tick* √)	
Full disclosure (*Please tick* √)			

Addendum 12b: Participants Demographic Details (IsiZulu)

Ukudalulela izingane ezizelwe nesandulela ngculazi isimo sazo se HIV: Izinto abanakekeli bezingane abahlangabezana nazo ngaphansi kwesi-Funda uMzinyathi, KwaZulu-Natal.

SECTION A: DEMOGRAPHIC DATA OF PARTICIPANTS

Isigaba seminyaka yomnakekeli wengane	**Tick √**	**Ubulili (Tick √)**		**Uhlobene kanjani nengane?**	**Tick √**
18-29 weminyaka		Owesifazane	Owesilisa	Umama wengane	
30-40 weminyaka		Owesifazane	Owesilisa	Ubaba wengane	
41-50 weminyaka		Owesifazane	Owesilisa	Ugogo/umkhulu wengane	
51-65 weminyaka		Owesifazane	Owesilisa	Okunye (*cacisa*):	
66 nangaphezulu		Owesifazane	Owesilisa		

Ubulili bengane			**Iminyaka**		**Ibanga lesikole**	
Isimo somshado somnakekeli wengane (*khetha okukodwa*)	akashadile	ushadile	wehlukanisile			
Inkolo yomnakekeli (*khetha okukodwa*)	ubuKhristu	Muslim	Nazaretha		Okunye:	
Ibanga lezimfundo lomnakekeli (*khetha okukodwa*)	Akafundile	Amabanga aphansi	Imfundo yamabanga aphezulu (S*econdary*)		Imfundo ephakeme (*Tertiary*)	
Imali engenayo ekhaya (*khetha okukodwa*)	Ngiyase-benza	Ngiyazise-benza	Isibonelelo sika hulumeni		Okunye:	

Izinga lokudalulela ingane isimo se-HIV: (*faka lolu phawu* √)

akuvezwanga lutho	
uKuveza kumaphakathi	
uKuveza okuphelele	

Addendum 13: Example of a participant's transcript

PARTICIPANT NO: C1P3

Good morning/afternoon

WHAT ARE CAREGIVERS' EXPERIENCES (NEGATIVE AND POSITIVE) OF DISCLOSING PERINATALLY INFECTED CHILDREN'S HIV STATUS TO THEM IN UMZINYATHI DISTRICT, KWAZULU-NATAL?	
RESEARCHER	Describe your experience of disclosing your child's HIV diagnosis to them. Chaza indlela noma izinto owahlangabezana nazo ngesikhathi udalulela ingane yakho isimo sayo se-HIV.
PARTICIPANT	***It was never easy [to disclose] because I ended up requesting the nurses at the clinic to help me disclose, because it was not easy for me to tell him.*** *The manner in which I found out that he also has this disease, you see, so it was not easy for me to tell him he has this disease and that he got it from me –* ***this made it more difficult because I feared that maybe he could end up doing something like attempting suicide*** *or end up doing something to me because I passed it on to him or maybe he can think that I never loved him or I don't love him or I did not want him.* ***And if it wasn't for the help of the nurses from the clinic, I think the child would not have known his status. They had to counsel me first to accept that I needed to tell him the truth, because even when I tried to tell him on my own I couldn't, but they [nurses] were there and helped me.***
RESEARCHER	Explain your preparation for the disclosure process. Provide information on your sources of knowledge on disclosure. Chaza kabanzi ngokuzilungiselela kwakho ukudalula isimo se-HIV enganeni. Chaza ngolwazi owawunalo.
PARTICIPANT	*There's no way I prepared myself to disclose, even to disclose I ended up asking a sister [nurse] to help me because I was seeing that he is growing and he understands things when talking to him, so I saw that it was better for him to know early before he is old, because when he is old he might take a decision to stop taking the medicines and die, so I asked the sister [nurse] to disclose to him/ to tell him.*
RESEARCHER	Do you think you were well prepared or had sufficient knowledge/information to initiate the disclosure process with your child?

