THE EFFECTS OF DELAYED DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH PERINATAL HIV: AN ANALYSIS OF MMAKAU VILLAGE, NORTH WEST, SOUTH AFRICA

MATSHEDISO MOHOJE
2010110860

Submitted in partial fulfilment of the requirements for the degree
Master of Disaster Management

in the

Disaster Management Training and Education Centre for Africa
Faculty of Natural and Agricultural Sciences

at the

UNIVERSITY OF THE FREE STATE

Study leader: Dr Alice Ncube

July 2021

DECLARATION

I, Matshediso Mohoje, pronounce that the dissertation that I have tendered for the Master's degree in Disaster Management at the University of the Free State, is my own work and has never been submitted toward another qualification or any institution of higher learning.

I further affirm that all sources employed throughout the collation of this research study are acknowledged.

30 July 2021

Matshediso Mohoje

Student number: 2010110860

ACKNOWLEDGEMENTS

I would first and foremost like to thank the Almighty God for granting me the strength and courage to undertake and complete this study. I further wish to give the greatest gratitude to my parents, Mr Mpho Mohoje and Mrs Malebona Mohoje for their undying love and support throughout the pursuance of my studies. My parents are literally my best friends and biggest cheerleaders, I am eternally grateful for their presence in my life. To my brother, Kutu Mohoje, thank you for always loving me and holding me in high regard, I love you so much Boeta!

To my God-given soulmate, Mama Asathi Soka, thank you for all you are and have been in my life. I have never quite met anyone like you in all the world; our bond is consummate and unparalleled. You are the strongest woman I know, the wittiest, the funniest! I love you with all my heart mama.

Special acknowledgement goes to my wonderful study supervisor, Dr Alice Ncube whom I love and respect very much. Thank you for your patience, informed guidance and reassuring comments. You are smart, strict, yet incredibly humble. I look up to you, I am grateful for you.

I would like to thank my good friend and study partner, Tendai “Dr T” Mapingure, who is one of the smartest human beings I have ever encountered. Thank you for your unwavering support. We have had sleepless nights, we have vented, we have felt defeated; but not once did we give up on our goal. I love you, I thank God for you. To Kgomotso Bessie, my good friend and study partner, we have been at this since our enrolment in the PGD programme. I never once imagined that our connection would be so strong. Thank you girl, I love and appreciate you.

I moreover wish to thank Dr Merlene Esau and Ms Vallery Poto, who have always encouraged me to pursue academics even when I did not believe in myself. Your faith in me has been remarkable. I love and appreciate you both so much.

To my smart and insanely innovative sister, Ausi Dimakatso Mosupi, thank you for translating my information sheets, consent forms and interview guides for me. I love and appreciate you so much. The NWDoH, thank you for allowing me to conduct my research study at Hoekfontein (Mmakau) clinic. A heartfelt thank you to all the healthcare workers and primary caregivers who partook in the study. Last but not least, my friends and family at large, thank you.

DEDICATION

I dedicate this Master's dissertation to my late sister, Malijeng Emily Mohoje, whom I loved and continue to love with all my might. My sister was passionate about life, about people, about knowledge and academics. She passed on whilst still pursuing her studies- I am merely continuing the journey for her. This one is for you Mjenks, I hope you are proud wherever you are. You were and still remain my big sister, my best friend, my role model, and my biggest inspiration. You have rested yes, but your spirit and legacy live on; they keep on multiplying and multiplying and multiplying! There truly is none like you, you are without equal. Love, always.

ABSTRACT

Since the global inception of Antiretroviral Therapy (ART), many children living with perinatal HIV (PHIV) are able to reach adolescence and even adulthood. Their increased survival necessitates the disclosure of their HIV status, a responsibility many primary caregivers and healthcare workers (HCWs) find daunting. Disclosure has been associated with health benefits such as acceptance of own status and adherence to ART. Irrespective of this, disclosure of HIV status to children and adolescents living in sub-Saharan African countries like South Africa, is often delayed- leading to consequences such as non-adherence to ART and psychosocial malfunction. The study evaluated primary caregivers' and HCWs' perceptions and experiences with disclosure and non-disclosure of HIV status to children and adolescents living with PHIV, and how either has impacted the psychosocial functioning of the children and adolescents concerned. The study embraced the mixed methods research design and made use of interview guides during semi-structured interviews. All participants were selected through purposive sampling. There were 18 primary caregivers of children receiving ART at Hoekfontein (Mmakau) clinic and 12 HCWs consisting of professional nurses, assistant nurses, lay counsellors and community health workers. The findings of the study revealed that most primary caregivers delayed disclosure because they lacked the skills to disclose. Some primary carergivers felt guilty and unaccepting of their own HIV status and thus delayed disclosure, which subsequently impacted their children's behavioural conduct. Primary caregivers reported behavioural changes such as disrespect, defaulting on treatment and poor school attendance following delayed disclosure of HIV status to their children. All HCWs understood the concept of child disclosure, but attested to lacking the necessary skills to implement timeous disclosure practices at their facility. Lack of training on guidelines as well as lack of resource materials and child-friendly spaces were some of the emerging themes. The findings of this study further confirm the critical need to train HCWs in public health facilities on the significance of age-appropriate child disclosure as per recommendations made by the World Health Organisation (WHO) and the South African National Department of Health (NDOH). Through training, HCWs can cascade the knowledge and skills learnt to primary caregivers concerned. This will not only help standardize disclosure practices, but will also aid in decreasing rates of delayed disclosure of HIV status to children and adolescents living with PHIV, and the impact that such delay can have on their psychosocial functioning.

Key words: Child disclosure, delayed disclosure, disclosure guidelines, perinatal HIV, HIV status, children, adolescents, primary caregivers, healthcare workers, South Africa

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
DSD	Department of Social Development
HCW	Healthcare worker
HIV	Human Immunodeficiency Virus
HSREC	Health Sciences Research Ethics Committee
MTCT	Mother-to-child transmission
NDMF	National Disaster Management Framework
NGO	Non-government organisation
NDOH	National Department of Health
OHCHR	Office of the United Nations High Commissioner for Human Rights
PAR	Pressure and Release
PHIV	Perinatal HIV
PMTCT	Prevention of mother-to-child transmission
SPSS	Statistical Package for Social Sciences
SRH	Sexual reproductive health
STI	Sexually transmitted infection
TIER	Three Interlinked Electronic System
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children’s Fund
UNISDR	United Nations International Strategy for Disaster Reduction
WHO	World Health Organization

GLOSSARY

Adherence— The degree to which a child follows his or her Human Immunodeficiency Virus (HIV) treatment regimen. This can be achieved through the abidance of treatment requirements such as consuming the suggested dosage at a stipulated time, in a recommended way (South African Department of Social Development [DSD], 2019).

Adolescence— The transitional phase of development between childhood and adulthood. It involves periods of early adolescence (10–14), middle adolescence (15–17) and late adolescence (18–19). These three periods of adolescence often correlate with phases in the psychological, physical and social development of children as they transition from childhood to adulthood (WHO, 2019).

Adolescent— A person transitioning from being a child to becoming an adult and is between the ages of 10 to19 (WHO, 2019).

Child— The United Nations Convention on the Rights of the Child (UNICEF,1989) and the South African Children's Act 38 of 2005 as amended, define a child as any person below the age of 18 years.

Child disclosure— Child disclosure is described as a gradual process in which children become aware of their HIV status or the status of their primary caregivers. During this process, children are provided with age-appropriate information regarding their illness. This process steadily moves from a point of non-disclosure to partial disclosure and ultimately full disclosure when a child has developed sufficient emotional and cognitive maturity to comprehend the information given (National Department of Health [NDOH], 2016).

Healthcare worker— A healthcare worker is defined as any person trained to provide disclosure services in a facility or community; such a person may be a nurse, doctor, psychologist, social worker, counsellor, community health worker or lay health worker (NDOH, 2016).

Primary caregiver— A primary caregiver is defined as a child's biological parent, legal guardian or any person responsible for the care and protection of a child (NDOH, 2016). Madiba (2016) extends that a primary caregiver is an adult who lives in the same household as the child, is accountable for the everyday care of the child, and is cognisant of the child's HIV status and antiretroviral therapy (ART) regimen.

Psychosocial functioning— Psychosocial functioning refers to a child's emotional and psychological well-being. It is a reflection of a child's ability to undertake tasks of everyday life and engage in relationships with other people in satisfying ways (DSD, 2019).

Psychosocial support— The ongoing care and support given to children and adolescents to meet their age-appropriate needs and identified physical, cognitive, emotional, social and spiritual needs through their interactions with their environments and people who care for them (DSD, 2019).

Vulnerable child— A child whose survival, development, care or protection may be compromised due to a situation, condition or circumstance that inhibits them from enjoying the fullness of their rights (DSD, 2019).

Chapter 1
INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

The South African Disaster Management Act 57 of 2002 as amended in 2015 (Act 16 of 2015) delineates a disaster as a continuous or unexpected event that occurs on a global or local scale, such that the affected are unable to cope with the resources they have, and there is need for external intervention. Such an event may be natural or man-made. A disaster can cause or threaten to cause injury, death and even disease. It can further disrupt the functioning of a community by harming its infrastructure and its environment. According to Wisner et al. (2004), HIV/AIDS is a slow-onset biological disaster that adversely affects a human being's physical, social and mental well-being and can lead to loss of human life if left untreated. Adams et al. (2008) opine that HIV/AIDS is a particularly devastating disaster for marginalised groups as they are oftentimes more susceptible to acquiring the disease.

1.2 Background of the study

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2020), approximately 37.6 million people are living with HIV/AIDS globally. Of these 37.6 million people, 1.8 million are children younger than 15 years. The majority of these children are located in sub-Saharan Africa and have contracted the disease through mother-to-child transmission (MTCT), which is also known as the vertical transmission of HIV. Critically, Maskew et al. (2019) expatiate that South Africa has a projected populace of 730 882 children and adolescents receiving the highly effective antiretroviral therapy (ART), which is one of the biggest programmes in the world.

Scholars, Ben-Farhat et al. (2017) state that many global developments were made to ensure a reduction in MTCT and child mortality; these developments were seen through the introduction of ART. Okechukwu et al. (2018) express that the provision of ART has meant that children who are infected with HIV now survive to an age that necessitates the disclosure of their HIV status.

The survival of perinatally infected children into adolescence and beyond, has resulted in the disclosure of their HIV status being a major challenge for their primary caregivers and healthcare workers (HCWs) providing HIV services in public health facilities (NDOH, 2016). According to Kidia et al. (2014) a significant number of children and adolescents receive

ART without being fully informed of their HIV status. Madiba and Mokgatle (2015) impart that when disclosure of HIV status is delayed, children may exhibit negative social behaviour as well as non-adherence to treatment which can generate a strain on their health and the healthcare system.

The World Health Organization (WHO) in 2011, issued guidelines on how to conduct the disclosure process based on a child's age and stage of development. These guidelines recommended partial disclosure to commence when a child is between the ages of six and seven, and gradually lead to full disclosure when a child reaches the age of twelve. The guidelines endorsed child disclosure as a process that is emotionally and psychologically beneficial to children living with PHIV (WHO, 2011). Despite the longstanding establishment of these guidelines, Bulali et al. (2018) unfold that child disclosure processes are still not practised accordingly, more so in lower and middle-income countries where resources tend to be limited.

In 2016, the South African National Department of Health subsequently developed its own set of contextually appropriate guidelines, namely, The South African Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases. These guidelines took into account the recommendations set out in the WHO guidelines of 2011. They were formulated upon the realisation that HCWs in South Africa were disempowered and without contextually appropriate guidelines and tools required to administer the disclosure process. Albeit the existence of these guidelines, most HCWs in South Africa still lack adequate knowledge and skills on how to help children and their primary caregivers through the disclosure process, hence the prevalence of delayed disclosure in South Africa (NDOH, 2016).

Madiba and Mokgatle (2015) found that in many developing countries, HCWs were inadequately trained and lacked the support of guidelines and policies that guided how, when, where and under which conditions HIV infected children and adolescents may be informed of their HIV status or the status of their primary caregivers. Similarly, Mutambo and Hlongwana (2019) complement that many HCWs across the world are still unclear on how to counsel clients during the disclosure process. The lack of training among HCWs on disclosure practices hampers effective service delivery and further affects primary caregivers' ability to make well-informed choices about the well-being of their HIV infected children. Mandalazi et al. (2014) provide that many primary caregivers are often reluctant to tell their perinatally infected children about their HIV status. One of the major obstructions to child disclosure is that primary caregivers, particularly those deriving from resource-limited settings, lack knowledge, guidance and skills on how to disclose to their HIV infected children. This inability to disclose timeously, affects the psychosocial functioning of children, including their access to HIV treatment, care and support services.

As such, this study aimed to evaluate primary caregivers' and HCWs' perceptions and experiences with disclosure (early or delayed) and non-disclosure of HIV status to children and adolescents living with PHIV in Mmakau village, and how either has had an impact on the psychosocial functioning of the children and adolescents concerned.

1.3 Description of study area

South Africa is a country situated at the tip of the African continent and is bordered by six neighbouring countries, namely Namibia, Zimbabwe, Mozambique, Botswana, Swaziland and Lesotho; South Africa encloses Lesotho completely. It has a diverse population, embraces eleven official languages and occupies various landscapes (South African Government, 2020). Figure 1.1 depicts South Africa on the globe as well as in Africa.

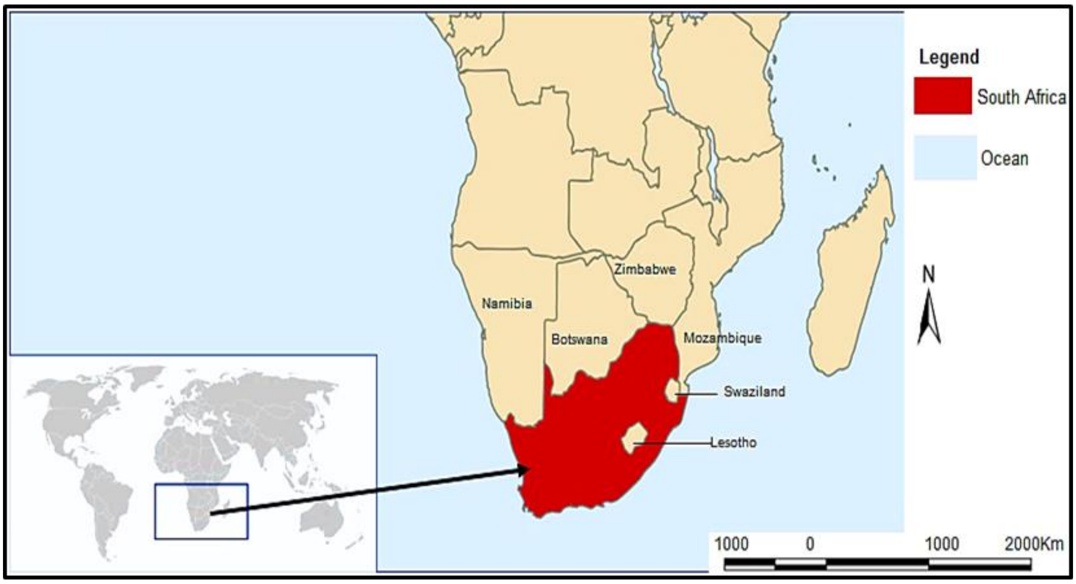

Figure 1.1: Location of South Africa on the globe and in Africa

Source: Adapted from Google Maps (2020)

The North West Development Corporation (2016) stipulates that there are nine provinces in South Africa which differ significantly in size. These provinces are the Free State, Northern Cape, Gauteng, Mpumalanga, Western Cape, Eastern Cape, KwaZulu-Natal, North West and Limpopo. For this research study, the province of interest is the North West province, which is also referred to as Bokone Bophirima or the Platinum province due to the wealth of metal it possesses underground. Mafikeng, previously known as Mahikeng, is the capital city of the North West province. The province is bordered by the country of Botswana and the Limpopo province in the north; the Gauteng province in the east; the

Northern Cape province in the west, and the Free State province towards the south (North West Development Corporation, 2016).

The North West province has a population of 3 748 438 inhabitants which constitute approximately 6.7% of the overall South African population. The main economic activities in the province are mining, manufacturing, infrastructure and construction. The province faces challenges such as unemployment and poverty. It is also largely rural with a poverty headcount of 8.8% and a poverty intensity of 42.5%. Access to water and electricity is 84% and 89% respectively (North West Province, 2017).

Moreover, there are four district municipalities in the North West province, and they are Bojanala, Dr Kenneth Kaunda, Ngaka Modiri Molema and Dr Ruth Mopati. Bojanala district is the biggest and most populated of the four districts, while Dr Ruth Mopati district is the least populated. Bojanala district is primarily populated due to commercial activities such as farming and mining. It has a size of 18 300 km² which covers 17% of the province's total area. The district moreover has a population of 1 671 586 people representing 44% of the whole province (North West Province, 2017). Table 1.1 depicts the socio-demographic information of Bojanala district.

Table 1.1: Socio-demographic information of Bojanala district

Gender	**Percentage (%)**
Male	57.70
Female	47.30
Total	100.0
Age group	**Percentage (%)**
0–14	30.3
15–64	64.8
65+	4.9
Total	100.0
Race	**Percentage (%)**
Black African	91.4
White	7.0
Coloured	1.0
Indian	0.6
Total	100.0
Language	**Percentage (%)**
Setswana	55.34
Xitsonga	8.06
Afrikaans	7.21
Xhosa	5.59
Sepedi	5.11
Sesotho	4.56

English IsiNdebele Other	3.87 2.70 7.56
Total	100.0

Source: North West Province (2017)

Bojanala district has the highest HIV prevalence in all four districts. The HIV prevalence in Bojanala district is 25.5% higher in women aged between 15 and 49 compared to 14.5% of men in the same age group. The prevalence of HIV varies according to geographical areas as well as population groups, hence the target response differs from area to area (North West, 2017). Table 1.2 displays the prevalence of HIV among all four districts in the North West province, South Africa.

Table 1.2: HIV prevalence among four districts in the North West Province, South Africa

No.	District	Number of people	Percentage (%)
1.	Bojanala	219 823	13.3
2.	Dr Kenneth Kaunda	105 640	12.9
3.	Ngaka Modiri Molema	97 770	11.9
4.	Dr Ruth Mompati	53 515	11.6

Source: North West Province (2017)

Furthermore, there are five local municipalities in the Bojanala district, namely Moretele, Kgetlengriver, Moses Kotane, Madibeng and Rustenburg. The area of focus for this research study is Mmakau village, which is located in Madibeng Local Municipality (Figure 1.2). Madibeng Local Municipality is the most populated sub-district in the Bojanala district and comprises 477 381 inhabitants and 160 724 households (North West Province, 2017).

Mmakau village has an area size of 17.73 km^2 and is known as the home of the Bakgatla ba Mmakau tribal authority, which is under the leadership of the Motsepe family. Of all the villages found in Madibeng Local Municipality, Mmakau village has the largest population of 58 055 inhabitants and 16 035 households. It encompasses three primary schools (Polonia, Moemise and Tlhopane) and three secondary schools (Sekwati, Tsogo and Malatse Motsepe). It has several public services such as waste management services, water, electricity, social services, a police station and a clinic known as Hoekfontein (Mmakau) clinic (Bojanala Platinum District Municipality, 2021). The map (Figure 1.2) depicts the North West province in South Africa and the study area, Mmakau village in the Bojanala district.

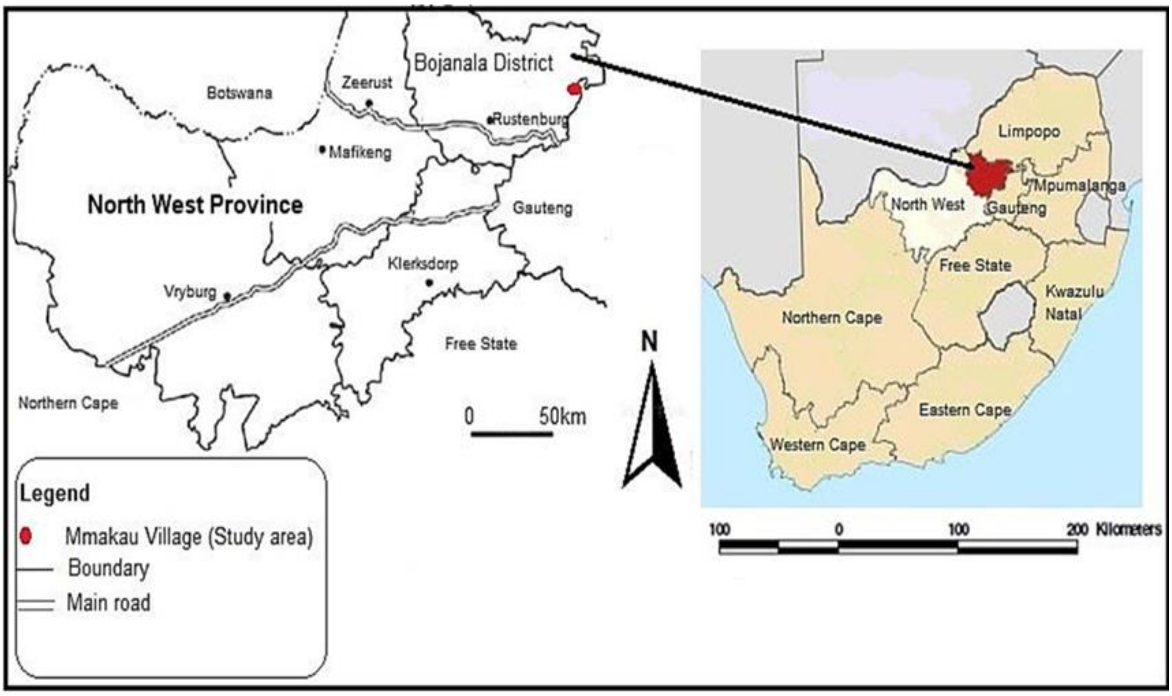

Figure 1.2: Location of North West province in South Africa and Mmakau village in Bojanala district

Source: Adopted from Google Maps (2020)

1.4 Research problem

The WHO (2011) and NDOH (2016) guidelines have described disclosure of HIV status to children living with PHIV as a critical component in the care and management of HIV. The guidelines express the crucial need for primary caregivers to disclose the HIV status of their children at an age-appropriate time, while HCWs help facilitate the process (WHO, 2011; NDOH, 2016). Despite this recommendation however, many children and adolescents living in sub-Saharan African countries are unaware of their HIV status; the prevalence of disclosure ranges from as low as 0-69 percent (Vaz et al., 2011; Vreeman et al., 2013; Ridgeway et al., 2018). Nzota et al. (2015) explain that most children are only informed of their status in their middle and late adolescent stages, which can pose dire implications on their psychosocial functioning, enrolment in HIV care and adherence to ART.

Madiba and Mokgatle (2015), inform that delayed disclosure of HIV status to children and adolescents living with PHIV is a problem that stems from various factors. Firstly, most primary caregivers struggle to disclose to their children because they lack the knowledge and skills to disclose, and are often of the view that children are too young to comprehend the implications of their HIV diagnosis. Mandalazi et al. (2014) pronounce that stigmatization of HIV/AIDS also contributes significantly to primary caregivers delaying disclosure. Most primary caregivers opt to conceal the true nature of their children’s illness because they fear being judged by people in their vicinities. Secondly, Sariah et al. (2016)

contend that even with existing guidelines demarcating the role of HCWs in the disclosure process, most HCWs in South Africa are still uncomfortable to carry out the process because they lack knowledge and skills and have not been adequately trained by their respective organisations. Penn (2015) articulates that most HCWs, particularly those in resource-limited settings, are still conflicted about whether the responsibility to disclose lies with them or with primary caregivers. This confusion and lack of skills to disclose, contribute to disclosure being overlooked and delayed, consequently affecting children’s right to know their HIV status, and depriving them of much-needed psychosocial support from HCWs.

Appiah et al. (2019) indicate that delay in disclosure can yield problems such as family fragmentation once children learn of their health status. Some children lose trust in their primary caregivers as they often feel betrayed by the secrecy and concealment of their illness. This can manifest into unsavoury changes within family structures as conflict and animosity begin to rise. Madiba (2016) informs that delayed disclosure deprives children the opportunity to make their own healthcare decisions such as accessing sexual and reproductive health (SRH) services from an earlier age. It can distort children’s view of the future as some may feel hopeless and only think of death as the final outcome. Their self-esteem becomes tainted as they often feel different from their peers or unloved by society. Appiah et al. (2019) extend that delayed disclosure sometimes leads to children absconding from home as they find it unbearable to reside with people who withheld such pivotal and life-changing information from them. This creates a conundrum of family disputes and prospects of having to place such children in alternative care due to disharmony.

Madiba (2016) utters that other problems associated with delayed disclosure are children engaging in substance abuse, performing poorly at school and ultimately dropping out of school after learning of their HIV status. Accidental disclosure and masking of HIV status by primary caregivers are also quite common. Oftentimes, out of fear and lack of skill to disclose, primary caregivers falsify their children’s ART medication by referring to it as flu medication or vitamins. Mororiseng (2021, interview 29 January 2021) supplements that many children in Mmakau village grow up believing this narrative until they inadvertently find out the truth from peers, extended family members or neighbours. Some children discover their status by conducting their own research using social media platforms such as Facebook and Twitter. This consequently places strain on the relationship between primary caregivers and their children as most children feel embarrassed to have learnt of their HIV status elsewhere. Consequently, some children suffer from mental health problems such as anxiety, depression, suicidal ideation and withdrawal from societal engagements. They fear going to the clinic to draw blood or collect their medication due to fear of stigma from peers and the community at large. They also default on ART, which inevitably leads to premature death and increased poverty in families as most of these children are already orphaned due to HIV/AIDS.

Furthermore, Montalto et al. (2017) enlighten that many adolescents become sexually active between the ages of 15 and 19 years. One in five youth aged between the ages of 15 and 24 years report a sexual debut before the age of 15, less than two-thirds of those youth report using a condom the first time they had sexual intercourse. As sexual relationships evolve, 89% of young women abandon condom use. Therefore, being unaware of own HIV status may increase the risk of adolescents engaging in risky sexual behaviour which can result in detrimental outcomes such as unplanned pregnancies, contraction of sexually transmitted infections (STIs). Mororiseng (2021) indicates that although most children and adolescents receiving ART in most public health facilities are generally virally suppressed, others are not suppressed due to inconsistent ART regimens. Those who are unsuppressed bear the potential risk of infecting and re-infecting others with HIV, especially in cases where sexual intercourse is had without any condom use.

Based on the aforesaid, crux of the problem is that delayed disclosure of HIV status to children and adolescents living with PHIV has a negative effect on their psychosocial functioning, and this is as a result of underliying factors such as primary caregivers and HCWs' lack of knowledge and skills to timeously disclose the HIV status of children as per existing disclosure guidelines developed by WHO and the NDOH. This study therefore envisaged that findings from the participants' percerptions and experiences, would propose possible mitigation strategies and recommendations that will assist in improving and standardising age-appropriate child disclosure practices, so that children living with PHIV in Mmakau village may be able to make timeous and conversant decisions about their health. This would subsequently aid in reducing children's non-adherence to treatment, thereby enhancing their overall psychosocial functioning.

1.5 Research questions

1.5.1 Main research question

Considering the aforementioned problem statement of challenges faced due to lack of disclosure, the main research question that the study sought to answer is as follows:

What impact does delayed disclosure of HIV status have on the psychosocial functioning of children and adolescents living with PHIV in Mmakau village?

1.5.2 Sub-research questions

The sub-research questions derived from the main research question were:

- Are the HCWs designated at Hoekfontein (Mmakau) clinic adequately skilled to facilitate the disclosure process with primary caregivers and their HIV positive children?

- What are the factors inhibiting primary caregivers of Mmakau village to disclose the HIV status of their HIV positive children at an age-appropriate time?

- Are existing disclosure guidelines and legislation adequately implemented and adhered to by HCWs?

- Do HCWs receive ongoing training on the role of disclosure on the well-being of children living with HIV?

1.6 Research objectives

1.6.1 Main research objective

Looking at the above research questions, the main objective of the study was to analyse the impact that delayed disclosure of HIV status has on the psychosocial functioning of children and adolescents living with HIV in Mmakau village.

1.6.2 Sub-research objectives

The sub-research objectives for the research study were:

- To evaluate how well-skilled HCWs designated at Hoekfontein (Mmakau) clinic are in facilitating the disclosure process with primary caregivers and their HIV positive children.

- To determine possible factors inhibiting primary caregivers of Mmakau village to disclose the HIV status of their HIV positive children at an age-appropriate time.

- To determine whether HCWs designated at Hoekfontein (Mmakau) clinic can carry out the process of disclosure appropriately and professionally as per relevant guidelines and legislation.

- To evaluate whether HCWs receive ongoing training on child disclosure and its importance on the well-being of children and adolescents living with HIV.

- To explore perceptions and experiences of HCWs with disclosure and non-disclosure so that strategies aimed at improving child disclosure services at Hoekfontein (Mmakau) clinic may be proposed.

1.7 Significance of the study

Various research studies have been conducted by scholars such as Madiba and Mokgatle (2015), Gyamfi et al. (2017), Hayfron Benjamin et al. (2018)) and Diko and Madiba (2021) on child and adolescent disclosure in the field of public health; however, this research study is the first to be undertaken in Mmakau village, Bojanala District, North West, South Africa, in the context of Disaster Management. Furthermore, previous research studies have emphasised the perceptions and experiences of primary caregivers with very little attention drawn to the perceptions and experiences of HCWs providing disclosure services to children and adolescents living with PHIV. The NDOH (2016) conveys that child disclosure plays a vital role in HIV treatment and support of perinatally infected children, but remains an unheeded and understudied topic in South Africa.

This research study is therefore significant as it utilised the results obtained from the participants to propose strategies and recommendations that inform HCWs and primary caregivers about the importance of age-appropriate child disclosure. These strategies and recommendations may be utilised to ensure effective HIV care and management of children and adolescents living with PHIV in Mmakau village.

1.8 Research design and methodology

1.8.1 Research design

Sileyew (2020) indicates that a research design is a blueprint or plan devised to indicate how researchers intend to conduct their study. Research designs are often divided into quantitative, qualitative and mixed-method approaches. This research study adopted the mixed methods research design. Creswell and Creswell (2018) indicate that mixed methods research designs integrate both quantitative and qualitative research designs and are more advantageous because they minimise limitations found in quantitative and qualitative research designs respectively. They also provide a deeper understanding of the presented problem.

According to Flick (2014), mixed methods research designs involve the collection of quantitative (close-ended) and qualitative (open-ended) data to respond to the research problem or questions. Creswell (2015) extends that the data collected using mixed methods research designs allow the researcher to gather comprehensive and extensive data that reflects the participants' points of view. This research study was predominantly qualitative with minor quantitative.

Rahman (2020) provides that the benefit of using qualitative research is that it allows the researcher to experience the participants' behaviour, opinions, motivations and experiences through first-hand interaction. Astalin (2013) edifies that qualitative research designs are particularly beneficial when a subject is too complex or sensitive to the social context. Qualitative research designs are also advantageous in that they are able to produce data that is richer and more insightful into underlying reasons and patterns of a phenomenon.

In particular, the researcher aimed to establish the participants' (primary caregivers and HCWs') various perceptions and experiences with disclosure and non-disclosure of HIV status to perinatally infected children. Through this design, the researcher was able to explore and compare the different viewpoints shared by participants.

Quantitative research designs involve the collection and analysis of numerical data to predict, describe or control variables. The primary goals of quantitative research designs are to make predictions, test relationships between variables and generalise results obtained to the broader population (Kotzé, van der Merwe and Gerber, 2015). Creswell and Creswell (2018) highlight that some of the benefits of using quantitative research designs are straightforwardness, accuracy, time efficiency when collecting data and allowance for duplication of results. The incorporation of quantitative research design in this study was to obtain factual information and strengthen the qualitative research design by broadening the scope of the data collected (Creswell and Creswell, 2018).

Furthermore, the research study was exploratory and explanatory. Leavy (2017) states that the exploratory approach is often used when a research topic is new, understudied or has gaps in knowledge. This approach makes it possible for the researcher to develop new ideas about the topic, allowing for further investigation. Conversely, Creswell and Creswell (2018) annotate that explanatory research is often used to explain causes and effects of a particular phenomenon and strives to find out why certain things are the way they are. Likewise, this study aimed to unearth reasons behind delayed disclosure of HIV status to children perinatally infected with HIV and the impact this has or may have had on their psychosocial functioning. These two approaches were befitting for this study as the chosen topic has some gaps in research. The utilisation of these approaches may also guide other scholars to formulate other research questions.

1.8.2 Research methodology

The research study adopted a phenomenological approach. According to Creswell and Creswell (2018), phenomenology is an investigative strategy that enables researchers to identify the quintessence of human experiences about a particular phenomenon as portrayed by participants. Matua and Van Der Wal (2015) provide that the understanding of people’s lived experiences deem phenomenology as both a method and a philosophy. It is a process that involves studying a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. Qutoshi (2018) states that when using phenomenology in the research process, the researcher must bracket or set aside his or her own lived experiences to fully comprehend those of the participants.

Based on the above, the research study employed a case study from a phenomenological perspective. The study focused on the perceptions and lived experiences of participants as well as the meaning they attached to those experiences. According to Astalin (2013), a case study encompasses an in-depth examination of a single person or organisation. It aims to describe in-depth experiences of a person, a family, a group, an institution or a community. The principal goal of a case study is to provide an accurate and complete description of a case. Creswell and Creswell (2018) provide that case studies further aim to expand our knowledge on human behaviour or attitude. They are often inclusive of observations and in-depth interviews with participants. Case studies provide an opportunity for intensive analysis of many specific details that are often overlooked by other methods. They involve a deep understanding of multiple types of data sources.

1.8.3 Population and sampling

1.8.3.1 Target population

According to De Vos et al. (2011), a target population is a group of individuals or objects possessing similar characteristics. All these individuals or objects derive from a specific population and normally have a common binding trait or characteristic. The target population for this study consisted of two groups of people, which were primary caregivers of children and adolescents living with PHIV, who had either disclosed or not disclosed their HIV status to them; and HCWs who provided HIV services to children and adolescents living with PHIV.

1.8.3.2 Sampling

As stated by De Vos et al. (2011), sampling is a set of observations that give an idea of what can be expected within the total population. Creswell and Creswell (2018) describe a sample as a sub-group of observations representing a larger population. This research study used purposive sampling. Purposive sampling is also known as judgemental sampling. It relies purely on the researcher’s judgement when selecting the units that are studied. According to Vasileiou et al. (2018), purposive sampling provides richly textured data that are pertinent to the phenomenon studied. Examples of purposive sampling include specific people, events, cases, organisations or pieces of data (De Vos et al., 2011).

Hoekfontein (Mmakau) clinic had a sum of 104 children and adolescents enrolled on the ART programme (TIER.Net, 2021). The total number of primary caregivers responsible for these children and adolescents was 182. Due to the sensitivity and complex nature of this study, only 10% of these primary caregivers were selected to participate. This amounted to 18 primary caregivers. Vasileiou et al. (2018) justify that sample sizes in studies that are predominantly qualitative are generally smaller because they aim to support the depth of case-oriented analysis. A small sample size makes it easier for researchers to understand a case or several cases by closely observing the details of each.

The criteria used to select primary caregivers as participants of the study was as follows: The participants had to be 18 years or older and have a child(ren) or be caring for a child(ren) living with PHIV between the ages of 6–18 years, and in receipt of ART medication at Hoekfontein (Mmakau) clinic. The participants had to be willing to avail themselves to participate in the study without the expectation of remuneration. The participants also had to have read and understood all contents outlined in the informed consent form provided by the researcher. After having understood and agreeing to the expectations of the research study, the participants were required to sign the informed consent form.

The primary caregivers were identified by the researcher, with the assistance of HCWs (professional nurses and tracers). They were recruited while waiting in queue for their monthly consultations and medication collection on behalf of their children. They were verbally informed of the study and its expectations before the interviews took place. Following agreement to participate in the interviews, the selected primary caregivers were given appointment dates that were convenient to their respective schedules. The researcher also requested their contact details to remind them of the appointments as the interview dates approached. This was also done to enable rescheduling of dates in cases of unforeseen circumstances. Data capturers assisted the researcher to retrieve the contact details of primary caregivers who claimed to have had cell phones but could not recall their cell numbers. These details were accessed from the clinic's database, which is known as the TIER.Net (Three Interlinked Electronic Registers) system, with the permission of the clinic’s operational manager. As described by Myburgh et al. (2020), the TIER. Net is a system comprising of a patient's socio-demographic details such as full names, identity numbers, contact details, physical address and details of next of kin.

The primary caregivers opted to have interviews on the same day as their next clinic appointment. As such, each interview was conducted after each primary caregiver was done consulting and collecting medication. This strategy helped to save time and limited unnecessary travel and contact during the COVID-19 pandemic.

Furthermore, the clinic had 24 HCWs comprising of professional nurses, assistant nurses, HIV counsellors, data capturers, patient tracers and community health workers rendering HIV services to children and adolescents living with HIV. To answer the research questions and meet the research objectives, the researcher requested the clinic’s operational manager to recruit 50% (12) HCWs to form part of the study’s sample size. This was because the operational manager knew the role and responsibility of each HCW as well as their availability during working hours. HCWs often have busy schedules, hence the decision to include only 12 to minimise their time off work. Following recruitment made by the operational manager, the researcher subsequently approached each of the 12 HCWs selected to verbally inform them of the study and its expectations. Each HCW was interviewed at a convenient date and time.

The criteria used to select HCWs as participants of the study was as follows: The participants had to be working at Hoekfontein (Mmakau) clinic and employed by the NDOH. The participants had to be designated providers of HIV related services to children and adolescents living with HIV. The participants had to be willing to avail themselves to participate in the study without the expectation of remuneration. The participants also had to have read and understood all contents outlined in the informed consent form provided by the researcher. After having understood and agreeing to the expectations of the research study, the participants had to sign the informed consent form.

1.8.4 Data collection tools and process

Creswell and Poth (2018) define data collection as a process where direct information is obtained from participants or other secondary data sources to realise the objectives of the research study. The researcher conducted semi-structured interviews with participants to obtain all necessary data to achieve the objectives of the study. According to De Vos et al. (2011), researchers use semi-structured interviews to get a clear picture of a participant's beliefs or perceptions regarding a particular topic. Interviews give both the researcher and participant some flexibility to follow up on questions for enhanced clarity. Semi-structured interviews are particularly beneficial when a research topic is complex or when an issue is personal or controversial.

DePoy and Gilson (2008) express that during semi-structured interviews, data and information are mainly collected through one-on-one interactions held by the researcher and a specific group of individuals possessing the information needed or required to complete the research study. Researchers use semi-structured interviews to enter an individual's world by getting a perspective on how they view life, explore their world or make sense of their daily experiences. The researcher had an interview guide (Appendix D and E) as a data collection tool. Menzies et al. (2016) provide that an interview guide is a list of questions that a researcher wants to ask participants during an interview. The interview guide helped the researcher to focus and organise her line of thinking before questioning the participants. It consisted of open and close-ended questions. The open-ended questions aimed to ensure that the viewpoints of participants were adequately voiced, while the close-ended questions aimed to collect factual data such as the participants' socio-demographic characteristics.

The researcher also used audio recordings to capture all information obtained during the interviews. Mary (2008), stipulates that audio recordings ensure transparency and accuracy during the data collection process. They also help review any information that may have been undetected during the interview process.

The researcher ascertained effective management of time. The Interviews took place at the clinic, in a private room, at a scheduled date and time, and took approximately 30 minutes. All COVID-19 protocols set by the NDOH were observed during the interviews. Face masks were worn at all times, hands were consistently sanitised and social distancing (1 m spacing) was maintained.

Setswana is the main and commonly spoken language in the North West province. Eight of the thirty participants preferred English as a medium of communication, while twenty-two preferred Setswana. Therefore, to accommodate all participants, the researcher conducted the interviews in both languages based on preference. The interview guide was drafted in both English and Setswana (Appendix D and E) respectively. All interviews conducted in Setswana were translated to English for data analysis purposes.

1.8.5 Data analysis

According to De Vos et al. (2011), all data collected from participants must be analysed. It is a process employed to make sense of the research study to reach certain findings. The findings of the research were both quantitative and qualitative, thus the analysis and presentation of the data were descriptive and thematic respectively. The data were summarised in charts, tabulations and themes.

Corbin and Strauss (2015) together with Flick (2014) state that using descriptive analysis in research helps the researcher to summarise, organise and describe questionnaires, observations and interviews. This makes it easy to interpret quantitative data. The qualitative data were analysed using coding. Creswell and Creswell (2018) define coding as a system that finds patterns and provides explanations by using deductive and inductive reasoning to classify data into fragments. It is a process of labelling and organising qualitative data to identify themes and the relationship between them (Caulfield, 2019). The researcher thus highlighted sections and phrases in the transcripts and came up with codes that briefly described their content.

Creswell (2015) describes thematic analysis as a method used to identify, analyse and report various themes or patterns when collecting qualitative data. Caulfield (2019) states that thematic analysis is typically applied to a set of texts, such as interview transcripts. The researcher evaluated the data obtained from participants and identified common themes, ideas, topics and patterns of meaning that showed up repetitively. The themes identified were integrated to give a detailed picture of the research topic.

The researcher used the Microsoft Excel software to analyse and interpret all qualitative data, and the Statistical Package for Social Sciences (SPSS) software to analyse and interpret all quantitative data obtained from the interview guides. According to Bree and Gallagher (2016), the Microsoft Excel software is a cost-effective and relatively easy method that can be used by researchers to analyse transcript data. It enables raw, handwritten data from interviews to be transferrable and thematically analysed. Arkkelin (2014) provides that the SPSS is a software developed to help various types of researchers to statistically manage and analyse social science data. Leedy and Ormrod (2015) state that the SPSS enables raw, handwritten data from interviews to be transferrable and thematically analysed.

1.8.6 Data reliability and validity

Scholars, Bashir et al. (2008) and De Vos et al. (2011) express that validity is the degree to which data is credible, believable and trustworthy. Such data can be defended when challenged. Validity and reliability are concepts used in research to ascertain accuracy and consistency. The researcher ensured that the questions asked during the interviews were synonymous and consistent with all participants involved. The Health Sciences Research Ethics Committee (HSREC) at the University of the Free State validated the interview guides utilised during data collection (Appendix A). The Research, Monitoring and Evaluation Directorate at the North West Department of Health also granted further validation (Appendix G). The interview guides are documented in the final collation of the study (Appendix D and E). This availability allows transparency and critique. It further provides the reader with a better understanding of all the channels followed by the researcher to gather, examine, interpret and reach conclusions of the data obtained.

1.9 Limitations and delimitations of the study

1.9.1 Limitations

Despite scheduled appointments with each HCW, unforeseeable work obligations served as constraints with some of the interviews; this was compounded by the current COVID-19 pandemic. Some HCWs had to step in and out of the interview due to a shortage of staff. They had to attend to patients in need of prompt medical attention. This hindered the flow of the interviews, but the researcher recorded all information on transcripts and tape recordings to enable recollection of all discussions held. The study was also geographically confined.

1.9.2 Delimitations

As mentioned by Mutumba et al. (2017), children who experience delayed disclosure of HIV status tend to display an array of behavioural risks and patterns such as substance abuse, dropping out of school, defaulting on treatment and inadvertent transmission of HIV to sexual partners. As such, a delimitation of this study was that it relied solely on the subjective responses of primary caregivers and HCWs regarding delayed disclosure of HIV status and did not entirely reflect the perceptions and experiences of the children or adolescents concerned. Another delimitation of this study was that the researcher did not interview the children and adolescents concerned to ascertain some of the findings discovered by Mutumba et al. (2017). The results obtained were also not large enough to be generalised to broader communities as the sample used was relatively small.

The inclusion of non-biological primary caregivers was essential in this study as most children living with PHIV are single or double orphaned. Their inclusion, however, may have influenced the research findings. Manderson et al. (2016) express that children are often placed in the care of non-biological primary caregivers following the death of one or both biological parents due to HIV/AIDS. Upon placement, many non-biological primary caregivers tend to impulsively disclose the status of children with little regard to how such disclosure may affect their overall psychosocial functioning. Non-biological primary caregivers may have little or no relationship with perinatally infected children as opposed to biological primary caregivers. As a result, their perceptions and experiences with child disclosure may be limited. They may not view child disclosure as an intricate and daunting task, as would biological primary caregivers. They may also not necessarily understand the magnitude and difficulty (for example fear, guilt, shame) often faced by biological primary caregivers when having to disclose the status of their perinatally infected children. This delimitation helps demonstrate the gaps in the literature by necessitating the need and importance of education and implementation of child and adolescent disclosure guidelines in public health facilities and local communities.

1.10 Ethical considerations

According to De Vos et al. (2011), ethics play a significant role in research and serve as a standard and basis upon which every researcher ought to evaluate their conduct. For this research study, the researcher considered the following:

The researcher applied for ethical clearance from the HSREC at the University of the Free State. After obtaining ethical clearance, with the certificate number UFS-HSD2020/1733/2906, the researcher sought permission to assume research at Hoekfontein (Mmakau) clinic from the North West Department of Health. The researcher also ensured that she conducted herself in a manner that upheld and adhered to the University’s ethical standards during her interaction with participants.

Before commencing with the interviews, the researcher provided all primary caregivers and HCWs with a brief explanation of what the study entailed and the expectations thereof. During the briefing sessions, the researcher assured participants that they were not in any way pressured to partake in the study, and that they could withdraw from the study at any given time (De Vos et al., 2011). Subsequently, the researcher requested all participants to sign and complete consent forms before engaging in individual in-depth interviews. The consent forms (Appendix B and C) were transcribed in both English and Setswana, at a readability level that was user friendly and easily understandable to all participants.

The researcher ensured that participants were protected and well respected at all times. Confidentiality was also upheld. Pseudonyms were used in this study to safeguard the identities of participants. The audio-recorded in-depth interviews were saved on a computer that had a secured password. The researcher did not deceive participants in any way. The research study was carried out in the most truthful, transparent and ethical manner possible.

The researcher is a qualified and registered social worker by profession and has received permission from the sub-district manager of the North West Department of Health to offer psychosocial counselling as well as disclosure and adherence support services to children, adolescents and adults in receipt of ART medication at public health facilities in Madibeng Local Municipality. As such, the researcher provided ongoing counselling to participants who presented the need for such intervention. Additionally, the researcher liaised with fellow social workers from the DSD who are designated to offer social services in Mmakau village, to assist in offering therapeutic counselling to primary caregivers who displayed feelings of distress during and after the interview sessions. The consultations with the social worker(s) upheld principles of confidentiality and professionalism. They were also free of charge.

1.11 Chapter outline

The research report comprises seven chapters. Chapter 1 provided an introduction and a brief background to the research study. It also presented the problem statement, research questions and objectives of the study. It explained the significance of the study and detailed the research methodology, design, population and sampling. It provided the limitations and delimitations of the study, followed by ethical considerations. Chapter 2 outlines the theoretical frameworks employed in the study. Chapter 3 covers international and national legislative frameworks pertinent to children living with HIV, while Chapter 4 provides a scholarly literature review on child disclosure from a global, regional, national and local perspective. Chapter 5 explains the research methodology adopted for this research study. Presentation, discussion and interpretation of the results are in Chapter 6, while conclusions and recommendations of the study are found in Chapter 7 of the research report.

1.12 Chapter summary

In conclusion, this chapter outlined the background of the study. It also demarcated the study area and expressed the research problem. It highlighted the significance of the study and discussed the research questions and objectives that guided the data collection process, and methodology employed for research. It moreover noted the limitations, delimitations and ethical considerations of the study.

Chapter 2
THEORETICAL FRAMEWORKS PERTINENT TO CHILDREN LIVING WITH HIV

2.1 Introduction

The theoretical framework functions as an imperative aspect of the research process. It serves as the cornerstone of all knowledge gathered factually and figuratively for a study. The theoretical framework reinforces the rationale, the problem statement, the significance as well as the questions and objectives of the study. It also serves as a fundamental base for the literature review, methodology and analysis of the study (Osanloo and Grant, 2014). Lysaght (2011) explains that without a theoretical framework, a research study lacks a clear vision and structure. Furthermore, Ravitch and Carl (2020) provide that a theoretical framework encompasses a theory or a range of theories that fortify a topic. The applied theory must be suitable, coherent, well understood and in alignment with the research questions.

This chapter outlines the Pressure and Release (PAR) model and explains in detail the Ecological model which serves as the main theoretical framework for the study. The PAR model is employed to illustrate how delayed disclosure of HIV status generates vulnerability in children and adolescents living with PHIV. The Ecological model is used to demonstrate the impact of delayed disclosure of HIV status on the overall psychosocial functioning of children and adolescents within their various ecological systems (micro, meso, exo and macro systems).

2.2 The Pressure and Release model

The Pressure and Release (PAR) model is a widely recognised model used to conceptualise risk in the context of disasters and emergencies. It is a comprehensive framework that demonstrates the role of vulnerability in disaster risk. To fully comprehend the potential or likelihood of risk, it is crucial to understand the element of vulnerability. Vulnerability is the most fundamental component of risk; risk cannot exist in absence of vulnerability. Risk is an intricate concept consisting of both hazard and vulnerability (Hammer et al., 2019). Smyth and Hai (2012) in concurrence with Wisner et al. (2004), express that the PAR model is designed to assist disaster risk managers to know how to react to people's vulnerability to disasters so that risk may be effectively reduced. The PAR model notions that vulnerability, which is also referred to as pressure, is entrenched in political and socio-economic processes and must be released to abate risk.

According to Aziz (2018), the PAR model demonstrates that disasters only occur when hazards affect vulnerable people. A community may be vulnerable for many years, however, if there is no triggering incident, there is no disaster. Wisner et al. (2004) thus developed a formula (*risk* = *vulnerability* + *hazard*) which is an amalgamation of key components required to formulate a disaster.

Firstly, Wisner et al. (2004) define a hazard as a harmful event or condition that threatens to cause or is likely to cause injury, disease or harm to the environment. Hazards may be natural or manmade. In the context of this study, the hazard identified is the Human Immunodeficiency Virus (HIV), which weakens the immune system by attacking cells that aid the body to fight infection. When a person’s immune system is weak, the human body becomes susceptible to other infectious diseases, which can lead to severe ailments and ultimately death (NDOH, 2016).

Secondly, Wisner et al. (2004) describe vulnerability as the extent to which a community, an area or a structure are disrupted or damaged by the impact of a specific hazard. It only exists when people are incapable of anticipating, withstanding or recovering from a hazard (Tsasis and Nirupama, 2008). Likewise, Khan et al. (2008) express that when a disaster occurs, a community often has inadequate measures to reduce the likelihood of its risk.

Lentoor (2017) moreover explains that vulnerability can be socio-economic or physical. Socio-economic vulnerability refers to the impact that a hazard may have had on the affected population and the intensity of such an impact. Physical vulnerability refers to whom or what may be harmed or destroyed by a hazard. In the context of this study, delayed disclosure of HIV status to children living with PHIV makes them and potential others, vulnerable to the adverse effects of HIV/AIDS. Failure to timeously inform children of their HIV status may lead to them experiencing ample challenges such as social behavioural problems, defaulting on treatment and mental health issues. Delayed disclosure may also contribute to a rupturing of family and peer relationships.

Thirdly, Wisner et al. (2004) define risk as a measure of anticipated losses due to a hazardous event within an environment, over a certain period. A community is at risk when it is exposed to a hazard and is likely to be affected negatively. Delayed disclosure of HIV status to children living with PHIV may lead to several risk factors. These risk factors are for instance, children’s engagement in uninformed-unprotected sexual intercourse with their partner(s), contraction of STIs, suicide ideation and untimely death (Lentoor, 2017).

Delayed disclosure of HIV status to children living with PHIV stems from several factors which will be explained using the PAR model as depicted in Figure 2.1.

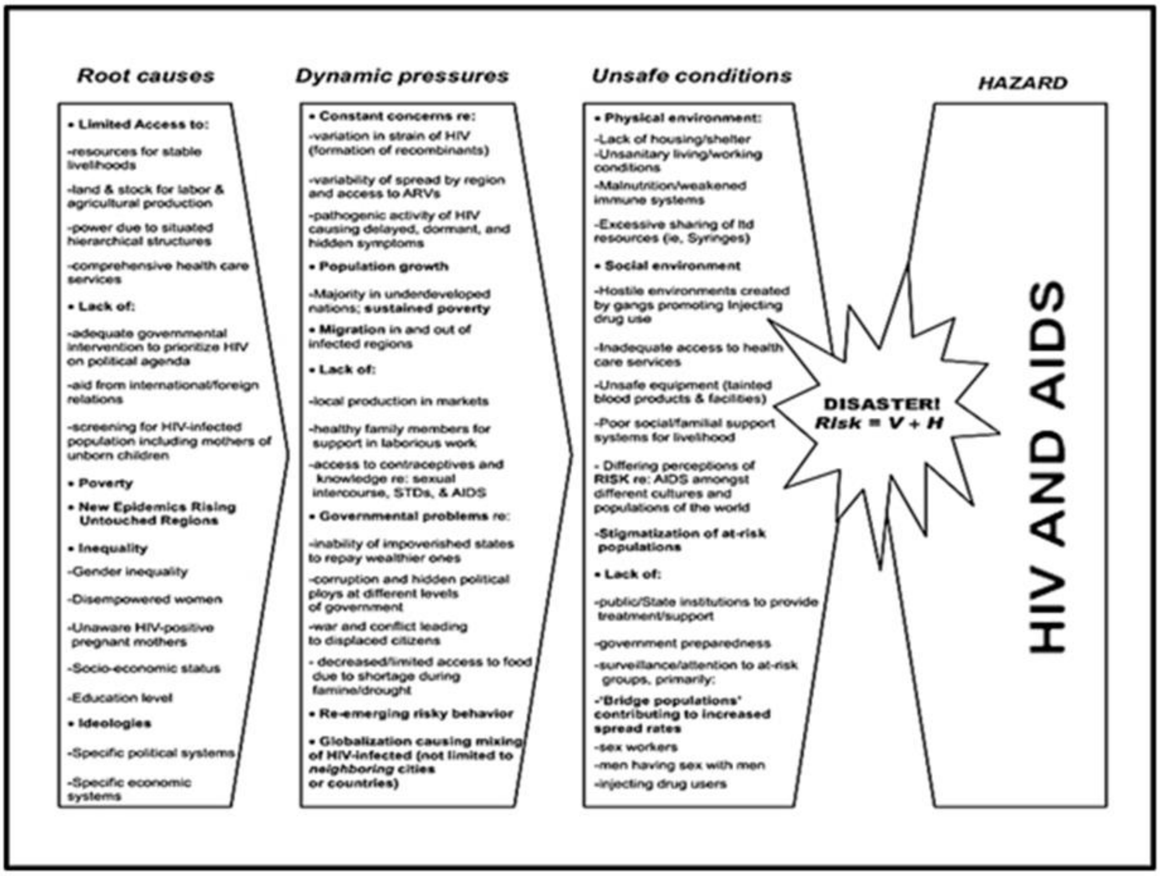

Figure 2.1: The progression of vulnerability to HIV/AIDS in the context of the Pressure and Release model
Source: Tsasis and Nirupama (2008)

Figure 2.1 illustrates that disasters only occur when people are vulnerable to a hazard such as HIV/AIDS. For a disaster to happen, vulnerability and hazard have to come together (Tsasis and Nirupama, 2008).

Khan et al. (2008) express that the PAR model contains three layers of social processes that lead to vulnerability. They are root causes, dynamic pressures and unsafe conditions. Root causes lead to dynamic pressures, which describe how unsafe conditions arose and persevered. Wisner et al. (2004) state that the progression to vulnerability in each step is a build-up from the previous step, which increases pressure on the entire system. When these steps combine with a hazard, they lead to disaster risk and ultimately a disaster.

Firstly, Wisner et al. (2004) explain root causes as underlying causes of vulnerability. Root causes are widespread, well-established economic, political and demographic processes within a society that result in vulnerability and reproduce vulnerability over time. Root causes have an influence on the distribution and sharing of resources among people; they also reflect the dissemination of power within a society. Delayed disclosure of HIV status to children living with PHIV has various root causes, and they are explored.

According to UNAIDS (2017a) more than 80% of children living with HIV are located in sub-Saharan Africa, a majority of which live in South Africa. Madiba and Mokgatle (2015) express that there is a great disparity between disclosure rates in developed countries and developing countries such as South Africa. Likewise, Aderomilehin et al. (2016) enlighten that disclosure rates in resource-limited countries vary from 11 to 38% while rates in resource-rich countries range between 10 and 77%. Resources are also limited as many HCWs in developing countries still lack the support of guidelines and policies on child and adolescent disclosure as opposed to HCWs in developed countries.

According to Madiba and Mokgatle (2015) and Sariah et al. (2016), most local clinics in sub-Saharan African countries have limited government resources available to ensure that child disclosure is implemented efficiently. Poor systems are in place to support HCWs in following the national guidelines and policies concerning child disclosure. It is as such, critical to address the existing gap between training offered on child disclosure guidelines and their actual implementation among HCWs, so that their performance may be maximised. Watermeyer (2015) emphasises that there has to be synergy between policy and practice.

Demmer (2011) expresses that delayed disclosure in the South African context is intensified by orphanhood due to HIV/AIDS. Children's primary caregivers may not be their biological parents, hence the struggle to disclose in a timeous manner. Societal inequalities such as stigma and discrimination delay disclosure. Some primary caregivers fear discussing HIV or sex with children as some cultures regard such topics as taboos. Watermeyer (2015) enunciates that low levels of literacy and education of primary caregivers contribute significantly to delayed disclosure. Limited opportunities to access information in less privileged areas also lead to delayed disclosure. High stress levels encountered by families due to poverty, unemployment and the HIV/AIDS pandemic, all play a role in delayed disclosure of HIV status to children and adolescents living with PHIV.

Secondly, Wisner et al. (2004) describe dynamic pressures as activities and processes that convert the impacts of root causes into vulnerability. Dynamic pressures include lack of access to resources, for example, lack of training on policies, guidelines and acquisition of professional skills. Studies show that despite available disclosure guidelines in South Africa, many HCWs still encounter challenges during the disclosure process due to lack of training (Madiba and Mokgatle, 2015; NDOH, 2016; Madiba and Diko, 2021).

The WHO guidelines of 2011 state that HCWs have the responsibility to support primary caregivers during disclosure, however without training this recommendation becomes futile (WHO, 2011). Beima-Sofie et al. (2014) magnify that failure to train HCWs results in failure to support primary caregivers. This delays disclosure and subsequently denies children the right and opportunity to make their own health decisions, thereby placing their lives at possible risk of adverse and life-threatening effects.

Thirdly, unsafe conditions are specific forms in which people's vulnerability is expressed in space and time in conjunction with a hazard. An environment often becomes unsafe due to poor planning, preparedness skills and inadequate coping capacities; this increases the vulnerability of such an environment (Wisner et al., 2004). Okechukwu et al. (2018) express that paucity of skills to disclose has contributed towards many children reaching the adolescent stage without knowing their diagnosis. This has considerable implications on their emotional well-being, health access and treatment adherence. Mengesha et al. (2018) explicate that delayed disclosure has dire repercussions such as unintentional transmission as children enter the pubertal stage and start engaging in romantic relationships and ultimately, sexual intercourse. Participating in sexual intercourse without knowledge of own HIV status is particularly concerning as it can result in unwanted teenage pregnancy which could also perpetuate the cycle of MTCT, especially when viral load is unsuppressed.