	Please explain. Ucabanga ukuthi ubuzilungiselele kahle noma ubunolwazi olwanele lokuqala inqubo yokudalulela ingane yakho isimo sayo se-HIV? Ngicela uchaze kabanzi.
PARTICIPANT	*As I have just said, I was not prepared to disclose and I did not know what to say to the child, that's why I ended up asking a sister [nurse] to help me.*
RESEARCHER	If you have not disclosed to your child, what are your challenges with starting disclosure process with your child? Uma ungakayitsheli ingane isimo sayo se-HIV, yiziphi izinselelo obhekene nazo ngokuqala inqubo yokudalulela ingane yakho isimo sayo se-HIV?
PARTICIPANT	*The manner in which I found out that he also has this disease.* *I was upset and I felt so bad even though I found out after delivery that I have this virus because during pregnancy I tested negative and before delivery I also tested negative, but after I have delivered and when I brought the child at the clinic to start immunization it was when we both tested positive,* ***and it was very hard for me to accept, and no one knew about it [at that time] in my family, it was not easy for me to tell them because I did not know how they would look at us, I was afraid to tell them. I ended up taking a decision that it's better for both of us not to take the medicine at all****. My family only found out because he [the child] got sick, we took him to the clinic – and it was when they [nurses] found out that I was not giving him his medicine.*
RESEARCHER	Why do you think it is difficult for caregivers to initiate the disclosure process with their children? Kungani kube nzima ukuthi abanakekeli bezingane baqale inqubo yokudalulela izingane zabo ngesimo sazo se-HIV?
PARTICIPANT	***It is that he will grow up maybe blaming his mother for infecting him with this virus and hating me and maybe end up committing suicide because he will think that it means that his mother never loved him. You find that sometimes you have more than two children but only one is HIV-positive, there will be that thing that, why is so and so not sick and I'm the only one who is sick and taking this medicine, then it means you did not love me… You love the other siblings, that is why they are fine, they are not on this treatment. So, I thought he would blame me, but I'm glad he did not.***
WHAT ARE THE FACTORS AFFECTING CAREGIVERS' DISCLOSING	

PERINATALLY HIV-INFECTED CHILDREN'S HIV STATUS TO THEM IN UMZINYATHI DISTRICT, KWAZULU-NATAL?	
RESEARCHER	What are the factors that promote or that can facilitate disclosure of HIV status to children by their caregivers? Yiziphi izinto ezingasiza noma ezingalekelela abanakekeli bezingane ukudalula isimo se-HIV sazo izingane?
PARTICIPANT	*As I have mentioned before that I was assisted by the nurses as the clinic. Without having someone to support you, it is not easy to tell the child something like this, but you will need someone like nurses to help you. They counselled and told me that it is better to tell the child while he is still young. So, I saw the need to let him know* ***so that he will grow up knowing that he has this disease and that if he wants to live long, he must take his medicine, take care of himself and protect himself so he cannot infect other people around him.***
RESEARCHER	What are the factors that can hinder caregivers from disclosing to their perinatally HIV-infected children? Yiziphi izinto ezingavimba abanakekeli bezingane ezizalwe ne-HIV ukuzidalulela isimo sazo se-HIV?
PARTICIPANT	*It is the fear of thinking to commit suicide because he will think that there's nothing he is living for especially if he found out late when he is old, the reason he is taking this medicine or might decide to stop taking them altogether. Or maybe might decide to purposefully infect others saying he cannot die alone.*
WHAT RECOMMENDATIONS CAN BE MADE TO CAREGIVERS TO IMPROVE HIV DISCLOSURE TO PERINATALLY HIV-INFECTED CHILDREN IN UMZINYATHI DISTRICT, KWAZULU-NATAL?	
RESEARCHER	What would make it easier for caregivers to disclose HIV diagnoses to children? Yini engenza kube lula kubanakekeli bezingane ukudalulela izingane isimo sazo se-HIV?
PARTICIPANT	- ***It's better to find someone who will be able to talk to him, explain to him, like nurses because they are the ones who know about our health, so it is easier to ask them to disclose if you're not able to or if it is difficult for you, because it is difficult. …really nurses should help us disclose.*** - *To have maybe someone like you [researcher] who is able to call/invite mothers and teach/train them how to tell a child, and when*

	the parent has the correct knowledge about HIV, it will be easy to disclose to the child. - *I think it is better to have someone who can train us so that it will be easy to disclose to children because we will have the right information.*
RESEARCHER	Who do you think should tell children about their HIV diagnosis and why? Ucabanga ukuthi ubani okufanele atshele izingane isimo sazo se-HIV, futhi kungani ucabanga kanjalo?
PARTICIPANT	*The parent herself – it is she who knows her child better, she knows where her child is weak, and where her child is strong, then she can start telling the child, and where she is not confident, then sisters [nurses] can intervene and assist.*
RESEARCHER	Please share an ideal disclosure process for children born with HIV. Iyiphi indlela engaba ngcono yokudalulela izingane ezizelwe ne-HIV isimo sazo se-HIV?
PARTICIPANT	*As I have just said before, it is to find someone [like a nurse] who will be able to talk to the child and explain to him. Nurses should help us disclose.*

We have come to the end of our interview, and I would like to thank you for being so open and honest about your disclosure journey.
Sesifike ekupheleni kwengxoxo yethu, futhi ngithanda ukubonga ngokuvuleleka nokuthembeka kwakho mayelana nohambo lwakho lokudalula.

Before we leave, I would like to know how you feel the interview went, if you are feeling uneasy about anything or if you require someone to speak to you.
Ngaphambi kokuba sihambe, ngingathanda ukwazi ukuthi uzwe ihamba kanjani ingxoxo yethu, noma uzizwa ungakhululekile nganoma yini noma uzizwa udinga umuntu ozokhuluma nawe.