To sum up, Smyth and Hai (2012) provide that *Release* in the PAR model means that the pressure that exists amid hazards and vulnerabilities must be released to lessen disaster risk. Hazards such as HIV/AIDS must be mitigated so that a population may become less vulnerable to its intensity. If an individual, community or environment has great capacity when faced with a disaster, the effect of the hazard may be reduced significantly as opposed to having little to no capacity. According to Khan et al. (2008), vulnerability ought to be lessened at different levels: activities must take place to turn unsafe conditions into safer conditions, which will result in dynamic pressures being reduced and root causes being addressed. By implementing activities aimed at disaster risk reduction, a community can control an adverse situation, manage disease, lessen injury and combat death. Such a community will be able to recover from the impact of the hazard and build resilience.

2.2.1 Evaluating the Pressure and Release model

Wisner et al. (2004) articulate that the PAR model is a fundamental instrument that can assess the progression of vulnerability to disasters, hence its incorporation into the study. Although the PAR model does not serve as the main theoretical model for study, the researcher found it necessary to integrate it as a means to demonstrate how delayed disclosure of HIV status yields vulnerability in children living with PHIV, in the context of disaster management. Smyth and Hai (2012) in accordance with Turner, Kasperson, Matson et al. (2003), state that even though the PAR model was developed to bring the human factor into disaster management, it places little focus on human-environment interactions and the vulnerability of the biophysical environment. Hammer et al. (2019) extend that the model is limited in showing how human beings interact with their environments and the impact that these interactions have on the occurrence of a hazard. In the context of this study, the PAR model, significant as it is, does not quite evince the impact of delayed disclosure of HIV status on the psychosocial functioning of children living with PHIV, and the relationships they have with themselves and their significant others.

2.3 The Ecological model

In 1986 Urie Brofenbrenner, an American psychologist, developed the Ecological model for child development (Gal, 2017). According to Brofenbrenner (1986), children form part of various systems and each system influences the other, thus affecting all aspects of their lives. The systems in which children exist, influence their development and behaviour. Similarly, the NDOH (2016) supplements that children are connected to their environments; they operate as systems, not as separate entities. As such, delayed child disclosure of HIV status has an impact on a child’s development, family life, school life and social life.

Contextually, Feldacker et al. (2011) enlighten that the Ecological model demonstrates how factors within and beyond the children themselves influence their experiences with health and illness. Mburu, Ram, Oxenham et al. (2014) edify that the Ecological model helps provide a comprehensive understanding of children’s health by identifying factors affecting their well-being at individual, family, community and structural environments. Scholars such as Stokols (1996), Mugavero et al. (2011) and Mburu et al. (2014) have previously employed the model and demonstrated how health not only affects the individual, but also their surrounding systems.

Likewise, this study adopted the Ecological model as the main theoretical framework to denote the impact of delayed disclosure of HIV status on the psychosocial functioning of children and adolescents living with PHIV. By employing this model, the study intends to exemplify how HIV not only affects children’s biophysical being, but also the environments in which they exist. Fundamentally, Mburu et al. (2014) contend that by focusing only on children’s biophysical factors whilst overlooking their social contexts, HCWs accomplish suboptimal health outcomes for children and their environments. Overlooking social contexts limits HCWs’ abilities to mitigate risk factors and negative experiences found at family, community and larger societal levels.

According to Brofenbrenner (1986), to comprehend children’s development within their environments, the following four interconnected systems need consideration: micro-system (individual level), mesosystem (family and peer level), exo-system (community level) as well as the macro-system (structural level). Figure 2.2 is a modified illustration of Brofenbrenner’s Ecological model.

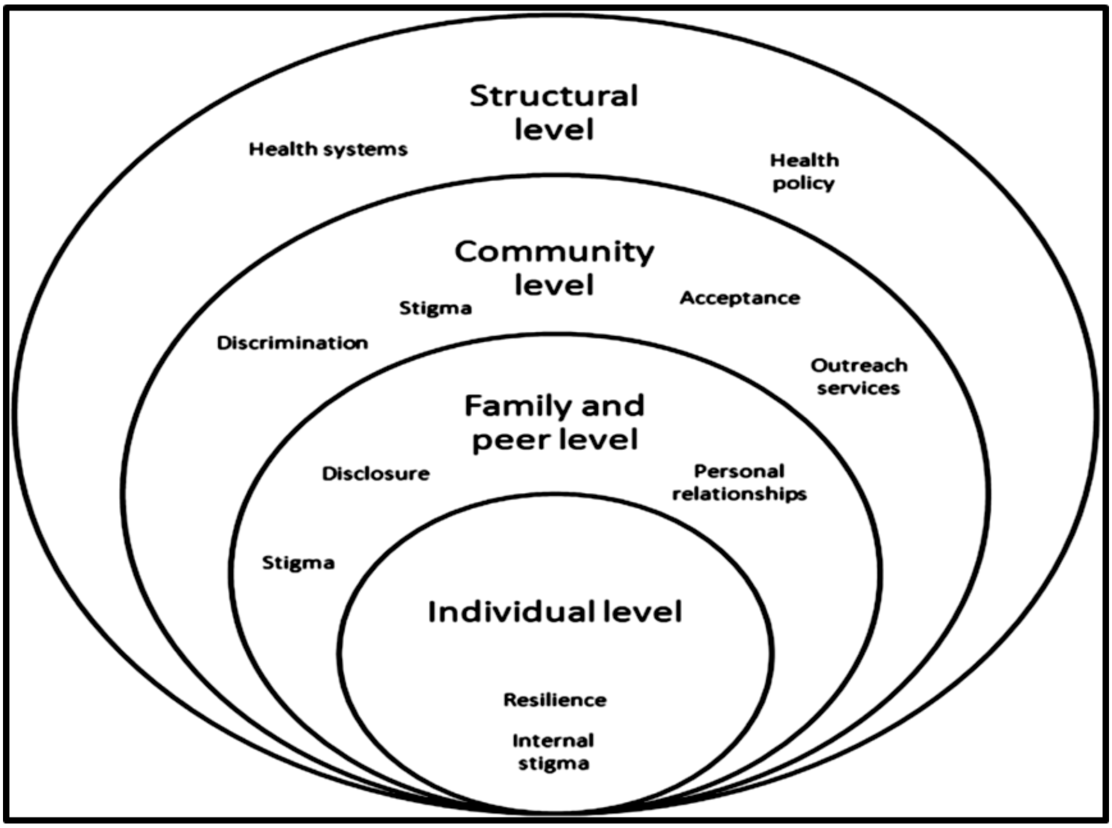

Figure 2.2: Factors influencing child disclosure in the context of the Ecological Model
Source: Mburu et al. (2014)

The micro-system (individual level): This system includes characteristics that influence a child’s behaviour such as knowledge, attitudes, skills and beliefs. Children’s direct interaction with their immediate family influences these characteristics. The micro-system is the closest layer to a child and incorporates structures to which a child has direct association. It is the most familiar learning environment where a child gains first-hand knowledge about the world (Rogoff, 2003). Chimphamba Gombachika et al. (2012) point out that the micro-system can serve as a nurturing or harmful atmosphere to a child's development. It is a preliminary setting where children develop trust and reciprocity with their family members.

Domek (2010) and Madiba (2016) mention that as children grow, many primary caregivers delay disclosing in an attempt to preserve the relationship they have already established with their children; this, however, does more harm than good to the existing relationship. Primary caregivers are often of the perception that children are too young and therefore not developmentally capable to understand their illness or the concepts associated with it. In contrast, Cantrell et al. (2013) construe this notion as flawed as with age, maturity and cognitive development, children are capable of understanding their illness and the effects thereof; hence the WHO (2011) guidelines recommended ages six to twelve as appropriate ages to assume the disclosure process.

Intrinsically, Santamaria et al. (2011) together with Butler et al. (2009), embrace the widely accepted cognitive development theory developed in 1936 by Swiss psychologist, Jean Piaget. In corroboration with Cantrell et al. (2013), this theory upholds that even young children can understand aspects related to their health and illness. According to Louw and Louw (2007), Piaget asserted that children in the *concrete operational stage* (age seven to eleven) can think concretely and logically. They can make several connections of causation to a single phenomenon and can recognise different hierarchies. Cantrell et al. (2013) expound that during this stage, children are capable of understanding their illness; they can understand that taking medication makes them strong whilst refusal to do so makes them weak and ill. Furthermore, Louw and Louw (2007) state that Piaget considered the *formal operational stage* (age eleven and older) as a period of formal and logical thinking. Herein, children start to think abstractly and hypothetically. Cantrell et al. (2013) supplement that during this stage, children can connect multiple reasons for their illness, including internal and external factors associated with their health.

According to Mengesha et al. (2018) research show that many caregivers use deception as a coping mechanism to conserve their relationship with their children. Deception involves intentionally falsifying answers to the questions that children may ask concerning their health status. Intentionally attributing a child's health condition to another unrelated health condition is also a form of deception. Namasopo-Oleja et al. (2015) aver that denying children appropriate information when responding to questions concerning their health may have a considerable effect on the child-primary caregiver relationship. This will also affect the quality of their life as they seek to find out the truth about their health status. Such denial further contributes to the infringement of children’s constitutional right to make independent choices concerning their health.

In essence, Chilemba and Phiri (2017) express that providing children with reliable and age-appropriate information reduces the chances of mistrust and misconceptions in family relationships. Such provision of information helps build children’s self-esteem and resilience, further reducing chances of harmful effects such as self-stigmatisation (thinking that they are worthless, unlovable or unlike others). Providing children with truthful information helps minimize mental health conditions such as anger, anxiety, withdrawal and depression.

Kiwanuka et al. (2014) in accordance with Beima-Sofie et al. (2014) stipulate that there is a great need for primary caregivers to be informed of the implications of deception on the child-primary caregiver relationship and the overall psychosocial functioning of children. Primary caregivers ought to be supported and equipped with adequate knowledge and skills on how to communicate truthfully when conveying HIV-related information to their perinatally infected children. This will aid in reducing feelings of doubt, fear and shame, which will in turn help maintain balance in family relationships and overall functioning.

The meso-system (family and peer level): This system involves the interaction of different microsystems in which children find themselves. They include environments that are external to a child’s immediate family such as clinics, hospitals, schools and nearby welfare services (Chimphamba Gombachika et al., 2012; Mburu et al., 2014; Gal, 2017).

Mburu et al. (2014) express that poor or delayed disclosure influences external relations that children have with persons other than their immediate families. Delayed disclosure can result in social and emotional difficulties for children as they progress into the adolescent stage. Tassiopoulos et al. (2013) state that delayed disclosure has a public health risk of furthering the transmission of HIV. Adolescents involved in romantic relationships may unwittingly infect their partners through their engagement in sexual intercourse. For example, perinatally infected adolescents who are not informed of their HIV status, may engage in unprotected sexual intercourse with their partners and unintentionally transmit the virus. This then results in the relationship being at risk of tarnishment, bringing about greater confusion and distress in the adolescents’ lives, as they were incognisant of their HIV-positive status before having sexual intercourse. The perinatally infected adolescents may even falsely believe that they were infected by their partners, which can create an even bigger dilemma by raising issues of mistrust, betrayal and misperception within the relationships. From this example, it becomes increasingly evident that delayed disclosure denies children and adolescents the opportunity to prevent the transmission of HIV through safer sexual practices and voluntary self-disclosure to their partners.

Moreover, delayed disclosure of HIV status also denies children and adolescents the opportunity to access early intervention services as well as psychosocial care and support services available within their environments. In a South African study undertaken by Watermeyer (2015), a participant who was a HCW, mentioned a case of an adolescent girl who had not been disclosed to. The adolescent girl discovered her HIV status at the clinic by inadvertently reading the information in her file and subsequently committed suicide. This scenario shows that had the adolescent girl been disclosed to at an age-appropriate and earlier phase of her life, she would have received gradual support that could have led to the acknowledgement and acceptance of her HIV status – death could have as such, been prevented. Mengesha et al. (2018) opine that rather than waiting until a child is considered old enough for disclosure, HCWs ought to provide consistent support to primary caregivers to prevent such encounters. According to Vreeman et al. (2013) when children are timeously informed of their HIV status, they are better able to seek community-based social support services that can assist in improving their coping skills.

As known, the adolescent stage is an empirical period where children explore various pathways to finding themselves (Louw and Louw 2007). Rehm et al. (2017) enlighten that as children transition into adolescence, they often explore risky behavioural practices such as substance and alcohol consumption with peers. Research shows that adolescents who consume alcohol are likely to experience their initial sexual debut at an early age and they may engage in sexual intercourse with multiple partners. Alcohol consumption further induces other dangerous practices such as sharing of used drug injections and substance abuse. Delayed disclosure, therefore increases the likelihood of disease progression through such behavioural practices (Morojele et al., 2012).

Mengesha et al. (2018) state that delayed disclosure can negatively affect children's attendance and performance at school. If children learn of their illness at a much later stage of their development, such children may withdraw socially from peers at school. Delayed disclosure may also cause children to abandon their treatment regimen and miss appointments at local clinics or hospitals. Abandonment of treatment leads to detrimental health consequences such as increased viral load, affecting the immune system. Abandonment of treatment can also cause drug-resistant HIV strains to the degree that even when children are reinitated on treatment, their bodies become resistant to the medication. Delayed disclosure of HIV status, therefore has a contributing effect on the deterioration of children's health and overall well-being.

The exo-system (community level): This is a system that a child has no direct contact with, but it has a notable influence on a child's development. Examples of the exo-system include parental social networks, extended family members, neighbourhoods, government and non-governmental agencies formulating child-related guidelines and policies (Gal, 2017).

Despite efforts made to curtail issues around HIV stigma, it still prevails in many communities (Vreeman et al., 2019). According to Prudden et al. (2017), HIV stigma is a significant barrier to accessing HIV services such as testing, treatment and disclosure support. Harper et al. (2014) pronounce that stigma is when an individual or a group of individuals possess a certain characteristic that others view as different and undesirable. Stigma often manifests negative treatment from others.

Gyamfi et al. (2017) found HIV stigma to be one of the leading causes of delayed disclosure of HIV status. The scholars discovered that oftentimes, primary caregivers are discouraged to disclose to their perinatally infected children with the fear of what people in their social circles, neighbourhoods or communities may say about their children or their family at large. Because of this inability to disclose, HIV infected children suffer the consequence of not knowing their HIV status at an age-appropriate time.

Macro-system (structural level): This system is the largest and most distant layer to a child, but has a great influence on a child's life. The macro-system represents larger social, economic, political and legal forces affecting children and their families. It also composes of a child's cultural patterns, values, beliefs and ideologies (Gal, 2017).

Various national and international laws that endorse the rights of children living with HIV, augment the Ecological model. Of prominence, the United Nations Convention on the Rights of the Child (UNCRC), the South African Constitution (Act 108 of 1996) and the South African Children's Act (No. 38 of 2005) as amended. These pieces of legislation emphasise children's rights to health and their right to participate in matters concerning their health and overall well-being (Budlender et al., 2008; Gal, 2017).

Delaying disclosure until a child has surpassed the recommended age for full disclosure (12), impedes the rights of the child. Such delay counteracts the widely acknowledged WHO child disclosure guidelines and the South African child and adolescent disclosure guidelines. The paucity of trained HCWs on HIV disclosure, begets poor implementation of existing guidelines and policies. As a result, children are deprived the opportunity to obtain important knowledge concerning their constitutional rights to health. Amongst others, delayed disclosure hinders a child's right to freedom of expression, participation, and access to information and health services (WHO, 2011; NDOH, 2016).

2.3.1 Adapting the Ecological model into disaster management

The South African Disaster Management Act (No. 57 of 2002) as amended in 2015, defines disaster management as an ongoing process consisting of multidisciplinary and multi-sectoral teams. The process involves planning and putting in place strategies aimed at preventing or reducing disaster risk; preparing for emergencies; mitigating the consequences brought by disasters; responding rapidly to disasters, and offering post-disaster recovery and rehabilitation. The act explains that often when disasters occur, societies are disrupted and are unable to cope with the resources at their disposal, hence the need and importance of disaster management. As argued by Stabinski et al. (2003) HIV/AIDS is a disaster that can lead to distressing effects that warrant a comprehensive disaster management response.

Wisner et al. (2004) stipulate that to understand the concept of disaster management, the following key components must be considered: vulnerability, risk, hazard and coping capacity. A combination of these components is what leads to a disaster. To manage a disaster efficiently, capacity has to be enhanced so that the vulnerability and risk brought by a hazard may be narrowed. The greater the capacity within an affected community, the more manageable the disaster will be. The lesser the capacity, the more challenging it will be to manage the disaster. As such, the Ecological model will be adapted into disaster management using the four key components as follows:

2.3.1.1 A holistic approach to how delayed disclosure ensues vulnerability in children and their surrounding systems

The South African Disaster Management Act (No. 57 of 2002) as amended in 2015, defines vulnerability as the extent to which a disaster adversely affects an individual, a family, a community or an area. Vulnerability involves conditions determined by physical, economic, environmental and social factors that intensify the susceptibility of a community to the impact of a hazard. Delayed disclosure of HIV status can affect the psychosocial functioning of children and their micro- and meso-systems (immediate families and adjacent surroundings). Failure to disclose the HIV status of perinatally infected children at the recommended age, heightens their vulnerability to the precarious effects of the hazardous HIV/AIDS pandemic as they grow up.

McHugh et al. (2018) postulate that each year, a significant number of perinatally infected children are orphaned and become vulnerable as a result of one or both their parents succumbing to Acquired Immunodeficiency Syndrome (AIDS). AIDS is the last stage of HIV infection and occurs when the virus severely impairs the immune system. Following the passing of their parent(s), most of these children are left vulnerable, having to survive into the adolescence stage and sometimes early adulthood without having been informed of their own HIV status by their deceased parent(s). Manderson et al. (2016) state that a considerable number of children living with PHIV, are often subjected to unstable living arrangements that involve the constant changing of primary caregivers such as grandparents and extended family members, which hampers their sense of belonging and the traditional structure of a family (micro-system). McHugh et al. (2018) moreover enlighten that often, primary caregivers, particularly elderly primary caregivers who offer to foster these children, face multiple socio-economic difficulties and have little knowledge on HIV, resulting in the psychosocial needs of the children in their care being overlooked and unmet.

Pertinent to the micro-system, Nyamukapa et al. (2008) state that even though primary caregivers have the principal role of informing children about their HIV status, fluctuations in caregiving arrangements due to orphanhood contribute to delayed disclosure and may interject children’s engagement with HIV care and treatment adherence. This negatively affects children’s health outcomes, behavioural patterns and overall psychosocial functioning. Manderson et al. (2016) illuminate that non-biological caregivers’ failure to disclose to children their status or the status of their deceased parent(s) at an age-appropriate time, may potentially lead to a further rupturing of family relationships, stimulating issues of mistrust between them and the children in their care.

Skovdal et al. (2011) explain that even with efforts such as foster care placements and other alternative placements, many children orphaned by AIDS still resort to risky behavioural practices as a means to survive or find solace following the death of their parent(s). This bears the potential risk of affecting the child’s meso-system (peers, partners, access to health services). Oftentimes, children bereaved by AIDS are likely to lose their property and inheritance, they suffer from poverty, malnutrition, and their psychosocial needs are easily neglected. As such, Baxter and Abdool Karim (2016) alert that economic vulnerability is a notable determinant of HIV vulnerability. For instance, poverty can thrust adolescents to engage in sex work. McClure et al. (2015) state that adolescents who are below the age of 18 and sell sex, are extremely vulnerable to HIV and other harmful STIs. Inguane et al. (2015) add that adolescents are more susceptible to HIV and STIs than older sex workers as they have less access to HIV testing, prevention and treatment services.

Adolescents who engage in sex work often encounter difficulties such as the inability to negotiate condom use and sexual health services because of their age and lack of authority.

Furthermore, Baxter and Abdool Karim (2016) in corroboration with UN Women (2016) state that economic vulnerability again has the propensity to influence the meso-system in that it may constrain young girls and young women to stay in relationships that condone gender-based violence, further exacerbating their vulnerability to HIV. Young girls and young women may enter into relationships with men who are much older and better able to provide for their basic needs. Stoebenau et al. (2016) amplify that intergenerational sex is one of the main drivers of the HIV/AIDS pandemic in sub-Saharan Africa. In many age-disparate sexual relationships, older partners are more likely to be living with HIV and may coerce younger partners into unprotected sexual intercourse. Coerced sexual intercourse is likely to expose younger persons already infected with PHIV, to STIs and re-infections. Such relationships are often transactional and commonly driven by the assumption that sex will take place in exchange for material benefits. Due to gender-related power dynamics, condom use in such instances is hardly, if at all, negotiated. This subsequently proliferates a younger partner's vulnerability to HIV as older partners may have already had multiple sexual partners. Through such practices, the WHO (2015b) expounds that children living with perinatal HIV may not only contract life-endangering STIs, they may also transfer the virus and also be re-infected with various strains of HIV. They may also be susceptible to other dangerous and illicit practices such as human trafficking, rape and statutory rape.

Moreover, the exo-system, which often consists of extended families, neighbours and the larger society, indirectly affects the micro-system by influencing primary caregivers' decision to delay the HIV status of their children. The exo-system can create vulnerability in perinatally infected children and their primary caregivers (Gal, 2017). Kiwanuka et al. (2014) indicate that one of the main factors distinguishing HIV/AIDS from other terminal or chronic diseases is the stigma attached to it. Stigma often derives from a dearth of knowledge about HIV and its various modes of transmission. Oftentimes, societies view HIV/AIDS as a condition only caused by sexual promiscuity, thereby passing harsh and uninformed judgement to those who have acquired it.

Mandalazi et al. (2014) extend that most biological caregivers fear disclosing the status of their children due to societal stigma. In particular, mothers who transmitted the virus to their children at birth and during breastfeeding, often experience feelings of guilt as family members at times criticise them for their children's diagnosis. They, therefore, delay disclosing to shield their children from being stigmatised. They also fear that by disclosing, they will automatically unmask their own HIV status, resulting in their children resenting and condemning them for disease acquisition. Close and Rigamonti (2006) alert that by enforcing this approach, primary caregivers make provision for stigma to create an atmosphere of secrecy within the family, which can cause tension in family relationships. An atmosphere of secrecy can intensify speculation from children and subsequently ensue psychological harm due to persistent overthinking. By labelling a child's HIV status a secret, the prevalence of stigma precipitates, subsequently impacting the micro-system.

Poindexter and Linsk (1999) impart that societal stigma can be significantly damaging to the micro-system when internalised. Internal stigma takes place when an individual becomes aware of the stigma imposed by members of society and consequently internalises and accepts the negative views deriving from society. This then becomes detrimental to the individual's self-image and overall self-worth. Internalised stigma impacts biological caregivers' ability to disclose, which consequently places a child in a vulnerable and compromised place. McHugh et al. (2018) explicate that most children depend on their biological caregivers for their HIV care and treatment, therefore withholding disclosure of HIV status for too long may affect children's capacity to adjust to the diagnosis when caregivers inevitably decide to tell them. Delaying the process of disclosure may endorse self-stigmatisation in a perinatally infected child and may in turn contribute to societal stigma. It can also negatively affect children as well as their primary caregivers in ways that have longstanding psychosocial effects. In particular, children are more likely to experience mental health conditions such as depression, withdrawal from peers and even suicide. Due to fear of being rejected and isolated, children may also be in denial about their HIV status, which can preclude them from seeking external social support from the meso-system.

The exo-system, for example neighbours and extended family members who may know of childen's health status, may intentionally or unintentionally disclose their HIV status before their primary caregivers can do so. In some instances, children accidentally learn of their HIV status by overhearing neighbours or extended family members mentioning the nature of their illness. At other times, neighbours, extended family members or even primary caregivers' social networks may scatter a child's HIV status across the neighbourhood or community before the child is informed. This can negatively affect the child's psychosocial functioning. It can also place the child-primary caregiver relationship at risk of being antagonistic and unreceptive, further disrupting the micro-system (DSD, 2019).

2.3.1.2 Risk imposed by delayed disclosure of HIV status

The United Nations International Strategy for Disaster Reduction (UNISDR, 2017) defines disaster risk as the degree to which people may lose their lives, health statuses, livelihoods or assets in the event of a disaster. These losses could affect a certain group of individuals or a community due to their exposure to a possible future hazard and their vulnerability to that hazard. Appiah et al. (2019) avow that delayed disclosure of HIV status reinforces the likelihood of risky behaviour and death in children and adolescents perinatally infected with HIV. According to Siegel (2015) transitioning from childhood to adolescence and eventually adulthood, involves discovering and navigating ways around gender customs, sexuality, peer relationships and economic responsibility (macro-system). During this time, many adolescents commence experimenting with sex, injecting drugs, alcohol and intimate relationships (meso-system). It is herein that their brain capacity starts developing decision-making skills, impulse control and future plans.

In disaster management, emphasis is always placed on the importance of preparedness, prevention and mitigation to minimise the repercussions of disasters during response. Failure to adequately prepare for disasters or the likelihood thereof can result in dire consequences (Torani et al., 2019). Appiah et al. (2019) reveal that in some cases, primary caregivers tend to delay the process of disclosure until a child’s illness has been severely aggravated. It is only after disease progression that some primary caregivers realise the need and importance of disclosure. According to STOPAIDS (2016), the physical development of a child, including pubescent changes, may be delayed if the disease greatly advances. Subsequently, as an HIV-positive child progresses into adolescence, they may appear to be much smaller than other adolescents are because their progress to becoming adults has been delayed by illness. If adolescents feel and see that they look different from their peers, they find it challenging to bond with them. This has an adversative effect on the interactions and attachments they wish to form with persons other than their primary caregivers and immediate families (meso-systems). Adolescents experiencing such changes may develop negative self-perceptions of themselves (micro-system) and may find it difficult to identify with peers their age. They may also feel sidelined and stigmatised by other adolescents due to their physical appearance. This can even thwart a child’s willingness to participate in extra-mural activities or attend school.

In addition, Appiah et al. (2019) elaborate that sometimes, delaying disclosure for too long affects the micro-system by forcing primary caregivers to circumstantially and unpreparedly inform their children of their HIV status. This comes after children stop or threaten to stop adhering to ART altogether. Most children become exasperated and exhausted from taking doses of pills they know nothing about. They get tired of having to constantly nag and ask numerous questions and getting deferred answers from their primary caregivers. Chandler and Ngoksin (2013) impart that children who have been taking ART for some time, have experienced ample changes in their ART doses and regimens over the years. They often think that the medication they are using is only temporary and will be discontinued at some point. It is when they transition into the adolescence stage that they become influenced by the macro-system and start becoming incrementally inquisitive. They wonder why they are still taking treatment and why their dosages keep changing and increasing instead of reaching dissolution. By constantly deferring the true nature of their children's medication, primary caregivers fuel the prospect of children learning of their status elsewhere. They exacerbate their chances of defaulting on treatment and dying prematurely.

Idele et al. (2014) inform that many children, irrespective of their HIV status, engage in risky behavioural practices during their transition from childhood to adolescence. Unprotected sexual intercourse, sharing of needles and the illegal use of substances are the most prevalent risky behaviours among adolescents (meso-system). Intriguingly, UNAIDS (2017a) provides that AIDS is still the leading cause of death amongst persons aged between the ages of 10 and 24 in Africa and the second leading cause of death worldwide. Appiah et al. (2019) alarmingly reveal that many adolescents engage in unprotected sexual intercourse and hardly use condoms even when they are aware that they are HIV positive. This nonchalant behaviour places them at risk of being re-infected with other strains of HIV and contracting injurious STIs. Perinatally infected children who are incognisant of their HIV status may unconsciously expose their partners to the risk of acquiring HIV during unprotected sexual intercourse. Kalembo et al. (2019) clarify that in most cases, adolescents casually engage in such practices because they are ill-informed about the intricacies of HIV; how to prevent it or how to maintain it. This highlights the need for education around issues of HIV and SRH (macro-system).

Global data suggests that only a fraction of children will have their first sexual experience before the age of 15 (STOPAIDS, 2016). UNICEF (2011) reports that a majority of young people become sexually active during late adolescence, hence the projection that between 30 and 50% of young girls will have had their first child before they reach the age of 19. Zgambo et al. (2018) elaborate that most pregnancies that occur during adolescence are unwanted and hardly ever intended. Early child bearing rises the risk for both the mother and her newborn baby. These risks range from a baby dying within the first weeks of birth or a baby being birthed as a stillborn. There is a risk of induced or spontaneous abortion, which may create complications, some of which may be fatal. There is also a likelihood that both the mother and her baby may be disabled following the birth process. Other risks include socio-economic disadvantages such as dropping out of school and being unable to provide for the baby due to poverty and unemployment (macro-system). Adolescents who fall pregnant while living with chronic illnesses such as HIV, are for these reasons at higher risk of morbidity and mortality.

Based on the aforementioned clause, it becomes ever more apparent that delayed disclosure of HIV status has the potential to repeat the cycle of HIV transmission, re-infection, and MTCT in pregnant adolescent girls. If adolescent girls do not know that they had already been infected with HIV before their sexual engagements, they will not even remotely think about accessing services such as SRH, prevention of mother-to-child transmission (PMTCT) and family planning. Delayed disclosure encumbers adolescents from accessing existing healthcare services and obtaining professional advice on life-changing health matters.

Concerningly, Close and Rigamonti (2006) state that adolescents who start using substances from an early age tend to use more substances as time progresses. Substances weaken the immune system and subsequently strengthen the virus; they make it difficult for the body to fight infection. In adolescents taking ART, when substances intersect with medication, they intensify their illness. As with ART, many substances are processed through the liver, hence a combination of ART and other substances may stay longer in the blood vessels spreading toxicity and chances of overdose. Therefore, informing children of their HIV status at an age-appropriate time, and educating them on the possible aftermaths of such behaviours (macro-system), may help guide them to wiser and safer life decisions.

2.3.1.3 Disaster risk reduction for children living with PHIV

The UNISDR (2017) defines disaster risk reduction as the practice of minimising the risks of disasters through organised efforts. These efforts aim to analyse and manage the causes of disasters by reducing people’s exposure to hazards and vulnerability. They aim to improve preparedness and mitigation strategies towards adverse events. Similarly, the South African Disaster Management Act (No. 57 of 2002) as amended in 2015, defines disaster risk reduction as either a policy goal, an objective or strategic measure employed for anticipating future disaster risk, reducing existing exposure, hazard or vulnerability, and improving resilience. Disaster risk reduction represents a child’s exo- and macro-systems. The systems are explained by Gal (2017) as layers or environments furthest to a child, that a child has little or no interaction with, but have the greatest influence on a child’s development. Therefore, the following guidelines and strategies (exo and macro-systems) have been put in place to influence a child’s micro and meso-systems:

Firstly, South Africa has adopted the UNAIDS 95-95-95 strategy which was formulated to end the HIV/AIDS pandemic by the year 2030. This strategy appeals for 95% of all people living with HIV to know their status, 95% of all people living with HIV to be initiated on treatment and the last 95% of people who have been initiated on treatment, to be virally suppressed by the end of 2030. In South Africa presently, a reported 84% of people know their status, 73% are initiated on treatment and 66% are virally suppressed. This simply shows that although there is noticeable progress, more intervention is needed to ensure that all children living with perinatal HIV also contribute towards the attainment of this goal by knowing their HIV status by 2030 (UNAIDS, 2020).

Secondly, the international HIV disclosure guidelines established by the WHO in 2011 and the NDOH in 2016, aim to assist children in knowing their status early on so that the prevalence of HIV/AIDS may be mitigated. They were compiled to provide HCWs with direction on how to gradually prepare primary caregivers and their children from a state of non-disclosure, to partial disclosure and ultimately full disclosure of HIV status at age 12. The guidelines suggest that gradual preparedness towards full disclosure helps improve a child’s overall well-being (physically, cognitively, emotionally and socially). Effective preparation further helps mitigate possibilities of uninformed, inadvertent disclosure that could result in detrimental effects on the child’s functioning (WHO, 2011; NDOH, 2016).

Furthermore, the NDOH aligns itself with the South African National Strategic Plan 2017–2022 which has four main objectives. They are: to address social and structural barriers to HIV, STI and tuberculosis prevention, care and impact; to prevent new HIV, STI and tuberculosis infections; to sustain health and wellness; and to increase the protection of human rights and improving access to justice. The National Strategic Plan stipulates that to manage the HIV/AIDS pandemic effectively, psychosocial care and support must be given to affected populations, particularly vulnerable populations such as women and children (South African National Aids Council [SANAC], 2017).

Lastly, the DSD, as the main custodian responsible for providing social services to vulnerable children, youth and societies in need, has in 2019 developed HIV testing services guidelines which comply with the NDOH child and adolescent disclosure guidelines of 2016. The social service sector in collaboration with other relevant sectors such as the South African DOH, aims to enhance access to HIV testing, adherence to ART and psychosocial support for beneficiaries in need of such services. There has been very little support provided to its beneficiaries because of unclear guidelines for social service providers, which has compromised effective service delivery to orphans and vulnerable children infected and affected by HIV. These guidelines therefore aim to create an enabling atmosphere for orphans and vulnerable children and their families so that they may be able to grow holistically, with fewer circumstances inhibiting them from realising their greatest potential (DSD, 2019).

The abovementioned guidelines and strategies form part of children's exo and macro-systems and can be beneficial to their psychosocial functioning and significantly improve the rates of disclosure in South Africa when implemented appropriately. Practically, the WHO (2011) affirms that disclosure conducted at the recommended age of 12 is more beneficial to a child's well-being (micro-system) than delayed disclosure. Kalembo et al. (2019) in consonance with Battles and Wiener (2002), provide that it is normal and expected for children to experience feelings of shock, sadness and despair following the disclosure of their HIV status, however, if they are informed at the recommended age and appropriate time, these feelings are often short-lived. Children are better able to seek supplementary support (meso-system) and take charge of their health when they are included in matters concerning their well-being.

The WHO (2011) states that there is substantial evidence that children who are made cognisant of their status around the age of 12, transition and adjust more easily to adolescent and adult roles because they were allowed to cultivate adaptive coping strategies. Kalembo et al. (2019) moreover explain that when children are younger, they are more resilient and accepting to change than when they are much older. Therefore, through the gradual process of disclosure, children can be motivated to adhere to their ART medication as prescribed, which will lead to them enjoying a healthy lifestyle and ultimately experience a bountiful and prosperous future.

2.3.1.4 Coping capacity to reduce the prevalence of delayed disclosure

The UNISDR (2017) defines coping capacity as the ability that people, organisations or systems have, using existing resources and skills to manage and overcome harmful conditions or disasters. Coping capacity requires resources, good management and continued awareness in both normal and adverse situations. Coping capacity reflects a child's micro, meso and exo-systems, and plays an important role in disaster risk reduction. The UNISDR (2017) moreover describes capacity as a blend of resources and strengths available within a household, organisation, community or society. An amalgamation of these strengths and resources may be used to accomplish agreed-upon goals. Capacity enables people to prevent, prepare for, mitigate, cope with, endure or speedily recover from the impact of a disaster. Capacity may include among others, physical means, collective coping abilities, social relationships, human knowledge and skills.

The NDOH (2016) highlights that because disclosure is an ongoing process that escalates gradually and not once-off, it ought to be provided taking into consideration all applicable guidelines (macro-system), in multiple settings. These settings include healthcare facilities such as clinics and hospitals, the South African DSD, the South African Department of Education, non-government organisations (NGOs) and community based organisations possessing appropriate skills and support (meso and exo-system). Inter-sectoral participation is fundamental to ensuring comprehensive support and service delivery to recipients.

McHugh et al. (2018) explain that successful disclosure requires the capacitation of both HCWs and primary caregivers with knowledge and skills on HIV/AIDS so that they may be able to provide holistic support to children concerned. As indicated in previous and recent research, many HCWs have limited skills to support primary caregivers on matters concerning HIV diagnosis and the disclosure thereof. There is also a shortage of manpower at clinics, which often limits the time required to render effective disclosure services to children and their primary caregivers. Kiwanuka et al. (2014) explain that many primary caregivers do not possess the capacity required to respond to the probable questions that their children could potentially ask once they discover their HIV status, hence the high prevalence of delayed disclosure in sub-Saharan Africa. Madiba and Mokgatle (2015) express that this is due to a lack of training and support on relevant guidelines offered to HCWs. Therefore, to enhance the capacity needed for disclosure, all relevant sectors should receive prioritised training (meso and exo-systems).

Notwithstanding the paucity of resources, there are often a selected few HCWs who get an opportunity to attend training (Madiba and Diko, 2021). Trained HCWs can for example provide in-service training to their colleagues who may have not had the opportunity to attend external training. This will maximise existing skills, consequently reaching more children and families in need of disclosure services (micro and meso-systems). It will also enhance referral and linkage systems amongst applicable stakeholders (NDOH, 2016).

Many government healthcare facilities are immensely busy and HCWs hardly find time to provide comprehensive disclosure and counselling services to patients infected and affected by HIV. This proves the need and significance of inter-sectoral collaboration (exo and macro-sysyems). The South African DOH (2016) enlightens that healthcare facilities should first undertake the process of case finding on their data systems before disclosure could take place. This involves finding HIV infected primary caregivers that have not brought in their children for testing, primary caregivers that are apprehensive about disclosing to their children, as well as children who are in receipt of ART but have not yet been informed.

These groups of people can also be found in the social system (communities). Following these findings, children and primary caregivers can be prepared for disclosure (micro and meso-systems).

The DSD designates social workers and social auxiliary workers across many communities in South Africa to offer social services and psychosocial support to vulnerable populaces (DSD, 2019). Mmakau village has area social workers designated to offer such services (meso-system). Therefore, in cases where children and their primary caregivers may require extensive counselling that may be beyond the capacity of some HCWs, such patients or beneficiaries may be referred to the DSD for further intervention, a practice that still needs to be honed, as there is still a gap in implementation.

Amzel et al. (2013) impart that when children have been disclosed to, such children can be referred to support groups within their communities. Zgambo et al. (2018) edify that peer support groups can assist children living with HIV to discover ways in which they can coexist with their health condition, adhere to ART medication, become resilient and understand that other children living with HIV experience similar challenges. Mmakau village has an NGO that offers such services to children, adolescents and their primary caregivers (meso-system). If the practice of child disclosure was to be amplified, more children would know of this establishment and therefore access its services to maximise its full potential.

Madiba and Mokgatle (2015) express that given that a wide range of children are scholars who attend school, educators can also play an indispensable role in ensuring that health education, particularly HIV/AIDS, is provided at school during suitable class periods. Such education can aid in providing children with factual knowledge, in so doing, dispel myths and fabrications surrounding the HIV/AIDS pandemic. McHugh et al. (2018) complement that schools can also be utilised as platforms to communicate pivotal information and messages regarding the prevention of maintenance of HIV (meso-system). This is particularly beneficial for children and adolescents who may not have a primary caregiver to share and discuss information concerning HIV/AIDS. As such, educators also play an essential role in influencing children and adolescents' health behaviour.

Lastly, Close and Rigamonti (2006) construe that stigma can be mitigated through support, awareness and education. Families, along with communities, should be educated and supported to curb the prevalence of HIV. Platforms such as clinics, hospitals, community halls and schools may be utilised to provide basic education on HIV/AIDS and its numerous modes of transmission (meso and exo- systems). Such attempts can reduce untrue myths, false rumours and stigma. Education can replace fear and ignorance with certainty, which will result in people learning to normalise, cope with and adjust to the HIV/AIDS pandemic.

2.3.1.5 Acclaiming the Ecological model

The Ecological model is the most suitable model for this research study as it can show the connection between behavioural and environmental changes (Feldacker et al., 2011). It can demonstrate the interaction between people and their biophysical environments and the contribution that these interactions make towards the HIV/AIDS pandemic. The model moreover provides a detailed and holistic illustration of how different socio-economic factors influence a person’s overall health and wellness (Mburu et al., 2014). It can also be adapted into disaster management to exemplify the risks and potential risks that delayed disclosure of HIV status can inflict on children living with perinatally acquired HIV.

2.4 Chapter summary

This chapter integrated the PAR model and the Ecological model. The PAR model was outlined to illustrate how delayed disclosure of HIV can breed vulnerability in children and adolescents living with PHIV. The Ecological model was employed as the main theoretical framework for the research study and was used to demonstrate how delayed disclosure can negatively affect the psychosocial functioning of children and adolescents living with PHIV within their various systems (micro, meso, exo and macro). The next chapter provides a detailed discussion of various international and national legislative acts and frameworks pertinent to HIV child disclosure in South Africa.

Chapter 3
LEGISLATIVE ACTS AND FRAMEWORKS RELATED TO CHILDREN LIVING WITH HIV

3.1 Introduction

This chapter presents legislative acts and frameworks relevant to children living with HIV. The chapter first discusses international legislation, followed by national legislation. The chapter reinforces children's rights to early disclosure and knowledge of their own HIV status. It also underpins children's rights to participation in matters concerning their health and general well-being.

3.2 International legislation and frameworks

3.2.1 The International Guidelines on HIV/AIDS and Human Rights, 1996

The International Guidelines on HIV/AIDS and Human Rights were adopted in 1996. They came as a request from the Commission on Human Rights, which highlighted the importance of providing governments with guidance and steps on how to safeguard the rights of people living with HIV. As the HIV/AIDS pandemic progressed, it became apparent that by protecting the human rights of people living with HIV, suffering reduces, lives are saved, public health is protected, and response to HIV is enhanced. Guideline 6 recommends that people must have access to prevention, treatment, care and support. To achieve this, governments must ensure that there are guidelines in place to support people living with HIV. Governments must also develop measures to observe and improve the availability and implementation of these guidelines (OHCHR, 2006).

Guideline 8 caters for women, children and other vulnerable groups. This guideline maintains that governments must ensure that children and adolescents have access to information and education regarding HIV prevention, care and overall health. This information must be tailored in an appropriate way to consider their age and capacity, and must enable them to take responsibility for their sexuality. The information must also take into cognisance the rights of the child to gain access to information, privacy, confidentiality and respect. The information must also provide clarity on informed consent, ways of prevention, as well as the rights, responsibilities and duties of parents. Children living with HIV should be educated about their rights. Governments must ensure that persons employed in childcare organisations receive ample training on issues related to children living with HIV so that they may be able to deal decisively with the needs of HIV infected and affected children (OHCHR, 2006).

3.2.2 The United Nations Convention on Rights of the Child and the African Charter on the Rights and Welfare of the Child

Section 39(2) of the South African Constitution stipulates that courts, tribunals and forums must consider international law when interpreting the South African Constitution. The United Nations Convention on the Rights of the Child (UNCRC) is recognised as the most vital international convention dealing directly with children's rights to healthcare services. Likewise, the African Charter on the Rights and Welfare of the Child embodies the same rights as the UNCRC. The South African government ratified both these conventions in the mid-1990s (Budlender et al., 2008). These conventions uphold that the best interests of a child should be of primary importance in all actions involving a child. They emphasise that no child may be deprived of the opportunity to receive quality medical care and that each child must enjoy a state of spiritual, mental and physical health. Consequently, the conventions apprise that children, who are age-appropriate and have the maturity to formulate their own views regarding their health, may not be prohibited to do so. Furthermore, all sectors of society should ensure that primary caregivers and the children in their care receive basic knowledge and education regarding the health and well-being of children (UNICEF, 1989).

3.2.3 Millennium Development Goals and Sustainable Development Goals

According to Sahn and Stifel (2003), the Millennium Development Goals were established in 2000 during the United Nations Millennium Declaration; eight goals were developed. With relevance to this study, Goal 6 had two commitments: to ensure that all persons living with HIV had access to treatment by 2010 and to halt and overturn the spread of HIV/AIDS by 2015. Prendergast et al. (2015) highlight that the intent of this goal was not achieved, hence the introduction of its successors, the Sustainable Development Goals in 2016. The Sustainable Development Goals are 17 international goals that promote fair and sustainable health for all persons, at all levels (Morton et al., 2017). Goal 3 aims to eradicate pandemics such as HIV/AIDS, tuberculosis and malaria by 2030. It also advocates for people to obtain appropriate information and education on HIV/AIDS and access to services such as SRH and family planning. It strives for integration of reproductive health into national strategies and programmes (WHO, 2020).

3.2.4 The Hyogo Framework and Sendai Framework

The Sendai Framework for Disaster Risk Reduction 2015–2030 follows on the Hyogo Framework for Action 2005–2015. The Hyogo Framework for Action aimed to reduce disaster risk and vulnerability to natural hazards and to build resilience to cope better following the occurrence of hazards (UNISDR, 2005). According to the UNSDR (2015), the Sendai Framework builds on the work done in HFA and emphasises that focus should not only be on natural hazards but also on man-made hazards and other related environmental, biological and technological hazards and risks. It also aims to reduce disaster risk in health. It calls governments to include people living with HIV in plans and policies so that they can manage their risks before, during and after a disaster. The framework emphasises that governments must strengthen policies regarding access to basic healthcare services such as child health and SRH amongst people disproportionately affected by disasters. It moreover calls for an integration of disaster management in primary, secondary and tertiary healthcare sectors. It encourages for HCWs to be trained and capacitated in disaster risk reduction approaches so that they may be able to provide informed mental health and psychosocial support services to individuals in need, and form collaboration with other vital sectors (UNISDR, 2015).

3.3 South African legislation and frameworks

South Africa is legally obligated and committed to adhere to all national and international frameworks established in respect of children living with HIV (NDOH, 2016).

3.3.1 The South African Constitution, Act 108 of 1996

The Constitution of the Republic of South Africa, Act (No. 108 of 1996) is the highest law of the country; all other legislative frameworks in the country are anchored onto it. Any bylaw or conduct contrary to the Constitution is deemed invalid. The Constitution serves as the groundwork for an autonomous South Africa, one that is free from repression and discrimination. The Bill of Rights, as enshrined in the Constitution, is the cornerstone of democracy and makes provision for human rights. In particular, section 28 of the Act emphasises the rights of children. The South African government holds the best interests of children in high regard, thus all decisions taken in respect of a child have to be delicately and lawfully considered (Budlender et al., 2008).

Section 28 of the Constitution stipulates that every child has the right to parental, family or alternative care when removed from their family environment. Secondly, a child has the right to basic healthcare services as well as social services. Section 32 of the Act specifies that everyone has the constitutional right to access information held by the government or by another person and that is required for the protection or exercise of that right.

Child disclosure has an impact on the rights of children. By delaying disclosure to a child living with PHIV, the rights of such a child become restricted rather than upheld. Children can form and articulate their own views when they reach the age of maturity, which allows them to receive appropriate information. Early disclosure helps to empower a child with decision-making skills and vital information regarding self-care and prevention of possible transmission. Delayed disclosure denies a child the opportunity to access these resources (NDOH, 2016; DSD, 2019).

3.3.2 The South African Children’s Act 38 of 2005 as amended

The South African Children’s Act (No. 38 of 2005) as amended, functions as the foundation for childcare and protection. It gives effect to the rights of children to social services, parental care, family care and appropriate alternative care. The Act also aims to protect children from neglect, maltreatment, abuse and degradation (Budlender et al., 2008). The DSD (2019) mandates all persons working with children to use the South African Children’s Act as a point of reference, especially during times of uncertainty about their role.

Nkomo et al. (2018) in agreement with Budlender et al. (2008), articulate that HIV/AIDS is one of the leading drivers of children needing services. The effects of HIV/AIDS have fragmented and shattered many families across South Africa. The epidemic has left multitudes of perinatally infected children orphaned. Following the death of their biological parent(s), most children living with HIV are vulnerable and as such, placed in alternative care such as foster care or children’s homes in terms of Section 150 of the Act. This is to preserve the child’s well-being. This transition, however, often proves difficult for new primary caregivers who face the daunting task of having to disclose their HIV status.

Moreover, section 7 of the Children’s Act, emphasises that the best interests of the child are of utmost importance in every matter concerning the child. The Act provides that when working with children, certain factors have to be deliberated. With specific reference to child disclosure, the Act elucidates that factors such as the nature of the personal relationship between children and their primary caregivers ought to be considered before taking the decision to disclose. The attitude of the primary caregiver and the child’s emotional and intellectual needs also have to be considered. The likely effect of disclosure on the child should there be a change in his or her circumstance, must be carefully considered. The age, maturity and developmental stage of the child must also be observed. The child’s intellectual, social, emotional and cultural developments are also noteworthy considerations to enable effective disclosure. Likewise, Naeem-Sheik and Gray (2005) enlighten that before undertaking the process of disclosure, the needs of the child and those of the primary caregiver and family at large, have to be taken into account. Forcing the process of disclosure before the family is ready may have negative effects on the psychosocial well-being of the child concerned. Disclosure must also be age-appropriate and further guided by appropriate tools that enable child participation.

Section 10 of the Children's Act expounds that children that are of age, maturity and appropriate stage of development may participate in any matter concerning their life and overall well-being; the children's views must be considered. Section 11 of the Act further explains that consideration must be given to children with chronic illnesses. They must be permitted to take part in cultural, religious, educational and social activities. A child's dignity must be upheld at all times and self-reliance must be fostered. Children should also receive access to support services. Budlender et al. (2008) add that the Act affords all children, irrespective of age, the right to access information, including information on sexuality and reproduction. The Act recognises each child as unique, with the capacity to evolve; hence children aged 12 and of sufficient maturity, are permitted to consent to medical treatment and surgical operations. As such, age-appropriate disclosure of HIV status to children is fundamental in helping them make independent and informed choices.

Notwithstanding the importance and beneficence of child disclosure, certain legal sanctions have to be adhered to, to avoid the occurrence of uninformed, accidental or inadvertent disclosure for example. Section 133 of the Children's Act states that children have the right to confidentiality of information regarding their HIV status. The DSD (2019) encourages HCWs working with children living with HIV, to refer to this section. The Act provides that no person may disclose a child's HIV status without consent. Consent for disclosure of HIV status may be given by the child if he or she is 12 years and older or if the child is under the age of 12 but is of sufficient maturity to understand the benefits, risks and social implications of such disclosure.

Furthermore, the same section of the Act states that the following persons may give consent to disclose the status of the child to a third party if a child is under the age of 12 and not of sufficient maturity to understand the complexities of HIV disclosure: the parent or caregiver of the child, a designated child protection organisation responsible for the placement of the child in alternative care, the superintendent or person in charge of a hospital if the child has no parent or caregiver. The children's court may also consent on behalf of the child if the status of the child is unreasonably withheld and if the child, parent or caregiver of the child are incapable of giving consent (South Africa, 2005a). The NDOH (2016) states that a healthcare team can also disclose the status of the child to each other to provide the best possible healthcare to the child concerned. Chibango (2013) highlights that section 133 of the Act is of great significance as it guides HCWs, persons working with children and the general public about the protection of children's rights, as failure to do so will result in unfavourable consequences.

3.3.3 The National Health Act 61 of 2003

According to section 1 of the National Health Act (No. 61 of 2003), a parent, guardian or any other person ratified by the law, may consent to receive medication on behalf of a child who is below the age of 12 and is not of maturity to give consent. Section 6 of the Act provides that consent should be informed, meaning that the person must be provided with complete knowledge and information concerning the variety of issues related to the health service sought. Furthermore, section 8 of the Act states that children have the right to participate and contribute in the decisions affecting their personal health or treatment, and if such children have the capacity to comprehend, then they must be informed despite not being able to give legal consent. Section 14 of the Act states that consent to disclose the HIV status of a child must be in writing (Hassim et al. 2008). Mahery (2006) articulates that in this way, the National Health Act (No. 61 of 2003) makes it an obligation for HCWs to explain to a child's primary caregiver (if the child is below the age needed for consent) and a child 12 years and older, to consent about the required health care service, treatment options and consequences of the choices made.

3.3.4 The South African Disaster Management Act 57 of 2002 as amended in Act 16 of 2015

Burger and Brynard (2001) categorise HIV/AIDS as a slow-onset disaster that contains all elements required to constitute a disaster. The scholars voice that if left untreated, HIV can progressively weaken a person's immune system by exposing it to opportunistic infections that lead to full-blown AIDS which then results in death. Consequently, the South African Disaster Management Act (No. 57 of 2002) as amended in 2015, specifies that a disaster must be managed to reduce its risk and negative effects.

Disaster management as defined by this Act is an ongoing process comprising of multidisciplinary and multi-sectoral teams. Effective disaster management requires that there be cohesive and well-coordinated disaster management policies and strategies that focus on preventing, reducing and mitigating the severity of disasters. The Act calls for effective preparedness, rapid response, rehabilitation and recovery following a disaster (South Africa, 2002). Similarly, the DSD (2019), consistent with the NDOH (2016), express that due to the high numbers of children living with HIV in South Africa, proactive participation is required from all stakeholders. The impact that HIV can have on a child's holistic development is quite significant. It is therefore paramount that effective mitigation strategies aimed at bettering the psychosocial functioning of children and their significant others are developed and implemented.

3.3.5 The South African National Disaster Management Framework, 2005

The South African National Disaster Management Framework (NDMF) (South Africa 2005b), is a lawful framework that has been endorsed by the South African Disaster Management Act (No. 57 of 2002) to recognise various risks and disasters taking place in South Africa. The framework makes provision for several measures that aim to lessen vulnerability in areas and communities likely to experience disasters. The framework consists of four key performance areas and three enablers essential to the achievement of the objectives set out in the key performance areas (South Africa, 2005b). For this research, Enablers 1 and 2 are fundamental to addressing the questions and objectives outlined in the research study.

Enabler 1 expresses that disaster management is a collaborative process. For the process to be successful there must be collaboration in all spheres of government, including NGOs, private sectors, communities and all other partners accountable for capacity building. There should also be an integrated communication link and information management system between all role-players involved in disaster management. Effective disaster management requires all role players to possess appropriate skills to manage risks continuously and to effectively envisage, prepare for, respond to and monitor different kinds of hazards (South Africa, 2005b).

Enabler 2 appeals for all role players and officials from sectors and disciplines involved in disaster management to be trained on programmes aimed at reducing and managing disaster risk. Such training may include workshops, in-service training, modular courses, short courses and so forth. This training is imperative to enhancing service delivery and must be undertaken so that role players may adopt a risk-avoidant culture. Training on pivotal aspects such as national guidelines, policies and programmes related to disaster risk, enables role-players to further cascade and impart knowledge to the public through well-versed awareness programmes (South Africa, 2005b).

With the above legislative acts and frameworks, it can be noted that the best interests of children living with HIV are at the heart of policies and guidelines developed both nationally and internationally. The legislative frameworks unanimously point out children's rights to obtaining age-appropriate information and education on HIV/AIDS, and how such provision will enable them to access available health care services and participate in all matters pertaining to their overall health and wellness on time. The frameworks also reiterate the importance of training all relevant role-players on policies and guidelines aimed at reducing disaster risk in the HIV/AIDS pandemic. They further encourage stakeholder participation so that the abovementioned children's rights may be realised.

3.4 Chapter summary

This chapter expressed in detail, various international and national legislative frameworks pertinent to children living with HIV. The chapter first discussed international guidelines on HIV/AIDS as well as the rights of children as per the UNCRC and the African Charter on the Rights and Welfare of the Child. Secondly, an outline of the Millennium and Sustainable Development Goals was provided. The chapter moreover underlined the Hyogo Framework for Action and the Sendai Framework for Disaster Risk Reduction. The South African Constitution, Children's Act, National Health Act, Disaster Management Act and National Disaster Management Framework were also discussed.

The next chapter focuses on the literature review. The chapter provides an in-depth explanation of the concept of child disclosure. It explores the types of child disclosure, the various levels of child disclosure, factors inhibiting timeous child disclosure, and factors promoting child disclosure. The chapter also explores what other scholars have discovered about child disclosure. The exploration hereof is imperative because it allows identification of gaps in the literature, which can be supplemented with empirical research.

Chapter 4
LITERATURE REVIEW

4.1 Introduction

The purpose of this chapter is to present a literature review in respect of the undertaken study. According to Creswell and Poth (2018), a literature review is an essential summary of a research topic and serves as the basis for a research study. It is often compiled to contextualise the research problem and outline existing evidence. Saunders et al. 2019) augment that a literature review aims to give the reader a clear picture of what is known and unknown about the presented research problem. It seeks to recognise gaps in research through the provision of scholarly reviews related to the topic on an international, regional and local scale.

This literature review provides a brief historical background of HIV/AIDS in the context of MTCT. It describes in detail, the concept of child disclosure, the types of child disclosure and the different levels thereof. Clarity on whose responsibility it is to disclose to children living with PHIV is provided. The literature review also explores scholarly findings on factors encouraging and discouraging primary caregivers and HCWs to disclose the HIV status of perinatally infected children at an age-appropriate time. Furthermore, a comparative analysis is drawn on reactions and experiences of children and adolescents after having experienced either early or delayed disclosure of their HIV status. The importance of psychosocial support post-disclosure, is delineated. The chapter moreover illustrates the relationship between disclosure (early and delayed) and risky behaviours among children and adolescents living with PHIV. Gaps identified in the existing literature on the prevalence of child disclosure both internationally and nationally, are accentuated.

4.2 The evolution of mother-to-child transmission

According to Barnett and Whiteside (2002), HIV/AIDS is one of the most severe pandemics in human history due to its rapid spread and magnitude of its impact. It is the first global pandemic to which the world became universally conscious. Hernes (2011) divulges that once a human being is infected, HIV conceals and reproduces itself in the body’s defence cells. If left untreated, it exposes the body to numerous opportunistic infections and ultimately death. Kassa (2018) articulates that despite many research studies denoting unprotected sexual intercourse as the main mode of HIV transmission, MTCT is also one of the most prevalent modes of HIV transmission in the world. According to AVERT (2016), almost all young children living with HIV have acquired the infection through MTCT. Mutabazi et al. (2017) explain that MTCT is particularly prevalent in children below the age of 15 years. Globally, there are currently more than 2 million children living with HIV/AIDS, 80% of which reside in sub-Saharan African countries, with 15% of them located in South Africa.

Flynn et al. (2020) in accordance with Mofenson (2010) profess that MTCT of HIV occurs during pregnancy (in utero), at labour (intrapartum) and postnatally through breastfeeding. During pregnancy, HIV transmission primarily occurs when the virus comes into direct contact with the foetus in the genital tract. During labour and delivery, HIV transmission occurs when an infant’s mucous membrane interacts with the virus in the blood and excretions during childbirth. Vitally, Odiachi (2017) and Flynn et al. (2020) enlighten that breastfeeding is the leading cause of MTCT among the aforementioned modes of transmission. About 60% of new infections occur during breastfeeding because of mothers’ poor adherence to ART following the birth of their children. Many women living with HIV continue to breastfeed their children even when their viral load is detectable and unsuppressed. In addition, MTCT is further proliferated by HIV infected women who breastfeed their children while having sores or cuts around their nipples.

Nyandat and Van Rensburg (2017) accentuate that women who take their ART medication whilst breastfeeding reduce the risk of MTCT to less than 5%. The risk of MTCT among women who are not breastfeeding and not on ART ranges between 15 and 30% while the risk among women who are breastfeeding and not on ART ranges between 20 and 45%. Without ART medication, a third of children who acquire HIV through MTCT will not live to see their first birthday, half of them will not even reach their second birthday (AVERT, 2016).

Moreover, West et al. (2019) alert that another detrimental factor contributing towards MTCT is mixed feeding, which is the leading type of breastfeeding in sub-Saharan Africa. Mixed feeding involves a child being fed both breastmilk and other forms of ingestible substances such as water, formula and non-human milk before the age of six months. In 2007, the South African infant feeding guidelines discouraged mixed feeding a child in the first six months due to its high risk of transmission. Mixing breastmilk with other fluids or foods can harm a child’s already fragile and permeable gut wall, allowing the virus to be easily transmissible to the child. In 2010, the WHO made a recommendation for all HIV positive mothers to exclusively breastfeed their children within the first six months of their upbringing whilst adhering to ART. It is only after these first six months that complementary foods may be introduced, with breastfeeding continuing for up to twenty-four months. Flynn et al. (2020) explain that this was recommended because exclusive breastfeeding not only affords children nutritional and life-preserving health benefits such as reduced infant infections and mortalities, but also aids in enhancing neurodevelopment and lowering the risk of HIV transmission. Despite this recommendation, most mothers living with HIV in sub-Saharan Africa still subject their children to mixed feeding within the first six months of their existence, further intensifying the prevalence of MTCT.