I feel our conversation has gone well, and I don't see the need to talk to anyone after this conversation.

Ngizizwa ngikhululekile, ingxoxo yethu ihambe kahle, angisiboni isidingo so kuthola umuntu engingakhaluma naye mayelana nesixoxe ngakho.

Addendum 14: Editor's Report

Date: September 9th 2025

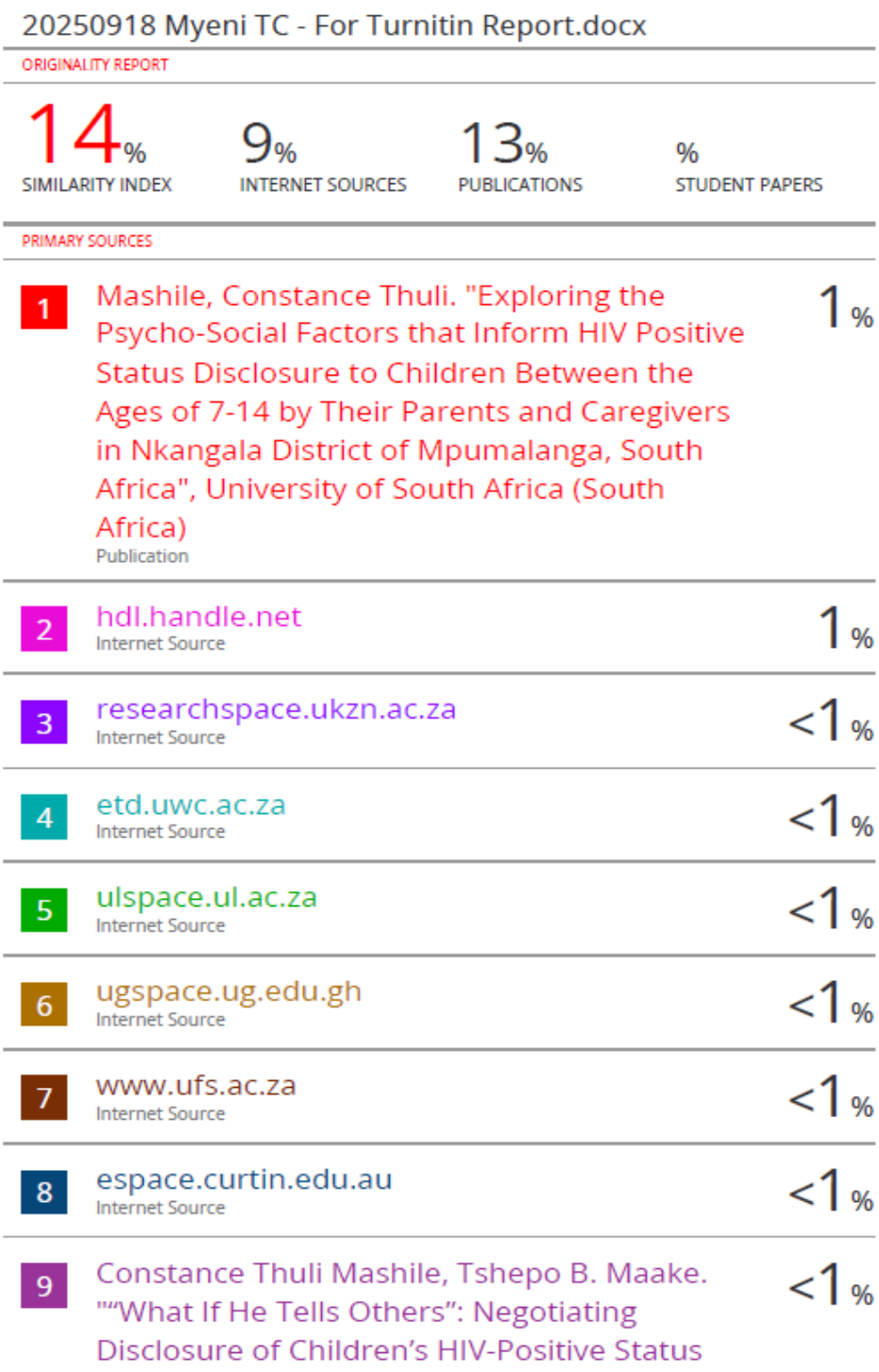
To Whom It May Concern

I am writing to confirm that the dissertation entitled
Disclosing perinatally infected children's HIV status to them: Experiences of caregivers in uMzinyathi District, KwaZulu-Natal.

By
T. C. Myeni
Supervisor Prof. D.M. Mulqueeny
has been edited for English language grammar, spelling and usage.

N.B. This letter is issued on the understanding that all corrections and amendments recommended, all anomalies and omissions highlighted, and all clarifications and reformulations requested have been addressed by the candidate to the satisfaction of the supervisor.

Addendum 15: Turnitin Report



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