According to Nabwera et al. (2017), multiple factors contribute towards women opting to mixed feed, particularly in low resource settings. To name a few, poverty, stigma, family structures and a lack of autonomy due to socio-cultural customs, all play a critical role in infant feeding. Similarly, West et al. (2019) state that the key barriers to exclusive breastfeeding include socio-economic factors such as employment, unemployment, familial and societal pressure, fear of vertical HIV transmission to the child and fear of inadvertent disclosure of own HIV status should people ask why they exclusively breastfeed.

West et al. (2019) in concurrence with Nabwera et al. (2017) further express that even though HCWs inform and counsel women about the perils of mixed feeding and benefits of exclusive breastfeeding, some still resort to mixed feeding because of family and cultural influence. For example, some women may initially be motivated to exclusively breastfeed, but subsequently find themselves compelled to mixed feed because extended family members such as mothers-in-law, aunts and grandmothers view exclusive breastfeeding as an injustice towards the child and a taboo towards traditional upbringing. Other extended family members even go as far as belittling mothers' parenting capabilities. Some women are primary breadwinners in their homes and are therefore obligated to work or seek employment. Due to this obligation, they struggle to keep up with exclusive breastfeeding as they have to leave their child(ren) with family members or significant others while they fend for their families. Consequently, persons who stay at home with the child(ren) in the mothers' absence, introduce them to various kinds of ingestible foods before the age of six months, hindering the progress made. Financial constraints and dietary factors impede exclusive feeding. Våga et al. (2014) state that even though some women may like to exclusively breastfeed their babies, they are incapable of doing so because they perceive their nutritional intake as insufficient to enhance the quantity and quality of their breastmilk. This observation demonstrates that cultural and socio-economic considerations can at times overwhelm stated intentions.

That said, the UNAIDS (2011) provides that since the inception of prevention of mother-to-child transmission (PMTCT) programmes in the early 1990s, the administration of ART has led to a substantial reduction in MTCT of HIV to newly born children. Notwithstanding these developments, records illustrate that in 2009, approximately 370 000 children were newly infected with HIV on a global scale. In the same year, an estimated 42 000 to 60 000 HIV infected women died from HIV infection and its various complications. Following these deaths, as of 2010, more than 90% of countries with high MTCT and high paediatric HIV infection were found in sub-Saharan Africa (UNAIDS, 2011). In 2011, UNAIDS established a Global Plan, focusing on the eradication of MTCT and keeping mothers alive. This contributed substantively to identifying and implementing interventions for PMTCT. Since the implementation of the UNAIDS Global Plan in 2011, the number of new HIV infections in children has decreased by 60% (UNAIDS, 2016).

Albeit the above-mentioned milestones of PMTCT, the UNAIDS (2016) unearths that in 2013, only 49% of HIV infected women continued taking their ART medication during breastfeeding compared to 62% of women who took their ART medication during pregnancy and at labour. In 2015, MTCT rates increased from 4.9% at six weeks to 8.9% at the end of breastfeeding. The UNAIDS (2016) further explains that women living with HIV are advised to give birth at a health facility and register their babies for care soon after delivery. They can do so at clinics or the nearest health facilities providing PMTCT. During the postnatal period, women are encouraged to attend the clinic with their babies at 7 days, at 6 weeks, at 10 weeks, at 14 weeks, at 6 months, at 9 months, at 12 months and again at 18 months whilst adhering to ART. Infants born to women living with HIV are tested for HIV at six weeks of age. In the face of these efforts, however, Nabwera et al. (2017) found that more than 65% of mothers living with HIV in rural Kenya do not complete the 18-month follow-up period, while approximately 43% drop out within the first two months of enrolment. Likewise, West et al. (2019) amplify that most women living with HIV in South Africa, default on their ART medication and remain virologically unsuppressed whilst breastfeeding. Clinic tracers and data capturers attempt to contact, trace and ascertain that women living with HIV receive messages regarding adherence, but at times fall short because once their babies are born, most women tend to minimise or lose their contact with public health facilities, making it even more difficult for HCWs to trace them. Some migrate to different locations or countries, while others provide incorrect contact details and physical addresses so that their whereabouts remain discreet and unknown. It then becomes increasingly challenging for HCWs to resupply these women with ART medication.

The WHO (2015a) states that it is of utmost importance for babies to be re-tested for HIV when they stop breastfeeding. Public health facilities offer this programme and encourage all mothers living with HIV to comply; however most mothers do not follow-up and do not bring their babies to the facilities to undergo this test as recommended. This reinforces the crucial need to educate and re-educate women living with HIV about the importance of ART continuation even after the birth of their children. Further education ought to be provided on the importance of exclusive breastfeeding to mitigate the harmful practice of mixed feeding (Sibanda et al., 2013; Rawizza et al., 2015; Myer et al., 2017).

In 2015, the WHO recommended for all women living with HIV to be initiated on lifelong ART irrespective of their CD4 cell count (an indicator of the level of HIV in one's body), which was inclusive of pregnant and breastfeeding women (WHO, 2015a). They launched this initiative in Malawi and referred to it as Option B+. Countries with a high burden of HIV such as South Africa subsequently adopted it. South Africa rolled out Option B+ in 2015 and saw that 91% of 1.1 million women receive ART, reducing viral load counts and dropping new infection rates in children by 60%. Approximately 150 000 new HIV infections occurred in 2015, which is a significant improvement from the 2009 statistic of 330 000 new infections. This enactment showed that when the virus is suppressed to an undetectable level, the onward transmission of HIV is highly unlikely in both the breastfeeding and post-breastfeeding phase (UNAIDS, 2016). The UNICEF (2016) contends that despite this feat, the number of new childhood infections is still high considering that PMTCT interventions are universally available.

The UNAIDS (2016) in concord with Chi et al. (2013) state that the path to combatting the HIV/AIDS pandemic remains a challenge in child and maternal services in sub-Saharan Africa; this is mainly due to limited health infrastructure and a high disease burden. Quite recently, the WHO (2019) discovered that approximately 160 000 new child infections were reported in Africa in 2018. Of the 160 000 newly infected children, 86% of them were situated in sub-Saharan Africa. Flynn et al. (2020) state that high-income countries, unlike low- and middle-income countries such as South Africa, have widespread access to interventions aimed at PMTCT. As such, these countries are better able to reduce the risk of MTCT to less than 1%. In the same light, the WHO (2019) signposts that high-income countries record almost zero new child HIV infections as well as maternal and child mortalities. On the contrary, most low- and middle-income countries, especially those in sub-Saharan Africa, record substantial numbers of new infections. This is because relatively few women and children have access to HIV prevention and treatment services.

To be precise, the WHO (2019) proclaims that globally, about 1.3 million pregnant women living with HIV needed PMTCT in 2018. Of the 1.3 million women, only 82% received ART medication to prevent MTCT of HIV. Coverage of ART among pregnant women living with HIV differs considerably across regions. In 2018, coverage of ART was estimated to be above 90% in the European regions, followed by 85% in the African regions and 68% in the Western Pacific regions. All other regions were relatively lower; inter alia, the South-East

Asia region had an ART coverage of 55% while the Eastern Mediterranean region only had 18% ART coverage. Prudden et al. (2017) state that access and adherence to lifelong ART can only be improved if there is an expansion of PMTCT services and ART treatment support programmes. Amongst others, psychosocial support services aimed at reducing stigma and rates of non-disclosure of HIV status among perinatally infected children are of fundamental importance to ensuring adherence to ART and improved well-being among children living with PHIV.

Odiachi (2017) in conjunction with Prudden et al. (2017) condition that MTCT does not only create physical health challenges, it also yields many other psychosocial challenges. In particular, having to disclose the HIV status of children born through MTCT has become a global concern, especially in sub-Saharan African countries such as South Africa. Multitudes of children across the globe are now living longer due to ART. Their improved survival has led to many primary caregivers and HCWs delaying the process of disclosure as they often feel overwhelmed and perplexed about how or when to inform them. This confusion is especially evident when most of these children transcend into the adolescence stage without knowledge of their HIV status. Research studies uncovered that unawareness of HIV status in perinatally infected children leads to a profusion of psychosocial problems for both these children and their significant others. As such, more intervention is needed to understand the concept of HIV child disclosure and its importance in the care and management of HIV/AIDS.

4.3 Defining child disclosure of HIV status

The Committee on Pediatric AIDS (1999) describe child disclosure as an incremental process of informing children of their HIV status. It commences with partial disclosure in younger children and subsequently leads to full disclosure in older children. Partial disclosure is a process that involves providing children with information that is consistent with HIV, without specifying or mentioning HIV. Full disclosure occurs when children are thoroughly informed of their HIV status. Full disclosure ought to be followed up with continuous education and support. This support includes informing children about how they acquired the infection as well as the nature of HIV and the significance of ART medication. Full disclosure ought to take place before the adolescence stage when children start managing their health care and are likely to engage in risky sexual behaviours.

Similarly, the WHO (2011) in its guidelines, describe child disclosure as a continual process of informing perinatally infected children of their HIV positive status. The guidelines describe that child disclosure is not a once-off event, but rather a gradual procedure that ensures at all times that the emotional and cognitive maturity of children is taken into consideration. This consideration provides children and their primary caregivers with enough time to slowly accept and adjust to the illness and the challenges it begets. The guidelines further endorse that children must be told of their HIV status by school-going age, which is between six and twelve years. Children younger than twelve years must be informed of their status partially to accommodate their cognitive skills and emotional maturity; this is done to prepare children for full disclosure once they reach the age of twelve (WHO, 2011).

Equally, the NDOH (2016) describes child disclosure as a process wherein children obtain knowledge of their HIV positive status and or the HIV positive status of their primary caregivers. It is an ongoing process that provides children with age-appropriate information about their illness and leads to full disclosure when children have the emotional and cognitive maturity to process and fully comprehend the information. Fundamentally, the DSD (2019) informs that child disclosure is a process comprising of multiple person-centred conversations over a period. It is progressive in nature and necessitates continuous psychosocial support to those affected.

4.4 Levels of child disclosure and appropriate timing

The NDOH (2016) consistent with the WHO (2011), acknowledge disclosure as an unremitting process that assumes five levels. The time frame of these levels should be in alignment with the age and maturity of children and they are as follows:

4.4.1 Level 1: Non-disclosure

At this level, children are unaware of their illness or the effect it has on their physical and overall psychosocial functioning (NDOH, 2016). Primary caregivers refrain from providing children with any information relating to their illness (Vaz et al., 2011). Nicastro et al. (2013) point out that during this time, questions posed by the children concerning the status of their health are typically disregarded or diverted with false information. Jemmott et al. (2014) add that at this level, primary caregivers tend to refer to or substitute the illness with an unrelated medical condition such as flu, pneumonia or asthma. They often deem these illnesses as more socially acceptable than HIV. Caregivers sometimes tell children that their ART medication is general daily vitamins necessary to maintain a healthy and balanced lifestyle.

4.4.2 Level 2: Partial disclosure

Herein, children are made aware of their illness without actually naming the illness. Ideally, partial disclosure ought to commence between the ages of six and eleven years. Normally, primary caregivers only provide children with restricted information regarding their illness during partial disclosure; they do not name the virus (NDOH, 2016). For example, HCWs or primary caregivers tell children that they have little soldiers in their bodies to help fight off the germs in their blood for their betterment. They tell the children that if they take their medication as prescribed, the germs will go to *"sleep"*. Right to Care (2016) provides that this concept is often used to help educate children on why they occasionally fall ill and why they have to attend clinics for regular check-ups and for drawing blood.

4.4.3 Level 3: Full disclosure

The WHO (2011) recommends for full disclosure to commence at the age of twelve years. Full disclosure is a process wherein children are made aware of their illness that is named HIV. During full disclosure, children are provided with detailed, age-appropriate information about the nature and complexity of their illness. Examples of this information are for instance how the virus transmits and how it affects the human body (NDOH, 2016; Right to Care, 2016).

4.4.4 Level 4: Health-promoting disclosure

At this level, children are acquainted with all the information pertinent to their illness. They are equipped with knowledge and skills that promote independence for their own health (NDOH, 2016). For example, the HCWs explaining the recommended dosages of daily medication and the importance thereof (Right to Care, 2016).

4.4.5 Level 5: Complete disclosure process

This is an all-encompassing level with a guidance process from a point of non-disclosure to a point of health-promoting disclosure and ultimately complete disclosure. This level may, for instance, involve primary caregivers explaining to their children how they acquired the disease and its transmittance. It may also include primary caregivers disclosing their own HIV status to their children. This process can only be successful if the children's primary caregivers conduct it gradually and progressively. Success is further guaranteed by guidance and support from HCWs who safeguard that the children concerned are provided with age-appropriate information to comprehend their diagnosis (NDOH, 2016).

4.5 Types of child disclosure

According to the NDOH (2016) and the DSD (2019), there are five types of disclosure patterns to which children may learn of their HIV status, namely:

4.5.1 Prepared disclosure

This type of disclosure involves the primary caregiver, HCW and child being fully prepared to engage in the disclosure process. During prepared disclosure, the best interests of the child, as well as the age and maturity of the child are considered. Factors such as home circumstances and support structures adjacent to the child are also evaluated to ensure optimal preparedness and readiness (NDOH, 2016; DSD, 2019).

4.5.2 Unprepared disclosure

Herein, either the primary caregivers, HCWs or children themselves are not fully prepared to engage in the disclosure process. For example, primary caregivers may not feel ready to engage in the process due to unacceptance of their status or the fear of rejection from their children, so they refrain from disclosing. HCWs may for example not feel prepared to facilitate disclosure due to a lack of knowledge and skills in HIV care and management. As a result, they resort to delaying the process (NDOH, 2016; DSD, 2019).

4.5.3 Involuntary disclosure

This type of disclosure involves a child’s primary caregiver being compelled to involuntarily disclose the status of the child due to critical circumstances. Albeit the Children’s Act (South Africa, 2005a) stipulates that one may not disclose the HIV status of a child without the voluntary consent of their primary caregiver, there are stipulations in the Act (section 132) that allow for the revelation a child’s HIV status without permission. For example when it is required for a child to be tested for HIV to confirm a suspicion that a HCW may have contracted HIV from the child during service delivery (NDOH, 2016; DSD, 2019).

4.5.4 Accidental or inadvertent disclosure

This type of disclosure occurs when children learn of their illness through an accidental incident. For example, coincidentally overhearing a family member divulging information concerning their health status to another related or unrelated individual (NDOH, 2016; DSD, 2019).

4.5.5 Complete disclosure

Herein, a child is taken from a period of non-disclosure to a period of complete disclosure that is in alignment with the children’s rights framework. This type of disclosure is well prepared for, is age-appropriate and takes place in an enabling environment. The complexity of a child’s situation guides the process. The children and their primary caregivers receive ample support (NDOH, 2016; DSD, 2019).

4.6 Importance of psychosocial support post-disclosure

The NDOH (2016) states that following complete disclosure, it is essential for primary caregivers to continue reinforcing ongoing engagement with their HIV-positive children as these children will most likely experience emotional, physical and cognitive developmental changes. Cantrell et al. (2013) express that such engagement allows children to ask questions about their health status and discuss issues relating to relationships and safer sexual practices.

The DSD (2019) adds that post-disclosure support is of fundamental importance as it helps to determine if children are effectively coping or dealing with their known HIV status. Following disclosure, children may display different reactions and may say different things regarding what they have learnt about their health status. It is as such, important for primary caregivers to receive guidance on what to expect should significant challenges or changes occur. The NDOH (2016) indicates that successful post-disclosure support requires that there be multidisciplinary participation from all relevant stakeholders. For example, children and or their primary caregivers may be referred or linked to educational support groups offered at local NGOs, community-based organisations or to an area social worker or psychologist for enhanced psychosocial intervention should the need arise (DSD, 2019).

4.7 Whose responsibility is it to disclose the HIV status of children?

Cantrell et al. (2013) highlight that one of the key concerns surrounding disclosure of HIV status to infected children is who should disclose their HIV status to them. Lesch et al. (2007) indicate that primary caregivers of children living with PHIV generally control the mode of communication between themselves and their children. As such, children have limited autonomy over when, where or how they will be informed about their HIV status. Penn (2015) in consensus with Watermeyer (2015), express that child disclosure is a complex process, which often poses a challenge to primary caregivers when having to decide the welfare of their children. It further perplexes HCWs, as they are also unclear of what their exact roles and responsibilities are during the disclosure process. HCWs are often uncertain if they should instigate the process of disclosure themselves or if they should just facilitate and offer support to children and primary caregivers concerned. According to the NDOH (2016), this is caused by HCWs having limited understanding of existing policies, guidelines and tools recommended for effective child disclosure. As a result, most HCWs lack the skills needed to execute the disclosure process.

To clear this confusion, the WHO (2011) guidelines clarified that it is the responsibility of primary caregivers to disclose to their children while HCWs facilitate and support the process. This recommendation assumes that disclosure initiated by primary caregivers minimises the risk associated with it. It also improves the child-primary caregiver relationship and enhances the child’s overall well-being. Likewise, Vreeman et al. (2013) augment that primary caregivers are considered the most suitable persons to disclose to their children. Research studies have revealed that in most cases, primary caregivers prefer to disclose to their children in the presence and guidance of HCWs. Some prefer HCWs to lead the process of disclosure due to their privation of factual knowledge and skills. Notwithstanding clarity provided by the WHO (2011), uncertainty still prevails amongst a majority of primary caregivers and HCWs on who should disclose to children. This confusion is evident in the ineffective implementation of child disclosure services in sub-Saharan African countries. There exists a noticeable gap between policy and practice; hence, more education and awareness programmes are necessary across all relevant sectors to ensure accurate execution of HIV child disclosure services (Sariah et al., 2016; Appiah et al., 2019).

4.8 Factors promoting child disclosure

According to Madiba and Mokgatle (2015), age-appropriate child disclosure has several notable health and psychosocial benefits for children living with perinatally acquired HIV. It helps create access to new and existing support structures. It also helps to improve their treatment adherence and reduces the levels of anxiety and uncertainty surrounding their well-being and future outcomes. Odiachi (2017) conducted a study in the United States of America and found that disclosing the HIV status of a child at an age-appropriate time, has positive outcomes such as slower disease progression and better adherence to treatment.

In an earlier study conducted by Bhattacharya et al. (2011) in India, the scholars found that primary caregivers possessing higher levels of education are more likely to initiate the disclosure process with their children as opposed to those with lower levels or no education at all. Those with lower educational levels often felt worried and ill-prepared to assume the process of disclosure; they feared that they could not respond to questions that could arise from their children during disclosure. This study was in agreement with findings made by Biadgilign et al. (2011) in Ethiopia and Lawan et al. (2016) in Nigeria, who subsequently discovered that awareness of HIV status amongst adolescents in their study correlated positively with the age, sex and educational level of their primary caregivers.

In congruence with Madiba and Mokgatle (2015), Vreeman et al. (2015) assumed a study in Kenya and learned that primary caregivers who had disclosed the HIV status of their children at the recommended age of 12, had more positive views about disclosure and attested to the benefits outweighing the risks. About 97% of primary caregivers reported disclosure as a helpful and beneficial process for improving children's adherence to treatment, while 82% reported disclosure to have improved their children's overall well-being. About 79% of primary caregivers in the study reported that their relationship with their children improved significantly following disclosure.

Moreover, Vreeman et al. (2015) further discovered that primary caregivers who had disclosed the status of their children early on, displayed fewer physical health symptoms compared to primary caregivers who had not disclosed at all. Primary caregivers, who had not disclosed, reported physical health symptoms as well as emotional and psychosocial challenges such as anxiety and depression due to the burden imposed by fear and inability to disclose at an age-appropriate time. Scholars, Kenu et al. (2014) uphold age-appropriate disclosure as beneficial to both primary caregivers and children. They conducted a study in Ghana and similarly found that primary caregivers, who disclosed their own HIV status and that of their perinatally infected children, experienced less stress and anxiety symptoms than those who had not disclosed. Disclosure enabled children to ask questions, clear misconceptions, grieve, access social support and adjust to their health situation.

In another Kenyan study, scholars John-Stewart et al. (2013) discovered that most primary caregivers viewed their children's increasing age as a motivating factor to disclose. They found that persistent questioning from children regarding their illness influenced timely disclosure. Some primary caregivers disclosed to their children because they feared that as their children grow older, they might learn of their status accidentally from others. Also in Kenya, authors Vreeman et al. (2014) consequently uncovered that most primary caregivers sought to disclose to their children once they were initiated on ART or if they have been on medication for a lengthy period. Some primary caregivers were motivated to disclose because they were concerned that their children may unwittingly transmit the virus to others once they start engaging in sexual activities. They thought that by disclosing, they would not only be protecting their children but other people as well. These findings were unanimous with a preceding study conducted in Ghana by Kallem et al. (2011).

Arrivé et al. (2012) took on a multi-centre cohort study in five paediatric clinics in Cote d'Ivoire, Senegal and Mali. This study aimed to explore whether children older than ten and living with PHIV were able to remain in care. Results stemming from this study revealed delayed disclosure and non-disclosure as significant determinants to poor retention in care.

The scholars found that retention in care was higher in adolescents informed earlier of their HIV status, compared to their counterparts not yet disclosed to. This was consistent with previous and recent research studies undertaken by scholars Kallem et al. (2011) in Ghana and Vreeman et al. (2015) in Kenya.

Lawan et al. (2016) undertook an empirical study in Nigeria and found a positive correlation between complete disclosure and ART adherence. Primary caregivers in this study expressed that following disclosure, their children understood how ART works and how it protects their bodies from illness. Children were self-motivated to cultivate their own strategies to ensure adherence, and were less dependent on their primary caregivers. Children also trusted that ART would protect them from opportunistic infections. Findings from this study were similar to those unveiled by Gyamfi et al. (2017) in Ghana.

Essentially, Kiwanuka et al. (2014) assumed a qualitative study in Uganda and established that most primary caregivers felt obligated to disclose to their children because it was their human right to know their HIV status. They felt that children, like adults, also have the right to access health information and participate in matters related to their health and overall well-being. These findings were synonymous with outcomes of a study conducted by Manye and Madiba (2015) in Botswana.

Furthermore, Beim-Sofie et al. (2014) found a family's structure to be a contributing factor to effective child disclosure amongst primary caregivers in Kenya. Children who came from stable home environments were more likely to be disclosed to than those coming from unstable home environments. Stable home environments were constructive enablers for age-appropriate disclosure. Atwiine et al. (2015) observed similar results in Uganda. In their study, the scholars identified that disclosure was more prevalent in household environments that had supportive family members. Disclosure was more likely to happen in households that had two or more children or additional family members, and less likely to occur in households with fewer adults and children. Primary caregivers reported that disclosing to adult members in their households or relevant people at the children's crèche or school, enhanced their ability to disclose to their children. They regarded having a support structure as an important element of the disclosure process.

Similar to findings discovered earlier by Bhattacharya et al. (2011) in India, Van Elsland et al. (2019) conducted a study in South Africa and also found a correlation between the higher educational status of primary caregivers and age-appropriate disclosure. Primary caregivers with a higher level of education reported higher rates of age-appropriate disclosure as opposed to those with little or no education. In contrast, Murnane et al. (2017)

in their South African study, found no correlation between primary caregivers' level of education and disclosure of HIV status to children.

Parallel to the aforementioned findings by Beima-Sofie et al. (2014) in Kenya and Atwiine et al. (2015) in Uganda, Van Elsland et al. (2019), also observed that a good family functioning promoted early disclosure in South Africa. Children who had an overall high family impact scale were more likely to be disclosed to than children belonging to a low family impact scale. Well-functioning families such as those deriving from households with better socio-economic status provided a better environment for enabling and promoting child disclosure. A supportive structure was beneficial to disclosure.

Conclusively, Watermeyer (2015) and Cluver et al. (2015) conducted their studies among HCWs and children living with perinatal HIV in South Africa. The authors found ART medication to be a significant component of children's acceptance of their HIV status. Children who knew their HIV status adhered to ART and developed a sense of ownership and autonomy over their illness. They also had better access to social support systems.

4.9 Factors impeding child disclosure

4.9.1 Perceptions and experiences of primary caregivers

Abebe and Teferra (2012) express that disclosure of HIV status to children living with PHIV often provokes fear and anxiety in primary caregivers; hence, many primary caregivers opt to avoid it for as long as they possibly can. The Committee on Pediatric AIDS (1999) provides that numerous factors such as personal beliefs, cultural beliefs, subjective experiences and social issues influence primary caregivers' decision to disclose or not disclose. Gachanja et al. (2014) extend that there is limited information about how primary caregivers prepare themselves for disclosure of HIV status to their perinatally infected children, and the resources they need. Planning for HIV disclosure differs for each primary caregiver because people's circumstances and perspectives vary; thus, the timing and approach taken towards the disclosure process also varies.

Scholars, DeSilva et al. (2018) explored the challenges and experiences of primary caregivers in China and found that stigma served as a major impediment toward successful child disclosure. Primary caregivers in this study were mainly concerned about their children being too young to keep a secret, fearing that they would receive societal judgement if persons outside of their family structure were to find out. Other factors impeding disclosure included fears of children being too young to comprehend the nature of the illness and disclosure bearing a psychological burden on children. In contrast, primary caregivers who had incrementally disclosed to their children through the process of partial, and ultimately full disclosure, rarely reported such challenges. Prior studies piloted in Malawi by Mandalazi et al. (2014), in Zambia by Mburu et al. (2014) and in Kenya by Vreeman et al. (2015) produced findings similar to the above.

DeSilva et al. (2018) moreover discovered that most primary caregivers in their study began the disclosure process using different forms of selective or deceptive information to communicate to children about their HIV status. They told children that they had less-stigmatised health conditions such as chronic respiratory issues or eye problems. This was to deflect any questions that children could potentially ask about HIV. Similarly, Lorenz et al. (2016) learned that in Uganda, when children asked their primary caregivers about their HIV status, they received responses that replaced HIV with socially acceptable illnesses such as Influenza. Other parents changed the discussion or simply ignored the questions.

Manye and Madiba (2015) enlighten that the use of deception is mostly associated with social and cultural taboos, which often prohibit discussions of sex and HIV, further decreasing chances of successful child disclosure outcomes. Fundamentally, Simoni et al. (2007) denote that there should be a distinction between gradual disclosure and deception. Strategies such as providing children with selective or misleading information are strategies that may prove useful to primary caregivers in the short term, but their continuous use may in the end, harm children and thwart their chances of understanding HIV/AIDS.

Studies conducted in Kenya by Gachanja et al. (2014) and in Uganda by Kiwanuka et al. (2014), revealed that even though many primary caregivers had intentions to disclose, they reported struggles with communication. A majority of primary caregivers in these studies stated that they did not know how, when or where to disclose. They stated that they did not always have the necessary support to help guide them in facilitating the process on their own. They further conveyed that they sought to disclose to their children, but did not trust their capabilities to handle the magnitude of the process. They emphasised the crucial need and importance of HCWs' support during disclosure.

Manderson et al. (2016) steered ethnographic studies in Eswatini, Lesotho and Zambia. The authors discovered that delayed disclosure was particularly high in resource-limited settings where most extended family members took care of children, while their parent(s) departed from home to look for work due to financial hardships. This resulted in changes in traditional family structures. The authors enlighten that many households were likely to fall apart due to consistent change of caregivers and increased rates of orphanhood.

Similar to Manderson et al. (2016), scholars, McHugh et al. (2018) investigated caregiving arrangements and their relation to non-disclosure and delayed disclosure of HIV status among children and adolescents in Harare, Zimbabwe. Their study highlighted unstable living arrangements as contributing factors towards delayed disclosure. The scholars found that the recurrent change of caregivers, which is often, but not exclusively caused by parental death, delays disclosure. A majority of participants in this study were elderly guardians who had to care for children due to the passing of their biological parents. These elderly guardians experienced socio-economic difficulties and had lower HIV literacy levels, which led to the children in their care being unsupported and unaware of their HIV status.

In Botswana, Manye and Madiba (2015) detected that biological mothers, in particular, delayed disclosing because the internal guilt of having infected their children with HIV through MTCT, overcame them. Biological mothers participating in this study expressed that they feared having to explain to their children how they themselves acquired HIV and how they further transmitted it to them. They expressed their fears of possible blame, rejection and anger that could result from their children after disclosure. Kiwanuka et al. (2014) learned that in Uganda, biological caregivers delayed disclosure because they had not yet acknowledged or accepted their own HIV status. Biological caregivers who had a negative or traumatic experience when disclosing their own HIV status to their partners or families, avoided disclosing to their children. Consistent with these empirical findings, were findings of a previous study conducted in Nigeria by Brown et al. (2011).

In a research study conducted in South Africa by Madiba (2012), primary caregiver readiness was a critical factor in the disclosure process. When primary caregivers are not ready to disclose, they simply avoid the process. Madiba and Mokgatle (2015) further discovered that most primary caregivers of children living with PHIV in South Africa, delayed disclosure because they often felt ill-equipped to undergo the process. Vreeman et al. (2015) underscore that there is an acute need to cultivate appropriate disclosure interventions that address primary caregivers' deep-seated fears of disclosing the HIV status of their perinatally infected children. By cultivating such interventions, rates of delayed disclosure in sub-Saharan African countries can be significantly reduced.

Madiba and Mokgatle (2017) enlighten that even though most primary caregivers in their South African study reported knowing the importance of early disclosure, they often delayed it because they lacked the necessary knowledge and skills required to adequately facilitate the process with their children. The findings of this study mirrored those of a cross-sectional study conducted by McHugh et al. (2018) in Harare, Zimbabwe. Both these studies echoed the essentiality of implementing developed guidelines to help equip primary caregivers with appropriate knowledge and skills needed for effective child disclosure and adherence support.

According to Van Elsland et al. (2019), in agreement with Madiba and Mokwena (2012), in South Africa, a majority of primary caregivers in their studies did not feel the need to disclose if their children did not ask any questions about their health or medication. They as such, regarded their children's silence as an indication that they are not yet ready for disclosure. Primary caregivers also delayed disclosure if their children were tolerant and adherent to ART. Some primary caregivers felt that there was no need to disclose if their children did not display any condition-related difficulties. The authors extend that oftentimes when families are in a good space, they feel no pressing need to commence the process. However, it is through such spaces, that positive disclosure can happen so that children can adjust quicker. Targeting such families for disclosure and adherence interventions can yield successful disclosure outcomes as they have enabling environments.

Furthermore, Van Elsland et al. (2019) together with Murnane et al. (2017) discovered that socio-economic characteristics such as family functioning and daily activities also influenced disclosure practices in South Africa. The scholars found that primary caregivers who lived in informal settlements experienced greater challenges when having to disclose to their children. This was mainly due to the densely populated informal living conditions and lacking the privacy needed to support the disclosure process.

Lorenz et al. (2016) accentuate that the aforementioned factors impede child disclosure and are further intensified by insufficient healthcare systems and HIV services such as disclosure counselling and psychosocial support for primary caregivers and their children. It also becomes increasingly evident that primary caregivers need substantial help in learning how, when and where to disclose the HIV status of their children. McHugh et al. (2018) complement that providing education and training that emphasise the importance of incremental disclosure may help alleviate the anxiety experienced by most primary caregivers when having to disclose to their children. Through such interventions, primary caregivers may finally understand that partial disclosure safeguards children from potential incidents such as unprepared or accidental disclosure. Additionally, incremental disclosure builds confidence in children and may stimulate children's abilities to understand the nature of their HIV diagnosis once they reach the stage of full disclosure.

4.9.2 Perceptions and experiences of healthcare workers

According to Watermeyer (2015), of all segments in HIV care and management, disclosure of HIV status to children and adolescents living with PHIV presents one of the biggest and most challenging concerns in healthcare systems. Crucially, Fair and Walker (2011) contend that to understand the concept of child disclosure, it is important to take into account the various perceptions and experiences of HCWs involved in HIV child disclosure services. Mutambo and Hlongwana (2019) extend that HCWs need to reinforce the implementation of HIV services in public health facilities. For this to be possible, a thorough analysis of existing barriers deterring HCWs from effectively providing these services to children concerned must be conducted. If these barriers are not properly understood, formulating context-specific and effective public health response programmes may be challenging.

In Tanzania, Sariah et al. (2016) found that despite the availability of WHO guidelines and subsequent national paediatric HIV guidelines, HCWs in most public health facilities remained confused and uncertain of their roles and responsibilities in disclosure services. The scholars discovered that this discrepancy was due to health departments' complete lack of prioritisation in adopting guidelines and standardizing national training amongst HCWs. Training among HCWs varied in content and duration, which led to some HCWs being more knowledgeable than others, differing in principle, skill and implementation. Similar discoveries were recounted in prior studies conducted in Kenya by Gachanja et al. (2014) and Kranzer et al. (2014) in Zimbabwe. HCWs in these studies reiterated the crucial need for training on child disclosure guidelines as a majority of them had only ever received job training upon initial appointment and not much else.

In a preceding study conducted in Uganda, Rujumba et al. (2010) highlighted gaps and shortfalls in the healthcare system. The scholars found that a lack of supportive learning material impeded disclosure services in public health facilities. Other prominent challenges included time constraints, shortage of skilled HCWs and limited workspace to provide confidential and quality based child-friendly services. Consistently, Kranzer et al. (2014) also learned that in Zimbabwe, HCWs reported a lack of child-friendly aides in public health facilities. They opined that such aides are pivotal in easing communication and safeguarding that children are addressed using age-appropriate language. Also in Zimbabwe, Busza et al. (2016) likewise uprooted barriers such as shortages of working tools and specialised staff members such as psychologists, social workers and counsellors. HCWs in these studies unanimously advocated for the government's intervention in prioritising capacity building and providing adequate tools of trade. They motioned that provision of such enablers will assist in keeping them abreast when facilitating disclosure processes.

Furthermore, Brandt et al. (2015) undertook a study in Namibia and found that one of the main barriers to successful child disclosure was the inconsistency of primary caregivers in accompanying their children to clinic appointments. This finding was tantamount to that of Biadgilign et al. (2011), who found that HCWs in their Ethiopian study struggled to implement efficient disclosure services because their legal guardians did not always accompany children to clinics. Furthermore, HCWs expressed their inability to provide effective HIV disclosure and counselling services because children did not always collect their own medication, instead primary caregivers collected it on their behalf and did not always collect it on time, which made it increasingly difficult to monitor children clinically and psychosocially. HCWs also struggled to effect disclosure services because most primary caregivers did not understand the benefits of disclosure and were thus unwilling to disclose to their children. In these studies, primary caregivers were the main barriers to age-appropriate disclosure and their children’s adherence to treatment.

Moreover, Mutanga et al. (2012) mentioned that in Zambia, structural barriers also impeded child disclosure services in some public health facilities, particularly those in rural areas as they had limited access to community-based HIV testing and counselling services for children. These communities also had trouble in identifying HIV infected infants. In agreement, De Schacht et al. (2014) discovered that in certain public facilities of rural Mozambique, HIV diagnosis in many children and adolescents only occurred in their late childhood after many years of ill-health. HCWs contributing to this study expressed that some primary caregivers only sought to bring their children for testing when they appeared to be chronically ill from recurring infections. The findings of these studies further revealed the skewed distribution of services across low, middle and high-income settings.

In a South African study pioneered by Watermeyer (2015), he found inconsistencies in knowledge and understanding of child disclosure. Findings in this study revealed that even though literature provides various definitions of child disclosure, most HCWs did not entirely understand the concept. One participant revealed that child disclosure meant only telling the children once-off about their HIV status. Consistent with Kranzer et al. (2014) in Zimbabwe, HCWs in this study also had little knowledge of laws and policies governing HIV. Others reported not knowing stipulations of the law regarding HIV testing and disclosure of a child’s HIV-positive status. Practically, some HCWs attested to disclosing to children in the absence of their primary caregivers and not following up on how the children were coping. This resulted in primary caregivers being furious with clinic management and felt that it infringed their right to disclose at their own pace. This study revealed that both new and experienced HCWs were unclear about the enactment of guidelines and policies, which caused tension between healthcare teams and contributed to deleterious patient outcomes. These studies called on health departments to prioritise training of their personnel to avoid the occurrence of continuous and imminent consequences.

Madiba and Mokgatle (2015) conducted a cross-sectional survey amid public health facilities in Mpumalanga and Gauteng provinces in South Africa. The findings of their survey produced similar results as those spearheaded by Kiwanuka et al. (2014) in Uganda and Motshome and Madiba (2014) in Botswana. In this survey, a majority of HCWs acknowledged that children have the right to be informed of their HIV status so that they may adhere to ART and take responsibility for their health. HCWs had different opinions about the appropriate age to disclose. Some HCWs reported ages 11–14 as appropriate, while others thought children should only be told of their HIV status when they are capable of understanding the disease and its implications, not when they are too young. Other HCWs perceived the pubertal phase as the right time to inform children of their HIV status because only then children are mature enough to understand their diagnosis.

Madiba and Mokgatle (2015) also discovered differences when asking HCWs about whose responsibility it was to disclose to children living with PHIV. A majority of HCWs stipulated that primary caregivers are the most suitable persons to disclose the status of their children as they know and understand them better and that their duty as HCWs is just to facilitate and guide the process. In contrast, a foregoing study conducted by Heeren et al. (2012) in South Africa, revealed that some HCWs were of the premise that they ought to lead disclosure and not primary caregivers. Even though most HCWs understood their stance in disclosure services, they readdressed the need for official training on disclosure counselling for children living with PHIV. They conveyed that the health department had never provided them with any formal or informal workshops on paediatric HIV management, hence the apparent dearth of skills and confidence during practice.

According to Beima-Sofie et al. (2014), training and workshops help provide HCWs with skills and enhance their confidence in helping primary caregivers to disclose. Madiba and Mokgatle (2015) state that to facilitate the disclosure process effectively, HCWs must adopt and adapt the WHO (2011) HIV disclosure guidelines into local communities and cultural contexts. These guidelines should form the foundation for furnishing HCWs with adequate skills required for child disclosure.

In furtherance and in harmony with Madiba and Mokgatle (2015), Hayfron-Benjamin et al. (2020) conducted an interventional study in Ghana on the training needs and experiences of HCWs working with adolescents living with HIV. During the pre-training survey, the scholars discovered that HCWs never received training nor did they know the laws or policies related to children and adolescents living with HIV. Post-training results improved significantly. All HCWs saw the importance of children and adolescents' rights in the HIV spectrum, they realised the relevance of policies and guidelines in service delivery. They also saw the need for psychosocial assessments and continuous health education when working with children and adolescents. Results also indicated a surge in HCWs' confidence, willingness and readiness to implement the knowledge and skills gained on new and existing guidelines and policies. In an earlier study, O'Malley et al. (2015) similarly discovered that trained HCWs in Namibia were better able to offer disclosure services than untrained HCWs. Trained HCWs were able to use helping aids such as storybooks to facilitate disclosure and educate children about basic concepts affiliated with HIV. These HCWs were able to refer newly disclosed-to children and adolescents to peer support groups so that they could receive assistance in their transition, through the provision of age-appropriate psychosocial care and support from peers in similar predicaments.

Healthcare workers partaking in studies conducted by Madiba (2016) and Mokgatle and Madiba (2015) in South Africa, argued that even though the WHO guidelines of 2011 provide guidance, they are not detailed enough about how certain activities ought to be carried out during disclosure processes. They also highlighted that the guidelines do not make provision for strategies to follow when approaching disclosure with adolescents, as they are limited to children aged 12; whereas most children living with PHIV in sub-Saharan Africa are not disclosed to until late adolescence. To build on the WHO guidelines, the NDOH in their adjusted guidelines of 2016, integrated both children and adolescents into a comprehensive HIV care programme.

Albeit the introduction of the newly adjusted guidelines, Madiba and Diko (2021) lengthen that HCWs in their recent South African study still reported lack of training as the most prominent barrier to successful disclosure. Other barriers included lack of disclosure materials, insufficient staff, high workload, scarcity of role players and poor referral networks among local stakeholders. A majority of HCWs in the study stressed that the NDOH does not capacitate them on new or existing health information, but as professionals, they are expected to handle complex issues such as disclosure. Other HCWs stated that they relied on their professional intuition to handle processes. Some resorted to using previous HIV Testing Counselling and Voluntary Counselling and Testing guidelines when conducting sessions. To alleviate the aforementioned inconsistencies, Sariah et al. (2016) uphold that health departments across all regions ought to prioritise and standardise training amongst all relevant personnel in public health facilities, so that effective implementation of child disclosure practices may be realised.

4.10 A comparative analysis of reactions and experiences of children and adolescents following disclosure of HIV status

4.10.1 Reactions and experiences with early disclosure

In their case study, Lawan et al. (2016) analysed the prevalence of disclosure and awareness of HIV status among adolescents attending an ART clinic in northern Kenya. The results revealed that adolescents who knew their HIV status understood the importance of practising safe sexual behaviour as well as the importance of protecting themselves and others from further transmission. Those who did not know their status did not fully comprehend the importance. Other positive outcomes associated with disclosure included adolescents gaining a better understanding of their health post-disclosure. Most adolescents reported better cooperation to treatment regimens and improved utilisation of clinical support services. Fewer behavioural difficulties were reported. Most adolescents supplied that following disclosure, their relationship and overall communication with their primary caregivers improved, their fears and anxieties were also allayed. These findings are parallel to those of a study conducted by Ugwu and Enah (2014) in Nigeria.

Also in Kenya, Vreeman et al. (2015) learned that adolescents who underwent disclosure at a much earlier phase of their development, did not experience increased emotional, mental or behavioural distress. On the contrary, disclosure was associated with a positive outlook on health and life in general. Adolescents in this study valued being informed on time as this helped them steadily come to terms with their illness. They expressed that early disclosure helped them hold open discussions with their primary caregivers about HIV. Through these discussions, they experienced lesser mental health difficulties such as stress, anxiety and depression. Their self-esteem also improved significantly. A recent study conducted in Kenya by Ngeno et al. (2019) echoed similar sentiments.

Contrastingly, Gitahi et al. (2020) also undertook a study in Kenya comprising of 58 adolescents living with PHIV and aged between 16–19 years. This study examined their psychosocial needs as they transitioned into late adolescence. Findings of this study revealed that there is limited data on the longstanding psychosocial effects of disclosure on adolescents, even when disclosure happened on time during early childhood. The scholars found that a majority of adolescents who were disclosed to between the ages of seven and twelve recounted to have coped well and felt relieved after disclosure. However, as they grew older and started discovering themselves, they began experiencing negative psychosocial issues such as acute anxiety, depression and post-traumatic stress disorder due to a lack of continuous psychosocial support from their significant others. As a result, these adolescents often faced internal struggles such as self-stigmatisation, low self-esteem and withdrawal. They also felt apprehensive about the impact that HIV would have on their future relationships with their romantic partners.

Notwithstanding the abovementioned negative feelings and psychosocial issues ensuing from early disclosure, Gitahi et al. (2020) express that a majority of adolescents in their study still maintained that awareness of their HIV status outweighed unawareness as it helped improve their adherence to ART. They elaborated that discovering their HIV status earlier enabled them to realise and comprehend the consequences of their non-adherence to ART. Knowing of primary caregivers, relatives or peers that died from HIV-related complications also heightened their determination to adhere to ART and mitigate the likelihood of opportunistic infections. This study was coherent with a foregoing study conducted by Haberer et al. (2011) in Zambia.

Akin to the above, Okawa et al. (2017) explored experiences and timing suggestions for disclosure among adolescents living with PHIV in Zambia. A majority of adolescents in this study viewed disclosure of HIV status as a constitutional right and as a preventative measure against ongoing transmission and reinfection of HIV. All adolescents viewed the age of 12 as the most suitable and appropriate age to fully disclose. This view is parallel to the recommendation made by the WHO guidelines of 2011. The adolescents further indicated that once disclosed to, they were able to understand the nature of their illness and treatment required. Early disclosure helped improve the overall quality of their lives.

Moreover, Brown et al. (2011) found miscellaneous reactions among children who had received early disclosure in Nigeria. Most children pointed out that they became depressed and displayed behavioural problems at home and school during initial disclosure. It was only when they received constant support from primary caregivers and HCWs that they began gaining perspective and knowledge about their illness. However, even with this support and perspective, they continued viewing HIV as an insurmountable challenge and thus remained rebellious and non-compliant. Some children claimed that unstable homes and financial circumstances contributed to their stress and anxiety levels. Most children reported that their adherence to ART also worsened after their initial disclosure, but improved as they gradually realised that they had little or no choice but to adhere to avoid aggravated illness and premature death. Despite the abovementioned mixed reviews, all children considered it better to know their status than not know at all. They further emphasised the need and importance of ongoing psychosocial support and medication reminders from their primary caregivers as disclosure of HIV status was a physically and emotionally taxing experience.

Scholars, Woollett (2016) and Madiba and Mokgatle (2016) conducted research studies in South Africa and unanimously learned that children who received incremental disclosure from ages six to twelve initially reported feelings of shock and distress after disclosure; these feelings were subsequently replaced by acceptance of own status and positive coping skills. A majority of children that participated in these studies expressed that their acceptance was primarily motivated by unwavering support from their families and accurate information provided by HCWs concerning their illness and the management thereof. The studies collectively deemed ongoing disclosure as beneficial in enhancing the well-being and overall psychosocial functioning of the children concerned.

Furthermore, Madiba and Mokgatle (2016) highlight that most children who partook in their study expressed that when their primary caregivers disclosed to them, they instructed them to remain discreet about their HIV status as a means to shield them from possible stigma and humiliation. Mweemba et al. (2015) illuminate that this notion is often fear-driven and does not always materialise as most primary caregivers perceive. Evidently, 81% of adolescents that partook in a study assumed by Okawa et al. (2017) in Zambia, knew their status from early childhood and did not self-disclose to others. Zgambo et al. (2018) had similar findings. The scholars edify that shielding children from a place of fear may seem conducive, but it is in essence, counterproductive as children need truthful and factual support, especially when matters involve their emotions and self-esteem. The scholars clarify that even if these children do not disclose their HIV status as per instruction, others who may know of their status, may intentionally or accidentally spread it out which may lead to them encountering social exclusion and other dangerous considerations such as suicide.

Madiba and Mokgatle (2016) extend that most adolescents who received early disclosure, understood that their status was sacred and that they were not obligated to disclose to anyone against their will. This exemplifies that primary caregivers can benefit from disclosure if they alleviate their fears of disclosing to their perinatally infected children. For this to happen, primary caregivers ought to redirect their fears of the unknown by engaging with their children about the positive and negative ramifications of self-disclosing their HIV status to others; and trust their ability to keep matters confidential. It is therefore critical for primary caregivers to be professionally guided by HCWs on how to provide children with compassionate, but also, realistic counsel. HCWs ought to provide frequent education and counselling support to primary caregivers and their children when they encounter challenges associated with disclosure. Hodgson et al. (2012) and Kidia et al. (2014) expand that it is not always true that persons outside of one's family may stigmatise, humiliate or spread rumours about their health status. Actually, peer support mitigates emotional stress, especially among other perinatally infected children. Research has shown that such children tend to motivate and support each other back to health.

Likewise, Zgambo et al. (2018) expand that children and adolescents living with PHIV must be encouraged to join peer support groups once they are fully informed of their HIV status and the complexities thereof. Amzel et al. (2013) enlighten that peer support groups assist children living with HIV to find better ways to coexist with their health condition, to be resilient, to adhere to ART medication, and to understand that other children are living with HIV and undergoing similar challenges.

Based on the aforementioned findings, it can be deduced that despite their variant perceptions and experiences, many children and adolescents living with PHIV find early disclosure, especially if it is supportive and ongoing, as a beneficial practice within the care and management of HIV. As such, the researcher finds it necessary to bring forth these pivotal observations made by Okawa et al. (2017). The scholars observed that many studies, much like the ones above, show that even though early child disclosure took place, the focus has mainly been on providing children with factual information such as HIV treatment, modes of transmission, risks of non-adherence, and benefits of adherence whilst placing diminutive focus on children's psychosocial well-being.

Okawa et al. (2017) further explain that following early disclosure, many children and adolescents barely knew how to deal with their emotions, develop self-esteem or plan for their ongoing futures. Although most children and adolescents in their study claimed to have received timeous disclosure, ongoing psychosocial support and follow-ups proved insufficient on the part of primary caregivers and HCWs. This gap moreover shows that even though disclosure processes have been endeavoured, there remains a great need to enhance their effectiveness in public health facilities and communities at large. Children and adolescents living with PHIV need to be supported through provision of holistic and continuous disclosure services.

4.10.2 Reactions and experiences with delayed disclosure

DeSilva et al. (2018) found that in China, some adolescents expressed that their primary caregivers only sought to disclose their HIV status when they fell critically ill due to poor adherence to ART, or when they suspected that they are engaging in risky sexual behavioural practices. The adolescents explained that disclosure was not only delayed but also done abruptly with little or no preparation. This led to anger, confusion and mistrust with their primary caregivers. It also distorted their outlook on life and hampered their societal relationships with their peers. Adolescents who experienced this contended that early disclosure would have been a better option than delayed disclosure. Gitahi et al. (2020) also encountered similar reactions among adolescents living with PHIV in Kenya.

Baker et al. (2018) explored perceptions and experiences of children living with PHIV in Lima Peru. A majority of children in this study experienced disclosure during their middle and late adolescence (ages 15–19) and wished to have been informed of their HIV status much earlier, at ages six or seven. They expressed that early disclosure though not always palatable, would have helped accelerate the acceptance of their status much quicker than delayed disclosure. They expatiated that delayed disclosure negatively affected their relationships with their loved ones and increased their frustrations and reluctance to consume ART medication, particularly because they were initially made to believe that their medication was just basic vitamins meant for good health.

In the same breath, Gitahi et al. (2020) unveiled that a majority of adolescents in their Kenyan study experienced disclosure in the latter years (13–16) of their adolescent phase and recalled immediate anger and disappointment about their HIV status. These adolescents claimed that their primary caregivers' inability to inform them of their HIV status at a much earlier phase of their childhood infuriated them. They reported that following delayed disclosure of their HIV status, they experienced sustained periods of anger, rebelliousness, suicide ideation and negative perceptions of the self. They noted that earlier disclosure would have placed them in a much better position to steadily accept and understand their illness. Remarkably, a majority of adolescents in this study did not blame their primary caregivers for having transmitted the disease; they instead upheld that it was not their fault. They however voiced that they were dismayed by the fact that disclosure of their HIV status occurred in the absence of valuable information such as how to prevent further transmission, how to disclose to their peers or sexual partners, as well as how to ensure safe conception should they wish to conceive an HIV-negative child.

Brown et al. (2011) moreover discovered that inadvertent disclosure and self-discovery of HIV diagnosis were quite common among children living with PHIV in Nigeria. Many children in this study reported having known of their HIV status before their primary caregivers or HCWs could inform them. They stated that they found out by recognising the names of their ART medication on the internet. Some learned of their status by overhearing conversations concerning their diagnosis at clinics and hospitals. Others were told by other children living with HIV or by accidentally going through their medical records and reading brochures at clinics. Most children described the process of self-discovery as painful and unsavoury because it ensued rage within them. For some, it led to a subsequent fracturing of existing relationships with their primary caregivers, as they felt betrayed by their non-disclosure. Despite feelings of anger due to self-discovery, most children articulated that all they wanted was the truth from their primary caregivers; they still yearned for their primary caregivers verify their PHIV status to them. Importantly, all children participating in this study concurred that primary caregivers must tell their children the truth early on so that adherence may be improved, speculations may be cleared and secondary transmission may be prevented. A study embarked on by Cluver et al. (2015) also presented similar reactions amongst adolescents living with HIV in South Africa.

4.11 Association between disclosure (early and delayed) and risky behaviour among children and adolescents living with perinatal HIV

Scholars, Lawan et al. (2016) orchestrated a study amid children and adolescents aged between 10 and 19 years in Nigeria. They found that adolescents who were timeously disclosed to were more aware of HIV transmission than their counterparts who had not yet been disclosed to. Paradoxically, the results of this study revealed that albeit knowledge of their own HIV status, their behaviour did not change. They still engaged in high-risk behaviour such as unprotected sexual intercourse with their partner(s), injecting drugs, using substances and drinking excessively. Some engaged in sexual practices whilst under the influence of drugs and alcohol. The study also revealed that sexually active adolescents seldom used condoms, whether disclosed to or not. Contrarily, earlier studies piloted by Guiella and Madise (2007) in Burkina Faso and Akwara et al. (2003) in Kenya, found no positive or negative affiliation between HIV awareness and risky sexual behaviour.

Distressingly, Lawan et al. (2016) also uncovered that most adolescents in their study were of the mistaken belief that they no longer had to fear HIV because they had already acquired it through MTCT, as such, it no longer served as a deterrent. This flawed notion is particularly problematic as it creates room for further transmission and reinfection, making it even harder to control the spread of the virus. Toska et al. (2015) expose that oftentimes, HCWs provide primary caregivers and their children with counselling services that focus on the benefits of the disclosure, with little attention drawn on the fears and risks associated with it. The results of this study challenged the assumption that early disclosure automatically protects romantic and sexual relationships of HIV positive adolescents who may be unequipped to negotiate safer sexual practices with their partners. They further demonstrate that there is an insistent need to effect interventions that aim to mitigate risks that could result post-disclosure. These interventions should provide children and adolescents with holistic knowledge that does not only encourage good health and adherence to ART, but also safe sexual practices and family planning services for example. The implementation of such interventions will help stimulate social behaviour change among children and adolescents infected and affected by HIV.

Moreover, Zgambo et al. (2018) assumed a systematic review using 36 articles from sub-Saharan countries such as Uganda, Kenya, Ghana, Nigeria, Cote d'Ivoire, Zambia, Zimbabwe, Malawi and South Africa. The study examined the sexual behaviour of adolescents living with HIV between the ages of 12 and 17. Findings revealed that a majority of adolescents who knew their HIV status did not disclose to their sexual partners and hardly knew the status of their partners. Adolescents who were unaware of their HIV status did not entirely comprehend the importance of sharing their status or knowing the status of their sexual partners. Furthermore, most adolescents who had received delayed disclosure were of the notion that HIV-positive couples are ineligible to conceive children, and were only meant to adopt should they wish to have them. Additionally, pregnant adolescents living with HIV shunned PMTCT services more than regular prenatal services.

Toska et al. (2015) found that even though most adolescents participating in their South African study knew their HIV status and its modes of transmission, they did not always engage in safe sexual practices. Adolescents who knew their HIV status from early childhood used condoms more than those who did not know, however, the use of condoms remained inconsistent and often involved difficult negotiations. Results of this study further exposed female participants as more sexually active than male paticipants. Most females reported gender and power disparities within their sexual relationships. These findings were also coherent with studies previously conducted by Agha (2012) in Mozambique and Rosenberg et al. (2013) in South Africa.

Toska et al. (2015) moreover discovered that most adolescents in their study feared disclosing their HIV status to their intimate partners because they feared being exposed, stigmatised, rejected or abandoned by their partners. Bernays et al. (2015) supplement that this fear is influenced by prior instructions given by primary caregivers to not share their status with anyone. Furthermore, Toska et al. (2015) learned that to preserve their relationships, most adolescents compensated by limiting condom use and agreeing to unprotected sexual intercourse with their partners. Other adolescents prioritised prevention of pregnancy and avoidance of HIV-related stigma above HIV disclosure, especially those involved in casual relationships. Some adolescents postponed disclosure until they felt that their relationships were stable enough, so they concealed their HIV status out of fear that their relationships would end after disclosing.

In another study conducted in South Africa, scholars, Vujovic et al. (2014) learned that most adolescent girls desired to gain more information about pregnancy, but lacked adequate SRH services in their vicinities. Some felt ashamed to seek advice on sexual matters because it could be interpreted as though they are sexually active and planning to have children. Other adolescents believed that primary caregivers and HCWs gave them wrong information to deter them from sexual activities. They, as a result, sought supplementary advice and information on SRH from peers and the internet. The findings of this study reflected those of Hodgson et al. (2012) in Zambia.

Through the findings of the abovementioned scholars, it becomes even more evident that most children and adolescents living with PHIV have a scant understanding of the complexities and dangers of HIV transmission despite being aware of their status. For example, prioritisation of contraceptives and neglect of condom use shows that many adolescents are still oblivious to the possibilities of contracting STIs, which could essentially harm their health and that of others. Contraceptives largely prevent unwanted teenage pregnancies, but they do not prevent STIs, onward transmission or reinfection; whereas condoms are a much safer preventative method. This simply validates that child disclosure is indeed an ongoing, dynamic process that requires consistent health education and psychosocial support from primary caregivers and HCWs to clear new and existing fallacies among children and adolescents living with PHIV.

4.12 Prevalence of child disclosure

According to McHugh et al. (2018), in an ideal world, all adolescents living with PHIV should be cognisant of their HIV status; however due to the aforementioned impediments to child disclosure, this is not the case. Various studies have shown that the percentage of children and adolescents who know their HIV status is from as low as 1.2% to 75% at various stages of their HIV care, the median is 20.4%. These percentages appear to be even lower in low-income and middle-income countries across the world and South Africa is no exception.

In their review on disclosure of HIV status to children living with PHIV, Pinzon-Iregeui et al. (2013) found that children located in low- and middle-income countries are less likely to be aware of their HIV status and only get to know of it in the later stages of their adolescence as opposed to children situated in high-income countries. Equally, Vreeman et al. (2015) state that despite the possible benefits of partially disclosing to children until they reach the age of 12 for full disclosure, a majority of older children and adolescents remain incognisant of their HIV status and are in critical need of adequate disclosure counselling services. Britto et al. (2016) report that rates of child disclosure by age 12 range from 0.1 to 50%.

The researcher employed previous and recent studies conducted by various scholars across the world in an attempt to demonstrate the prevalence of child disclosure over the past and recent years. In their study, DeSilva et al. (2018) found that disclosure rates amongst adolescent girls aged 10–15 in China, were a low 31.5%. A majority of primary caregivers in this study had not yet disclosed, and they expressed that they would only be willing to do so when their children reached the age of 14 or older.

In Thailand, the prevalence of child disclosure was 21% among children aged 6-10. Results of this study revealed increasing age as the determining factor for disclosure. The prevalence of disclosure was much higher amongst adolescents, ranging from 30% in adolescents aged 11–14, 56% in adolescents aged 12–17 and 74% in adolescents aged 13–14 (Sirikum et al., 2014).

Gyamfi et al. (2017) administered a cross-sectional study with a sample of 118 primary caregivers of perinatally infected children and adolescents aged 4–19 in Ghana**.** The prevalence of disclosure in this study was 33% with the majority of children disclosed to at the ages of 12 and 16 years. Similarly, Hayfron-Benjamin et al. (2020) conducted a subsequent study in Ghana and observed an even lesser proportion (23.3%) of children who had been disclosed to. Disclosure was predominantly done amongst adolescents aged 14 and above and seldom in younger age groups. In their study, Ngeno et al. (2019) found that only 36% of adolescents knew their HIV status by the age of 12. Primary caregiver reasons for non-disclosure were synonymous with those discovered by Gyamfi et al. (2017) and Hayfron-Benjamin et al. (2020).

Studies that came before the ones mentioned above, revealed an even lower rate of child disclosure. To name a few, Brown et al. (2011) found the prevalence of disclosure amongst children aged 6-10 in Nigeria, to be as low as 9%. In Addis Ababa, Ethiopia, Abebe and Teferra (2012) found disclosure rates among children aged 6-10 to be as little as 12%. Furthermore, Tadesse et al. (2015) found that in Southern Ethiopia*,* disclosure rates between children aged 5-10 were as low as 8%. Atwiine et al. (2015) in their Ugandan study reported the prevalence of disclosure among children aged 5-8 to be as low as 9.5%.

In South Africa, Toska et al. (2015) found a significantly higher percentage (62%) of disclosure among children and adolescents aged 10–19, many of which were informed of their HIV status during middle adolescence. Similar findings were discovered in another South African study conducted by Cluver et al. (2015) where the rate of disclosure was 70% amongst adolescents aged 10–19. In contrast, Murnane et al. (2017) conducted a cohort study among 550 perinatally infected children aged 4-9 in South Africa and discovered that only 50 (9%) of them had been partially disclosed to. The low prevalence of disclosure in this study was consistent with multiple other studies undertaken in South Africa by scholars, Kallem et al. (2011), Madiba and Mokwena (2012) and Mahloko and Madiba (2012).

With the discrepancies in the findings above, the researcher notes that even though disclosure rates have marginally increased in recent studies as compared to previous studies, the prevalence thereof remains considerably low across most sub-Saharan countries. As such, Van Elsland et al. (2019), in accordance with Kiwanuka et al. (2014), reiterate that disclosure services can only be enhanced if more HCWs in public health facilities are sufficiently trained and empowered with enough knowledge and skills to promote disclosure practices with primary caregivers and their children. This is particularly crucial for public health facilities in low- and middle-income countries where multitudes of perinatally infected children survive into adolescence, early adulthood and beyond.

4.13 Chapter summary

In summation, this chapter provided a brief historical background of HIV/AIDS in the context of MTCT. It outlined the concept of child disclosure, the levels as well as the types of child disclosure. The chapter moreover explained the importance of psychosocial support and clarified confusion surrounding persons responsible for child disclosure. The researcher discussed factors promoting and impeding disclosure, followed by reactions and experiences of perinatally infected children regarding early and delayed disclosure. The association between disclosure and risky behaviour among children and adolescents living with PHIV were also delineated. The chapter concluded with the prevalence of child disclosure in high-, middle- and low-income countries. The next chapter covers the research design and methodology.

Chapter 5
RESEARCH METHODOLOGY

5.1 Introduction

The primary purpose of this chapter is to provide a detailed description of the methodology used for the research study. The chapter provides an overview of research. It moreover provides an explanation of the research method, research design, target population, sample size as well as data collection and data analysis of the procedures followed.

5.2 An overview of research

According to Soanes et al. (2006), research is a methodical investigation that is undertaken to realise new facts and obtain additional information. Ghauri and Grønhaug (2010) provide that research is a systematic process carried out with the primary purpose of finding answers to a question or a variation of questions. It is grounded on logical relationships and not just common beliefs, hence the need to justify the methodologies used to collect data. Research makes it possible for researchers to develop a plausible argument detailing why the results obtained prove meaningful; it further dilates upon limitations encountered during the study and the causes thereof.

Saunders et al. (2019) enlighten that choosing the correct methodology to collect data assists researchers to ascertain whether the data collected, is indeed valid and reliable. A research question can only be tested when the research is designed using accurate research plans and accurate research methodologies. A well-structured research plan is beneficial because it permits effective communication and duplication amongst researchers, which in turn limit the prospects of unintended mistakes. A research plan also enables scientific logic and reasoning.

5.3 Research philosophy and methodology

This research study embraced the phenomenological approach. According to Qutoshi (2018), phenomenology forms part of the interpretivist paradigm that is both a philosophy and a methodology. The interpretivist paradigm focuses on people rather than physical objects. Mackenzie and Knipe (2006) explain that in research, the interpretivist paradigm aims to understand human experiences by suggesting that reality is created through social constructivism.

According to Groenewald (2004), phenomenology is a philosophical method developed by the German philosopher, Edmund Husserl in the early 1900s. Creswell and Creswell (2018) state that phenomenological researchers are mostly interested in understanding psychological and social phenomena from the perceptions of participants involved. Researchers employing phenomenology are largely concerned with lived experiences of participants involved in their research studies. Through the phenomenological approach, researchers can collect data using tools such as interviews, discussions and observations (Matua and Van Der Wal, 2015).

Creswell and Creswell (2018) explain that researchers employing the phenomenological method are likely to depend on qualitative research designs or an amalgamation of both qualitative and quantitative research designs (mixed methods research designs). Qutoshi (2018) impart that phenomenological studies aim to broaden the human mind and improve patterns of thinking about a phenomenon.

Based on the aforementioned descriptions, the researcher carried out a case study approach from a phenomenological perspective. Creswell and Creswell (2018) explain that the employment of case studies helps researchers to conduct a detailed investigation of individual or group experiences. Qutoshi (2018) provides that case studies are advantageous because they provide a complete review of a topic as opposed to standalone research methods. They also reduce the likelihood of bias, as they can capture a wide range of perspectives. As such, the case study focused on the perceptions and experiences of primary caregivers with disclosure and non-disclosure of HIV status to their perinatally infected children, and the meaning they attached to those experiences. The researcher also explored the perceptions and experiences of HCWs providing disclosure services to children and adolescents in receipt of ART medication at Hoekfontein (Mmakau) clinic.

5.4 Research design

According to Sileyew (2020), a research design is a plan devised to indicate how research should be conducted. Likewise, Saunders et al. (2019) stipulate that a research design is a strategy used to demonstrate how a researcher intends to answer his or her research questions. It specifies the source or sources from which data will be collected as well as how the data will be collected and analysed. Creswell (2015) enlightens that research designs are often divided into quantitative, qualitative and mixed methods approaches. For this research, which was a case study, the researcher employed the mixed methods research design. Data were collected through semi-structured interviews, which comprised of open and closed-ended questions. The researcher interviewed 30 participants (18 primary caregivers and 12 HCWs). All participants involved were verbally informed of the purpose and relevance of the study. Interviews took place following agreement and signing of informed consent documents. All interviews were transcribed, audio-recorded and captured on the Microsoft Excel and SPSS software programmes for data analysis.

5.4.1 Mixed methods research designs

The research study adopted the mixed methods research design. According to Creswell (2003), mixed methods research designs imply that data are assimilated or mixed at a particular stage of the research process. The employment of mixed methods research designs shows that neither qualitative nor quantitative data are sufficient in themselves to capture the trends and details of a situation. When combined, both qualitative and quantitative data balance each other to produce a more detailed and complete analysis.

Furthermore, Creswell and Creswell (2018) extend that data collected using mixed methods research designs allow the researcher to gather comprehensive and extensive information that reflects the participants’ points of view. Bazeley (2009) explains that mixed methods research designs involve using mixed data (text and numerical) and alternative tools (analysis and statistics) whilst applying the same method. It is a type of design where a researcher uses quantitative research for one phase of the study and qualitative research for another phase of the study.

Creswell (2015) indicated that combining qualitative and quantitative research designs allows the researcher to develop different perspectives from which a phenomenon may be studied. The utilisation of both qualitative and quantitative research designs makes it possible for a researcher to cross-validate or triangulate the same phenomenon by combining two or more data sources. This helps to provide the researcher with a more detailed and comprehensive understanding of the phenomenon.

Bryman (2006) developed a list of substantial justifications for carrying out mixed methods research and they are:

- **Completeness–** Research problems and sub-problems can only be fully addressed when data is collected, analysed and interpreted using both qualitative and quantitative data.
- **Credibility–** The employment of both qualitative and quantitative approaches augments the integrity of research findings.

- **Complementarity–** Qualitative aspects of a research study can recompense for the weaknesses found in quantitative research, and vice versa. For instance, results obtained in structured and unstructured interviews may have a small number of individuals which may brew concerns about generalisability; these results can however be reproduced by issuing out questionnaires to a larger, more illustrative sample.

- **Context–** The combination of qualitative and quantitative approaches is justified in cases where qualitative research helps provide a contextual understanding that is coupled with either generalisable, externally valid findings or broad relationships among variables.

- **Illustration–** The use of qualitative data helps demonstrate quantitative findings; *"it puts flesh to the bones of dry"* quantitative data.

- **Resolution of unclear findings–** Results in quantitative data may sometimes seem contradictory and inconsistent, thus the incorporation of qualitative data helps the researcher reveal underlying meanings and nuances to makes sense of the numerical data.

- **Triangulation–** A researcher can present a more convincing case of specific conclusions if both quantitative and qualitative data result in those conclusions.

According to Schoonenboom and Johnson (2017), the overarching goal of mixed methods research designs is to combine qualitative and quantitative data components, broaden and strengthen a study's conclusion and contribute to the available literature.

5.4.1.1 Process of carrying out a mixed-method research design

Figure 5.1 illustrates various steps undertaken to adopt a mixed methods research design. The diagram illustrates the 13 steps employed by the researcher from the preparation phase of the research study, throughout the data analysis phase of the study. It shows the rationale and processes followed towards the successful integration of qualitative and quantitative research designs in mixed methods research studies. Johnson et al. (2007) supplement that using both qualitative and quantitative approaches in mixed methods research studies provides a deeper and more detailed understanding of the phenomenon investigated.

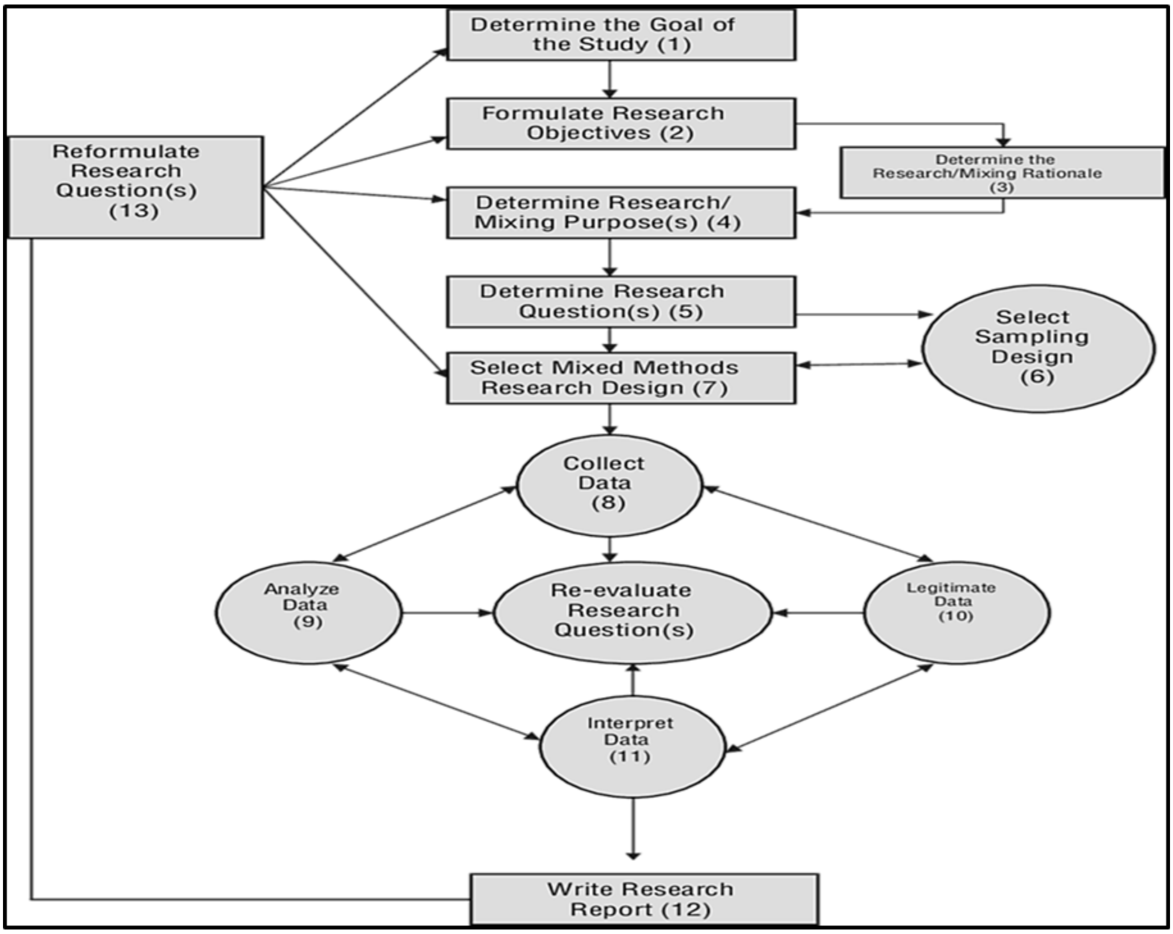

Figure 5.1: Steps indicating the process of mixed methods research
Source: Adopted from Onwuegbuzie et al. (2013)

5.4.2 Qualitative research designs

Lauer and Asher (1988) contend that enquiry in any discipline begins in qualitative form. Qualitative research can be found in many academic disciplines such as sociology, anthropology, psychology, history, biology, medicine, education and political science to name a few. It is normally adopted when there is limited information on a particular topic, when variables are unknown or when a relatable theory base is missing or insufficient. A qualitative study assists in defining what needs to be studied.

This research study was predominantly qualitative with minor quantitative. Schoonenboom and Johnson (2017) enlighten that mixed methods research studies that are qualitatively driven are the kind of studies that rely on the interpretative view of the research process whilst simultaneously recognising the addition of quantitative data. This approach benefits most research projects. Qutoshi (2018) divulges that in mixed methods research designs, quantitative data is mainly used to intensify description and underpin qualitative data.

Denzin and Lincoln (2018) moreover express that qualitative research designs often link with interpretative philosophy. This is because researchers employing these designs need to make sense of the subjective and socially constructed meanings of the phenomenon studied. Leedy and Ormrod (2015) state that this is sometimes referred to as naturalistic research since researchers need to operate within a natural setting to gain access to meanings, participation and a thorough understanding of participants. Furthermore, Denzin and Lincoln (2018) explain that to ensure success in qualitative research, researchers must not only gain physical access to participants, they must also build rapport and demonstrate sensitivity when obtaining access to their cognitive data. Therefore, persons who consent to partake in qualitative research are not seen as mere respondents, but as participants involved in the collection of data.

In qualitative research, meanings result from words and imageries, not figures. Words and imageries may display numerous and unclear meanings, hence the need for researchers to explore and make sense of these meanings with participants. As such, qualitative research often uses methodologies such as semi-structured or unstructured interviews to allow for questions, focus or procedures that change or develop during a naturalistic and interactive research process (Creswell and Creswell, 2018). Denzin and Lincoln (2018) specify that using a single data collection tool such as a semi-structured or unstructured interview is known as a mono method qualitative study.

Leedy and Ormrod (2015) provide that qualitative research studies generally focus on phenomena that are happening or have previously happened in natural settings *"in the real world"*. They involve studying and capturing the intricacy of those phenomena. Researchers assuming qualitative research methods rarely attempt to simplify their observations, they instead recognise that the issue studied has many layers and dimensions and try to interpret it in its multidimensional form.

Additionally, Leedy and Ormrod (2015) supply that often in qualitative research, the methodology contains an iterative procedure where a researcher moves back-and-forth between gathering data and analysing data. This is the constant comparative method. For instance, a researcher may gather preliminary data in a naturalistic setting and review the data for potential patterns. The researcher may also go back to the setting to gather supplementary data that validate, simplify or contradict those patterns. This allows the researcher to conduct a more detailed and comprehensive analysis of the data.

The following are benefits of using qualitative research designs (Leedy and Ormrod, 2015):

- **Exploration–**This helps researchers gain insight into a phenomenon or topics that are insufficiently studied.

- **Multi-layered description–**This can expose the multifaceted nature of certain settings, systems, processes, situations, relationships or people.

- **Verification–**This allows researchers to test the legitimacy of certain theories, assumptions, generalisations or claims within real-life contexts.

- **Theory development–**This enables researchers to develop new theoretical concepts and perspectives related to a phenomenon.

- **Problem identification–**This enables researchers to unearth critical problems, conundrums or impediments that exist within a phenomenon.

- **Evaluation–**This makes it possible for researchers to analyse the efficiency of certain policies, innovations and practices.

Based on the above, the research study utilised the qualitative research design to explore participants' perceptions and experiences with disclosure and non-disclosure of HIV status to children living with PHIV.

5.4.3 Quantitative research designs

According to Coghlan and Brydon-Miller (2014), quantitative research refers to a set of assumptions, plans and techniques used to study social, economic and psychological processes through numerical patterns. The gathering of quantitative information permits researchers to conduct a statistical analysis that aggregates data and demonstrates relationships between data. Allen (2017) conditions that quantitative research aims to produce knowledge and understanding about the social world. It uses scientific inquiry and relies on observable or measurable data to analyse questions about a sample population. Kotzé et al. (2015) provide that quantitative research aims to determine facts, test theories, demonstrate associations between variables and predict outcomes.

Saunders et al. (2019) inform that quantitative research designs are typically affiliated with positivism. They usually incorporate controls to ascertain the validity of the data. Quantitative data are usually collected in a standardised manner, hence researchers need to ensure that the questions asked are clearly expressed and equally understood by each participant. Researchers employing quantitative research designs are independent of those being studied. O'Leary (2004) states that quantitative research designs are investigative.

They produce numerical data that allows percentages to be highlighted, hypotheses to be tested and measures to be obtained. Quantitative data must be processed for it to turn out as useful information. Techniques such as charts, graphs and statistics are often used in quantitative research to help the researcher explore, describe, present and assess trends and relationships found in data.

According to Sukamolson (2007), quantitative research designs have several benefits:

- They can provide researchers with quantitative (numerical, measurable) answers that non-numerical methods such as qualitative research designs cannot provide.
- Numerical or statistical changes are accurately studied by using quantitative research designs.
- Quantitative research designs allow researchers to produce data that are precise, consistent and reliable.
- Fewer variables are included in quantitative research. Data often consists of close-ended questions making the process of data collection faster and easier.
- Quantitative research can be used to describe certain phenomena; it is mostly used to test hypotheses (Sukamolson, 2007).

This research study mainly employed quantitative research designs to obtain participants' socio-demographic information as well as some of their perceptions on child disclosure processes. The quantitative data were obtained by asking the close-ended questions presented in the interview guides (Appendix D and E).

5.5 Target population and sampling selection

5.5.1 Target population

De Vos et al. (2011) describe a target population as a group of individuals or objects possessing similar characteristics. All these individuals or objects derive from a specific population and normally have a common binding trait or characteristic. The target population for this study were primary caregivers of children and adolescents living with PHIV who had either disclosed or not disclosed their HIV status. HCWs who work at Hoekfontein (Mmakau) clinic and provide HIV services to children and adolescents living with HIV also formed part of the target population.

5.5.2 Sampling selection

The most suitable sampling method for this research study was purposive sampling. According to Bernard (2017), purposive sampling, also referred to as judgement sampling, is a type of sampling where a deliberate selection of participants takes place based on the qualities they possess. It is a non-random method that does not require underlying theories or a fixed number of participants. In simple terms, the researcher decides on what needs to be known and elects people who are willing and able to provide the relevant information based on their knowledge or experiences.

Creswell and Plano Clark (2011) impart that qualitative research normally uses purposive sampling to identify and select cases that are rich in information, using available resources. According to Bernard (2017), participants chosen for purposive sampling are often well-informed and proficient about the studied phenomenon. Together with their knowledge and experience, participants need to be available and willing to participate. They must also have the ability to articulate their opinions and experiences in an expressive, reflective and articulate manner. Etikan et al. (2016) state that the main idea behind purposive sampling is to focus on people possessing similar traits or specific characteristics that can assist researchers with their studies.

Due to the complexity and sensitive nature of this study, only 10% of the 182 primary caregivers were purposively sampled to participate. This amounted to a total of 18 primary caregivers, all of which showed willingness and agreed to participate in the study. As mentioned earlier by Vasileiou et al. (2018), studies that are predominantly qualitative often have a smaller sample size because they are mainly concerned with finding the meaning of a case(s) and gaining a thorough understanding of a phenomenon.

The primary caregivers were identified by the researcher, with the assistance of HCWs. They were selected whilst they waited in line to collect ART medication on behalf of their children. After agreeing to participate, the selected primary caregivers were scheduled for individual interview sessions at the clinic. Before the interviews could take place, the researcher informed the participants about the study and its expectations. Information sheets were provided for further reading and informed consent forms were signed (Appendix B).

Furthermore, the clinic had 24 HCWs rendering HIV services to children and adolescents living with HIV (Mororiseng 2021, interview 29 January 2021). The operational manager recruited only 50% (12) of the HCWs to form part of the study's sample size. This was because the operational manager knew their roles, responsibilities and availability during working hours. Following recruitment, the researcher approached each of the 12 HCWs selected and verbally informed them of the study and its expectations. The researcher conducted interviews with each HCW at an appropriate date and time. All HCWs signed the informed consent forms before the interviews could take place (Appendix C).

5.6 Data collection procedure

According to Bernard (2017), data collection is a crucial element in the research process; one that is meant to contribute to an enhanced comprehension of a theoretical framework. Tongco (2007) states that it is of paramount importance for data to be collected with sound judgement. How it is collected and from whom, is crucial, more so because no amount of data analysis can conceal data that has been improperly or incorrectly collected.

The researcher conducted semi-structured interviews (one-on-one interactions) with participants to obtain all data needed to achieve the objectives of the study. As noted by De Vos et al. (2011), researchers use semi-structured interviews to gain an understanding of participants' perceptions on a certain topic. Semi-structured interviews are beneficial when a research topic is complex or when an issue is personal or controversial.

Furthermore, the researcher made use of interview guides (Appendix D and E) as data collection tools. As described by Menzies et al. (2016), interview guides consist of a list of questions that a researcher asks participants during interviews. The interview guides consisted of open and close-ended questions. The open-ended questions allowed for the viewpoints of participants to be adequately voiced, while the close-ended questions gathered factual data such as the participants' socio-demographic characteristics. To accommodate all participants, the interview guides were drafted in both English and Setswana respectively. Twenty-two interviewees preferred interviews conducted in Setswana while eight interviewees preferred interviews conducted in English. All interviews conducted in Setswana were translated to English to enable analysis of data.

To ensure further accuracy and consistency, the researcher used an audio recording as a tool to capture all information acquired during the one-on-one interviews. According to Mary (2008), audio recording is a transparent technique used to ensure precision during data collection. Recorded interviews allow the interviewer and interviewee to build rapport and cultivate a meaningful relationship during proceedings. This leads the interviewee to disclose more in-depth and thorough information. Sullivan (2010) edifies that audio recording improves the quality of the information provided. It provides a true and unbiased narration of the interview, which paints a holistic picture of the phenomenon studied. It also permits the researcher to replay, review and possibly identify important information that might have been overlooked during interview proceedings.

Furthermore, effective time-management took place; each interview lasted approximately 30 minutes. All interviews took place at the clinic, in a private room, at a scheduled date and time. The researcher ensured that all COVID-19 health protocols were adhered to during the interview sessions.

5.7 Data analysis

The qualitative data were captured on the Microsoft Excel software programme and were analysed using thematic analysis. This process involved identifying patterns and relationships deriving from the participants' responses. Caulfied (2019) describes thematic analysis as a methodology used to organize and code information into categories of themes and sub-themes. As such, the researcher first translated the Setswana recorded and written transcripts to English. This was verified by re-reading and re-listening to the recording audio to ensure accuracy and understanding of the data collected. After translating the audio recordings and familiarising with the transcripts, the researcher summarised all qualitative data by identifying codes and themes that emerged from the participants' responses. The quantitative data were captured on the Statistical Package for Social Sciences (SPSS) software programme and analysed using descriptive analysis.

5.8 Data reliability and validity

According to Mohajan (2017), data reliability and validity are two of the most vital features when evaluating any measurement tool used in research. Haynes et al. (2017) state that validity concerns itself with what the tool measures and how well it does so. Reliability relates to the faith that one can have in the data obtained from the tool or instrument used. To ensure validity, the researcher used interview guides (Appendix D and E) that asked appropriate and consistent questions to all participants involved. Reliability was ensured by including the interview guides in the research report to allow transparent evaluation and review from readers.

5.9 Limitations and delimitations of the study

Time served as a limitation in this study. Some HCWs had to attend to work obligations during the interviews but subsequently returned to finish off the rest of the sessions. This disturbed the flow of discussions but was mitigated by using audio recordings to safeguard that all information was captured. A delimitation of the study was that the study relied solely on the perceptions and experiences of primary caregivers and HCWs, and not of the children and adolescents concerned. The results of the study were also not large enough to be generalised due to the study’s small sample size.

5.10 Ethical considerations

Resnik (2020) stipulates that ethics uphold essential values such as trust, respect, fairness and accountability in research. They are norms put in place to distinguish between acceptable and unacceptable conduct. They moreover ensure that researchers are held accountable to the participants and public. As stated by Simelane-Mnisi (2018), every researcher needs to obtain ethical clearance before the commencement of the research study. The researcher thus obtained ethical clearance from the HSREC at the University of the Free State (Appendix A) and the North West Department of Health (Appendix F and G) before collecting data. All participants gave informed consent before the interviews took place. Participation was voluntary and confidential. The researcher also avoided plagiarism by ensuring that all sources cited in the report were rightfully acknowledged.

5.11 Chapter summary

In this chapter, the researcher provided an overview of research. A description of the research philosophy and methodology adopted was also given. The research study embraced phenomenology as its philosophical method, a method deriving from the interpretivist paradigm. The chapter also discussed in detail, the mixed methods research design, which consisted of both qualitative and quantitative research designs. The main aim of the discussion was to strengthen and motivate why the researcher chose to incorporate both designs instead of just one. The inclusion of both designs proved complementary and assisted the researcher to fully comprehend the phenomenon studied. Target population and sampling methods were also explained in this chapter. The study made use of purposive sampling while the target population consisted of a selection of primary caregivers caring for children living with PHIV and HCWs providing HIV services at Hoekfontein (Mmakau) clinic. The chapter moreover explained procedures followed to collect and analyse the data obtained. Data validity and reliability were discussed. Limitations, delimitations and ethical considerations of the study were also highlighted. The next chapter displays the results of the in-depth interviews. It also aims to ensure that conclusions emanating from the literature review, are supported with empirical research.

Chapter 6
PRESENTATION AND DISCUSSION OF RESULTS

6.1 Introduction

The results of the study are presented and discussed in this chapter. Wisdom and Creswell (2013) state that presentation and discussion of results is done to unearth significant findings from the empirical research. As such, the socio-demographic information will set the stage for a detailed exploration of the participants' perceptions and experiences with disclosure and non-disclosure of HIV status to children living with PHIV. A total of thirty (N=30) participants were successfully interviewed using semi-structured interview guides (Appendix D and E). Paricipants consisted of 18 primary caregivers and 12 HCWs. All of the participants recruited agreed to participate in the study and provided valuable information towards the study's objectives.

6.2 Participants' socio-demographic information

Table 6.1: Socio-demographic information of HCWs

Characteristics	Number of responses	Percentage (%)
Gender		
Male	3	25.0
Female	9	75.0
Age		
18–29	1	8.3
30–39	5	41.6
40–49	3	25.0
50–59	3	25.0
60+	0	0.0
Profession		
Professional nurse	4	33.3
Assistant nurse	1	8.3
Lay counsellor	4	33.3
Community health worker	3	25.0
Duration of service		
1–5 years	3	25.0
6–10 years	2	16.6
11–15 years	5	41.6
16–20 years	1	8.3
30+	1	8.3
Roles and responsibilities		
Primary healthcare	5	41.6
HIV testing, counselling and adherence support	4	33.3
Patient registrations, tracing defaulters and adherence	3	25.0

6.2.1 Composition of HCWs

There were more female HCWs (75%) than male HCWs (25%). Female HCWs outnumbered male HCWs because the overall composition of the clinic staff is predominantly female. Their ages ranged from 18 to 59 years as indicated in Table 6.1. Most HCWs (41.6%) were between the ages of 30–39 years. This was because most HCWs at the clinic were still in their prime working years while senior HCWs had already retired. There were only three (10%) HCWs between the ages of 50–59 years still working at the clinic.

6.2.2 Duration of service at the NDOH

A majority, five (41.6%) of the HCWs had 11–15 years of work experience under the employment of the NDOH. Three (25%) HCWs had 1–5 years in service, while two (16.6%) had work experience of 6–10 years. The minority, 8.3% (one) was a HCW who had served 16–20 years. A further 8.3% (one) of the HCWs served more than 30 years. All HCWs were designated to offer HIV services to children, adolescents and adults living with HIV and receiving ART medication at Hoekfontein (Mmakau) clinic.

6.2.3 Roles and responsibilities of HCWs at the clinic

Five (41.6%) of the participants were professional and assistant nurses responsible for primary health care services which include, but are not limited to infant immunisations, antenatal and postnatal care, PMTCT, child and adult health, HIV testing and counselling. Furthermore, four (33.3%) were lay counsellors responsible for providing children, adolescents and adults with adherence suppprt and pre- and post-HIV counselling. The remaining three (25%) were community health workers designated to ensure that all clinic patients are registered on the clinic database. The community health workers also had the duty to trace and provide adherence support to patients defaulting on chronic medication such as ART.

Table 6.2: Socio-demographic information of primary caregivers

Characteristics	Number of responses	Percentage (%)
Gender		
Male	1	5.5
Female	17	94.5

Age		
18–29	2	11.11
30–39	8	44.4
40–49	4	22.2
50–59	0	0.0
60+	4	22.2
Level of education		
Primary education	6	33.3
Secondary education	9	50.0
TVET college	2	11.1
University education	1	5.6
Relation to the child		
Biological caregiver	8	44.4
Non-biological caregiver	10	55.6
Disclosed		
Yes	11	61.1
No	7	38.9
Age group of child in care		
6–8	1	5.6
9–11	1	5.6
12–14	4	22.2
15–17	10	55.6
18–19	2	11.1

Source: Field survey (2021)

6.2.4 Composition of primary caregivers

The percentage of female primary caregivers (94.5%) outweighed that of male primary caregivers (5.5%). Furthermore, the majority (55.6%) of primary caregivers' relation to their children was non-biological, while the minority was biological (44.4%). This was because most children living with PHIV and in receipt of ART medication at Hoekfontein (Mmakau) clinic are orphaned due to HIV/AIDS and are placed in foster care with caregivers such as maternal grandmothers, paternal grandmothers, aunts and biological sisters. These results confirm findings made by Nyamukapa et al. (2008), Manderson et al. (2016) and McHugh et al. (2018) who also found that most children living with PHIV are orphaned by HIV/AIDS, which often subjects them to foster care or alternative placements.

6.2.5 Educational level of primary caregivers

A majority of primary caregivers, nine (50%), had secondary education, while six (33.3%) only had primary education. Two (11.1%) primary caregivers furthered their studies at Technical Vocational Education and Training College (TVET College) while one (5.6%) possessed university education. Scholars such as Bhattacharya et al. (2011) and Lawan et al. (2016) found that primary caregivers' who had a higher level of education had a better understanding of disclosing the status of their children at the recommended age of 12.

Synonymous with Bhattacharya et al. (2011) and Lawan et al. (2016), the two (11.1%) primary caregivers who had furthered their studies at TVET College, as well as the one (5.6%) who had pursued university education, stated to have disclosed at the recommended age of 12 because they feared the possible risks related to delayed disclosure and therefore requested guidance from HCWs. For primary caregivers who possessed secondary education, six (33.3%) had disclosed compared to three (16.7%) who had not disclosed. Only two (11.1%) primary caregivers who had primary education had disclosed as opposed to four (22.2%) who had not yet disclosed the HIV status of their children. Primary caregivers who had not disclosed expressed that they did not know how or when to disclose. They expressed the critical need for education and informed guidance on disclosure and its importance to the well-being of their children.

6.2.6 Prevalence of disclosure

A majority, 61.1% which represented eleven primary caregivers, had disclosed the status of their children as opposed to seven (38.9%) who had not yet disclosed. The results further revealed that disclosure was more prevalent among non-biological caregivers as seven (38.8%) of them had disclosed to their children as compared to four (22.2%) biological caregivers who had disclosed. In contrast, rates of non-disclosure were higher among biological caregivers than non-biological caregivers. Four (22.2%) biological caregivers had not disclosed compared to three (16.6%) non-biological caregivers who had not disclosed. Manye and Madiba (2015) found that biological caregivers delayed disclosure due to factors such as internal guilt of vertical transmission and unacceptance of their own status. This research study produced similar findings.

6.2.7 Age of the children in the care of primary caregivers

The results revealed that the majority, ten (55.6%) children under the care of primary caregivers were aged between 15–17 years. Children aged between 12–14 years were four (22.2%), while those aged between 18–19 years were two (11%). Children aged between the ages of 6-8 and 8–9 years were the least at one (5.6%) respectively. All children and adolescents under the care of primary caregivers were between the ages of 6–18 years, which was the age category required for the study.

6.2.8 Persons living in the household

Table 6.3 indicates participants’ responses regarding persons living with them and their children within their households. Participants were eligible to select more than one response to this question. Fish (2011) defines multiple response questions as questions to which participants or respondents may select more than one option.

Table 6.2: Other persons living with the primary caregiver and child

Persons in household	Number of responses (N=18)	Percentage (%)
Aunt	10	55.6
Uncle	2	11.1
Grandfather	5	27.8
Grandmother	6	33.3
Siblings	7	38.9
Nephews	8	44.4
Nieces	7	38.9
Cousins	6	33.3

Source: Field survey (2021)

Literature has shown that many children living with PHIV are orphaned due to the inimical effects of HIV/AIDS (Manderson et al., 2016). As a result, their micro-system, which encompasses immediate family members, is fractured and children are subjected to alternative placements with extended family members (Brofenbrenner, 1986; Manderson et al., 2016). In alignment with theory and literature, the results of this study produced similar findings. Ten (55.6%) primary caregivers stated that they, together with the children in their care, live with aunts. Eight (44.4%) primary caregivers stated to have nephews living with them and their children. Seven (38.9%) primary caregivers indicated that their family composition consisted of siblings and nieces. Six (33.3%) primary caregivers selected grandmothers and cousins as other people living with them and their children. Five (27.8%) primary caregivers indicated that other extended family members included grandfathers, while two (11.1%) primary caregivers indicated that they also live with uncles.

6.2.9 Knowledge of child's HIV status within the household

Table 6.3: Knowledge of HIV status among other persons in the household

Responses	Percentage (%)
Yes	94.4
No	5.6
Total	100

Source: Field survey (2021)

A majority, seventeen (94.4%) primary caregivers revealed that all family members in the household knew the HIV status of their children. Beima-Sofie et al. (2014) and Atwiine et al. (2015) found that many primary caregivers living in stable and enabling family environments tend to disclose the status of their children to other members of the family to gain support. This research study echoed the same sentiments. A small minority, one (5.6%) primary caregiver alluded to not disclosing her own status and that of her child to the family. Consistent with studies conducted by Kiwanuka et al. (2014) and Manye and Madiba (2015), oftentimes, as in the case of this one primary caregiver, biological caregivers' inability to accept their own HIV status often leads to the intensified inability to disclose to their children and other family members.

6.2.10 External individuals' knowledge of child's HIV status

Table 6.4: Knowledge of HIV status among persons external to the family

Responses	Percentage (%)
Yes	38.9
No	61.1
Total	100

Source: Field survey (2021)

A majority, eleven (61.1%) primary caregivers voiced that persons outside of their immediate family did not know their children's HIV status. The remaining seven (38.9%) attested to other persons knowing. Those who disclosed declared that they informed persons in the meso-system such as extended family members, school teachers and close neighbours to gain additional support in cases of unforeseen predicaments (Brofenbrenner, 1986). De Silva et al. (2018) found fear of stigma and societal judgement in the exo-system (community level) to be substantial barriers to primary caregivers disclosing to persons outside of their immediate families or seeking auxiliary support. In likeness with De Silva et al. (2018), most primary caregivers in this study did not disclose to external individuals because they feared being ostracised by society.

6.3 Participants' perceptions on disclosure and non-disclosure

This section of the chapter presents HCWs and primary caregivers' perceptions regarding disclosure and non-disclosure of HIV status to children and adolescents living with PHIV. The first part of the section provides perceptions of HCWs on child disclosure services. The second part of the section makes provision for perceptions of primary caregivers with disclosure and non-disclosure of HIV status.

6.3.1 Perceptions of HCWs with child disclosure services

6.3.1.1 Knowledge and understanding of child disclosure

The HCWs were asked whether they knew and understood what child disclosure is. All twelve (100%) HCWs as indicated in Figure 6.1, responded positively by answering yes to the question probed.

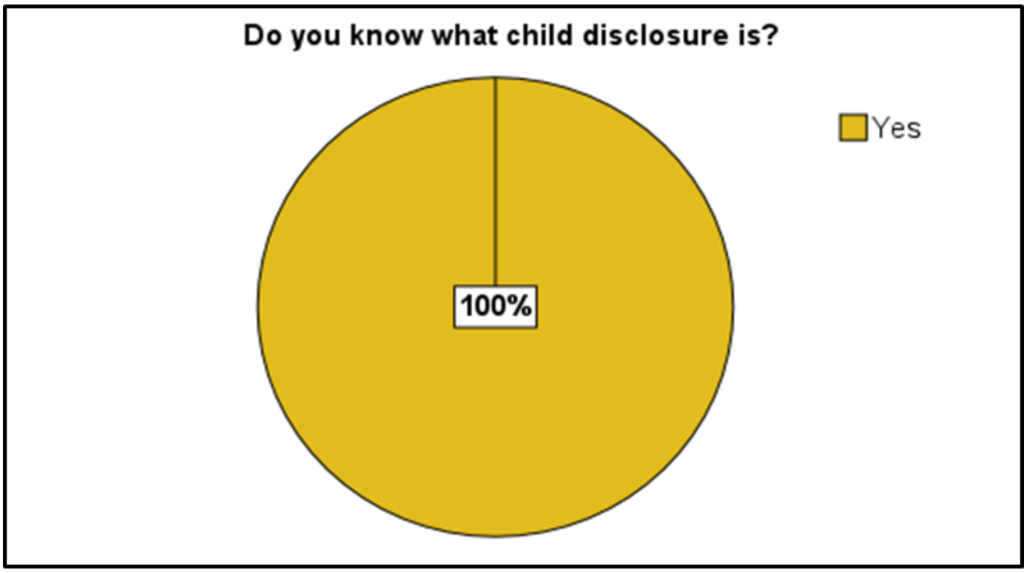

Figure 6.1: Knowledge and understanding of child disclosure
Source: Field survey (2021)

Their responses when defining child disclosure tallied with definitions and descriptions provided in theory by the WHO (2011), the NDOH (2016), and the DSD (2019). They reported that child disclosure is not a once-off event, but rather an ongoing process that requires unwavering support from primary caregivers, HCWs and all relevant stakeholders.

6.3.1.2 Awareness of existing disclosure guidelines

Table 6.6: Awareness of existing disclosure guidelines

Responses	Percentage (%)
Yes	58.3
No	41.7
Total	100

Source: Field survey (2021)

Questioned whether they were aware of existing child and adolescent disclosure guidelines developed by the NDOH in 2016, seven (58.3%) HCWs responded yes, while five (41.7%) attested to not being aware of their existence. The discrepancy in these results as illustrated in Table 6.6, confirms gaps identified in the literature on the need for continuous awareness, education and training of HCWs on the longstanding WHO guidelines of 2011 and context-specific guidelines such as those advanced by the NDOH in 2016.

6.3.1.3 Implementation of disclosure guidelines

Asked whether they implement the existing child and adolescent disclosure guidelines, nine (75%) HCWs declared no, while three (25%) confirmed implementing the guidelines during service delivery. Table 6.7 details the HCWs' responses.

Table 6.7: Implementation of existing guidelines

Responses	Percentage (%)
Yes	25
No	75
Total	100

Source: Field survey (2021)

These results reflect findings of past and recent studies conducted by scholars such as Kranzer et al. (2014) and Madiba and Diko (2021) who discovered poor implementation of guidelines amongst most HCWs in public health facilities, particularly in low-resource settings across sub-Saharan African countries. The HCWs who answered no, mentioned several grounds for non-implementation and they are abridged and quantified in Table 6.8.

6.3.1.4 Grounds for non-implementation of existing guidelines

Table 6.8: Non-implementation of existing guidelines

Reasons	Percentage (%)
Lack of training and reading material	66.7
Hardly find time, overwhelming workload	16.6
Refer patients to social worker due to lack of skill	16.6
Total	100

Source: Field survey (2021)

Similar to participants in studies conducted by Watermeyer (2015), Busza et al. (2016) and Madiba and Diko (2021), Table 6.8 displays that the majority, eight (66.7%) of the HCWs in this research study also noted lack of training and reading material at the clinic as prominent reasons for non-implementation of the guidelines. The HCWs emphasised that they do not receive any in-service or external training on the guidelines. Respectively, two (16.6%)

HCWs highlighted lack of time and overwhelming workload as constraints to effective implementation. The other two (16.6%) expressed that they do not implement the guidelines because they perceive child disclosure to be a process specifically formulated for social workers as they possess better interpersonal skills to manage its complexities. The results further reveal the crucial need for enhanced education and training to nullify misconceptions and uncertainties surrounding child disclosure services (Madiba and Diko, 2021).

6.3.1.5 Frequency of training on disclosure guidelines

Figure 6.2 displays the regularity of training received by HCWs.

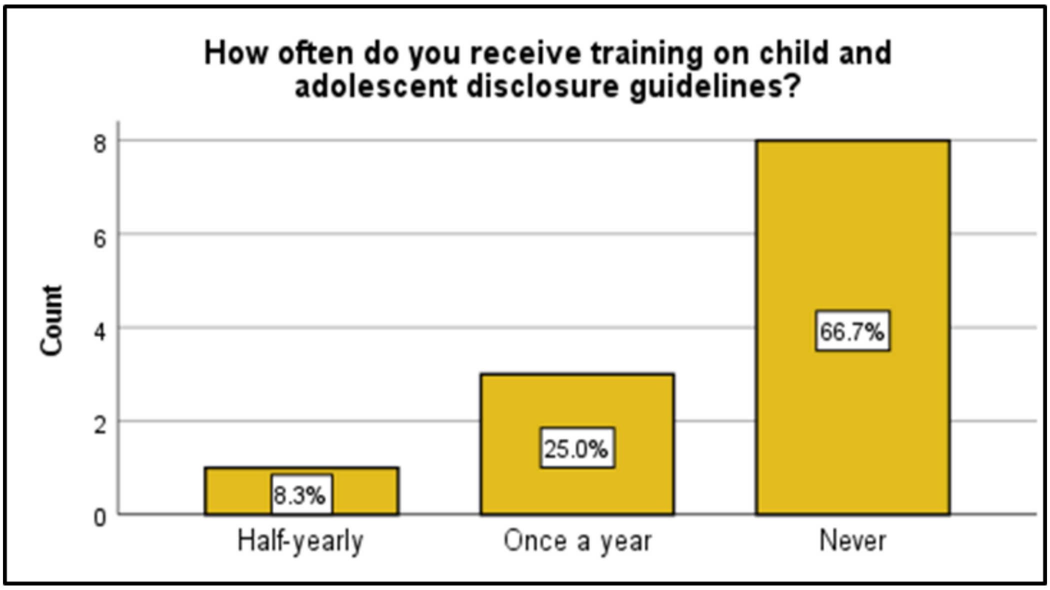

Figure 6.2: Frequency of training on guidelines
Source: Field survey (2021)

In agreement with scholars, Kranzer et al. (2014), Sariah et al. (2016) and Madiba and Diko (2021), the results of this study likewise revealed that the majority, eight (66.7%) of the HCWs had never received any formal or informal training on child and adolescent disclosure guidelines. A low, 25% (three) of the HCWs reported to only receiving training once a year. An even lower percentage, 8.3% (one) of the HCWs claimed to receive training half-yearly. This revelation exposes the absence of synergy between policy and practice. The variance in these responses shows that there are still gaps that ought to be filled through equal capacity building amongst all HCWs designated to provide services to children and adolescents living with HIV in Mmakau village.

6.3.1.6 Necessity of training on existing guidelines

Figure 6.3 depicts HCWs' perceptions regarding training on existing guidelines.

Figure 6.3: Necessity of training on existing disclosure guidelines

Source: Field survey (2021)

Asked whether they perceived training as necessary, all twelve (100%) HCWs agreed to its essentiality. The HCWs viewed training as an indispensable tool to developing and enhancing professional skills. They voiced that through adequate training, they would be able to make well-informed, ethical decisions that are in line with health acts and policies. These results prove synonymous with those of a study conducted by scholars Hayfron-Benjamin et al. (2020). Enabler 2 of the NDMF provides that the training of officials on programmes aimed at reducing and managing disaster risk is paramount because it enables them to cascade and impart knowledge to the affected individuals and the general public (South Africa, 2005b).

6.3.1.7 Provision of follow-up training on disclosure guidelines

Responses of HCWs regarding follow-up training received on the guidelines are indicated in Table 6.9.

Table 6.9: Provision of follow-up training on guidelines

Responses	Percentage (%)
Yes	25
No	75
Total	100

Source: Field survey (2021)

When asked about the provision of follow-up training, nine (75%) HCWs stated that they had never received follow-up training on child and adolescent disclosure guidelines. Only three (25%) attested to having received follow-up training when invited or selected to attend external workshops. These results are another indication that the NDOH needs to enhance its capacity-building strategies.

6.3.1.8 Monitoring and evaluation done on guidelines

Table 6.10 reflects the HCWs' views on monitoring and evaluation of disclosure.

Table 6.10: Monitoring and evaluation of child and adolescent disclosure guidelines

Responses	Percentage (%)
Yes	83.3
I am not sure	16.7
Total	100

Source: Field survey (2021)

The NDOH (2016) denotes monitoring and evaluation of guidelines as a fundamental component to successful disclosure services. The department deems disclosure as a multifactorial process and not a single event that can be measured like a diagnostic test or a single visit to the clinic. Asked whether monitoring and evaluation were done to ensure effective implementation of the guidelines, ten (83.3%) HCWs responded yes while two (16.7%) stated that they were not sure. The HCWs who answered yes, succinctly elaborated that the clinic's operational manager holds monthly meetings to holistically discuss progress made on all health and psychosocial services rendered to patients.

6.3.1.9 Skills to facilitate the disclosure process as per guidelines

Table 6.11 demonstrates HCWs' views on their skills to adequately facilitate the disclosure process as per existing guidelines.

Table 6.11: Possession of skills to facilitate disclosure

Responses	Percentage (%)
Strongly agree	16.7
Agree	16.7
Neither agree nor disagree	16.7
Disagree	33.3
Strongly disagree	16.7
Total	100

Source: Field survey (2021)

Asked about their skills and competence to facilitate the disclosure process, only two (16.7%) HCWs strongly agreed. A further two (16.7%) neither agreed nor disagreed with being skilled enough to facilitate the process. Contrarily, a slightly higher number of HCWs, six (33.3%), disagreed with having adequate skills to facilitate disclosure with children and their primary caregivers. The last two (16.7%) strongly disagreed with being adequately skilled. The variances in these results reiterate the need to train HCWs on available guidelines so that disclosure services may be standardised.

6.3.1.10 Suggested measures to enhance skills on disclosure services

Table 6.12 displays HCWs’ responses to suggested measures aimed at improving child and adolescent disclosure services at Hoekfontein (Mmakau) clinic. Asked what they thought could be done to enhance their knowledge and skills on child disclosure services, ten (83.3%) HCWs strongly agreed that there should be frequency in training on child disclosure guidelines; two (16.7%) HCWs agreed to this motion. A majority, ten (83.3%) of the HCWs suggested that provision should be made for tangible resources such as manuals and booklets; two (16.7%) also agreed. Eleven (91.7%) HCWs suggested that there should to be child-friendly spaces at their facility; one (8.3%) agreed to this suggestion. All HCWs (100%) strongly agreed that disclosure would be more effective if there was an increase in the time allocated for disclosure sessions. Nine (75%) HCWs strongly suggested the employment of more skilled staff, three (25%) agreed. Furthemore, nine (75%) HCWs strongly agreed on the need to strengthen referral and linkages systems amongst all relevant stakeholders. The remaining three (25%) also agreed. These results once again resound views shared by participants in previous and recent studies conducted by Rujumba et al. (2010), Gachanja et al. (2014), Busza et al. (2016) and Madiba and Diko (2021), to name a few.

Table 6.12: Suggestions toward improved disclosure services at clinic

Measures	Number of responses (N=12)	Percentage (%)
Frequent training on child disclosure guidelines		
Strongly agree	10	83.3
Agee	2	16.7
Provision of tangible resources (e.g. manuals)		
Strongly agree	10	83.3
Agee	2	16.7
Provision of child-friendly spaces		
Strongly agree	11	91.7
Agee	1	8.3

Increased time allocation for disclosure services Strongly agree	12	100
Employment of more skilled staff Strongly agree Agee	9 3	75 25
Strengthen referral and linkages systems amongst stakeholders Strongly agree Agee	9 3	75 25

Source: Field survey (2021)

6.3.2 Perceptions of primary caregivers and HCWs with disclosure and non-disclosure

6.3.2.1 Perception on whose responsibility it is to disclose to children

Table 6.13 illustrates participants' (both HCWs and primary caregivers') perceptions on whose responsibility it is to disclose the HIV status of children living with PHIV.

Table 6.13: Responsibility to disclose HIV status

Responsibility	Number of responses (N=30)	Percentage (%)
HCWs' perception		
Primary caregiver	12	100
Primary caregivers' perception		
Primary caregiver Healthcare worker	16 2	88.8 11.2

Source: Field survey (2021)

Asked whose responsibility they perceived it was to disclose to children living with PHIV, all twelve (100%) HCWs declared primary caregivers as the most suitable persons to disclose to children. Sixteen (88.8%) primary caregivers also concurred that the responsibility to disclose lies with them and not HCWs. These results are synonymous with recommendations made by the WHO (2011) and the NDOH (2016). Only two (11.2%) primary caregivers deemed HCWs as responsible persons to disclose to their children. This discrepancy although nominal, confirms the prevailing confusion found in the literature on whose responsibility it is to disclose to children living with PHIV (Sariah et al., 2016; Appiah et al., 2019). The continuation of such confusion contributes to the prevalence of delayed disclosure amongst resource-limited communities such as Mmakau village, hence the need for continuous awareness and education among communities.

6.3.2.2 Perceived age for disclosure

Table 6.14 demonstrates participants' perceptions on the age they deemed suitable for disclosure. The table provides a comparative analysis between HCWs and primary caregivers who had not yet disclosed and who had already disclosed the HIV status of the children in their care.

Table 6.14: Age deemed suitable for disclosure

Responses	Number of responses (N=30)	Percentage (%)
Perception of HCWs		
Age		
10	1	3
11	1	3
12	5	17
13	2	7
14	1	3
15	2	7
Perception of primary caregivers who had not yet disclosed		
Age		
15	2	7
16	2	7
17	2	7
18	1	3
Perception of primary caregivers who had already disclosed		
Age disclosed		
11	1	3
12	3	10
14	2	7
15	4	13
18	1	3

Source: Field survey (2021)

The results of this study varied significantly as with studies conducted by Lawan et al. (2016) and Sariah et al. (2016). Five (26%) HCWs viewed the age of 12 as the most appropriate age to disclose– this being in line with the recommendations made by the WHO (2011) and subsequently, the NDOH (2016). Two (11%) HCWs viewed the age of 13 as the most suitable age to disclose while a further two (11%) viewed the age of 15 as the most suitable age for disclosure. Respectively, other HCWs (5%) perceived ages 10, 11 and 14 as the most appropriate ages for disclosure. On the contrary, primary caregivers who had not yet disclosed the HIV status of their children considered ages in middle (15-17) and late adolescence (18-19) as the most appropriate ages for disclosure. Two (11%) primary caregivers projected age 15 as the most suitable age for disclosure. Two (11%) perceived age 16 as the most suitable, while the other two (11%) saw the age of 17 as the most suitable age to disclose the HIV status of children. One (5%) primary caregiver deemed age 18 as the most appropriate age to disclose.

Furthermore, four (13%) of the primary caregivers who had already disclosed, perceived the age of 15 as the most suitable age to disclose and thus disclosed at that age because they considered it a period that signifies maturity in their children. Three (10%) primary caregivers perceived the age of 12 as the most suitable age to disclose the HIV status of their children and therefore disclosed at that time. Two (7%) primary caregivers disclosed when their children were 14 years old. One (3%) primary caregiver disclosed at the age of 11, while the other one (3%) disclsosed at the age of 18. Evident in these results, as in literature, delayed disclosure outweighs early or timely disclosure (Madiba and Mokgatle, 2017). Even though some primary caregivers disclosed to their children at the recommended age of 12, a notable percentage of primary caregivers only sought to disclose to children in their middle (15-17) and late adolescent (18-19) stages as they deemed children to only be of sufficient maturity during these stages.These differences uncover the lack of knowledge and understanding on the recommendations set out in existing guidelines. More educational intervention is as such, needed.

6.4 Participants’ experiences with disclosure and non-disclosure

This section presents qualitative data (open-ended) questions asked during semi-structured interviews with participants. The study used thematic analysis to analyse all qualitative data obtained. Nowell et al. (2017) describe thematic analysis as a process undergone by researchers to label and organise qualitative data to identify common themes and establish relationships between them. As such, the researcher first identified codes and meanings emerging from the data by repeatedly reading and familiarising herself with participants’ transcripts. Interview guides written in Setswana were translated verbatim to allow thorough interpretation. Following this procedure, themes and sub-themes were identified and subsequently analysed on the Microsoft Excel software programme.

Ten (10) main themes and forty-two (42) sub-themes influencing disclosure and non-disclosure of HIV status to children living with PHIV were generated. The first part of this section provides experiences of HCWs with child disclosure services at Hoekfontein (Mmakau) clinic. The second part of the section provides experiences of non-disclosed primary caregivers, and the third and final part of the section delineates the experiences of primary caregivers who had disclosed the HIV status of their children before the commencement of the research study.

6.4.1 Experiences of HCWs with child disclosure services

Limitations to successful disclosure

Many participants described child disclosure as an indispensable component in the care and management of HIV but attested to its implementation being poor at Hoekfontein (Mmakau) clinic due to several limitations.

Lack of training

Participants viewed lack of standardised training as the main impediment towards successful disclosure services. They also noted unequal provision of training opportunities among personnel providing HIV services, as a barrier to successful disclosure practices at Hoekfontein (Mmakau) clinic.

> ***Participant 2, lay counsellor:*** *"I think if the department should make sure that all of us are trained the same way, things would be better. There is a tendency of constantly employing one person to attend the same training over and over. This is unfair because other HCWs are not able to learn and grow. I for one have been trained more than my colleagues and have books and material that they don't have. I find this to be the main reason things are not working out, it's not equal."*

> ***Participant 10, professional nurse:*** *"We are not trained yet we are expected to do our work exceptionally well. I have worked for this department for over 30 years, but I have never received any training on child disclosure guidelines. I just use my professional intuition when faced with difficult situations. I also just call the area social workers, which is also a problem because they are not always there to assist."*

> ***Participant 8, professional nurse:*** *"The last time I received training was in 2017, no follow-up training was conducted after that. It is now 2021 and no refresher training course or some kind of workshop has been provided to us as HCWs."*

Shortage of skilled staff, child-friendly spaces and resources

Participants revealed that they do not have sufficient skilled staff to carry out the process as recommended. They also noted a lack of child-friendly spaces to initiate the process. Lack of resources such as reading material (guidelines) on disclosure were some of the notable barriers to the effective implementation of child disclosure services. These findings mirror those of participants in studies conducted by scholars, De Schact et al. (2014) and Busza et al. (2016).

> ***Participant 1, lay counsellor:*** *“We don’t have our own stationed social worker and this is a problem. Remember HIV is not just a health matter, but a social one as well, so sometimes we are faced with situations that we cannot handle, like for example, a child failing to take ART medication because they don’t have enough food or they don’t receive foster care grants at home. Some of these children complain that the medication hurts their tummies when they have not eaten, so if there was a social worker specifically based at our clinic, things like defaulting would be reduced. The department needs to hire at least one social worker, it will help a lot.”*
>
> ***Participant 8, professional nurse:*** *“Our clinic is so small, we even use a mobile container to see some of our patients, sometimes, the kitchen if all rooms are occupied. There isn’t enough space to ensure patient-client confidentiality; hence, we don’t conduct these sessions. If we could at least get a nice room for children, it would make a difference because children like stuff like pictures and colour.”*
>
> ***Participant 12, community healthcare worker:*** *“We don’t have any reading materials to guide us, therefore, we are unable to carry out the sessions with children and their primary caregivers, we consult among each other and do what we can as best as we possibly can.”*

Overwhelming workload

As with previous and recent studies conducted by Sariah et al. (2016) and Madiba and Diko (2021), participants in this study also noted overwhelming workload schedules and time constraints as barriers to disclosure. They expressed that they hardly find time because they incessantly have to attend to patients.

> ***Participant 4, professional nurse:*** *“I am one of the senior nurses at the clinic; I am always running around, seeing patient after patient, even now during this interview, I have to rush. We are really overloaded with work, so that’s why we don’t facilitate disclosure the way we should.”*
>
> ***Participant 11, community healthcare worker:*** *“We don’t have time, we don’t have time at all, we are expected to do household visits every day to trace patients and this takes up most of our day. We also walk while doing this, so it’s a lot.*

Falsification of illness and non-accompanying to the clinic

Participants expressed that primary caregivers contribute significantly to non-disclosure and delayed disclosure of HIV status to children and adolescents living with PHIV. They stated that primary caregivers tend to complicate the process by providing children with untrue information regarding their diagnosis. They are also inconsistent in accompanying their children to the clinic, making it even harder for HCWs to implement the process. Manye and Madiba (2015) state that this practice does more harm than primary caregivers often realise; it leads to children being vulnerable and at risk of defaulting on ART medication.

> ***Participant 3, lay counsellor:*** *"Another issue is really parents and caregivers of these children. They make our work even more difficult. They do not bring their children in for viral load check-ups; they also don't come with them to the clinic to collect their medication. This makes it hard to trace these children and bring them back to care. Most of these children don't know why they are taking those pills."*

> ***Participant 6, professional nurse:*** *"Parents are untruthful. You find that you want to help a child, but his or her mother keeps telling the child that the pills are for eye problems. Even when you explain the dangers of lying, some parents disregard our advice, making disclosure even more difficult than it already is."*

Negative experiences with delayed disclosure

Participants expressed that in their various experiences as HCWs in the HIV/AIDS sector, children who are unaware of their HIV status, or who have learned of their HIV status in the latter stages of their adolescence, experience a range of health and behavioural problems as opposed to their counterparts who were informed earlier in their upbringing.

Defaulting from ART intensifies disease progression

Defaulting on ART medication was highlighted as one of the negative experiences with delayed disclosure. This implies that children did not take their medication as prescribed, which in turn made them ill quicker.

> ***Participant 9, community healthcare worker:*** *"In my experience, children who are told late in their adolescence default terribly from ART and end up getting sick quicker than those who know. They really can't handle the trauma when they are older, they just give up."*

> ***Participant 7, assistant nurse:*** *"Because they don't understand how critical it is for them to take ART frequently, children who don't know their status are ignorant and inconsistent in their regime. They have very high viral loads, they are not suppressed and it's worrying because some end up dying earlier than they should."*

Discovery of HIV status through voluntary testing

Alarmingly, most participants described non-disclosure and delayed disclosure of HIV status as practices that may seem conducive in the initial stages, but can in the end, be detrimental to the psychosocial functioning of children living with PHIV. They bear risks that can result in premature death.

> ***Participant 10, professional nurse:*** *"Some of these children learn of their HIV status unexpectedly when they come in for Voluntary Testing. For example, a group of young adolescent girls once came to the clinic with pure intentions to just test and know their HIV statuses. Following individual pre and post counselling sessions, one of them learned that she was HIV-positive. This girl was distraught because to her knowledge she was still a virgin and had never engaged in sexual activities. It was only after checking the details on her mother's file that we discovered that she was born with HIV and had never been informed. This completely shattered the girl, she considered suicide, but we helped her through it, fortunately. Others are not so fortunate, they actually succeed at committing suicide."*

Inadvertent transmission to others

Inadvertent or accidental transmission of HIV was noted as a consequence of delayed disclosure of HIV status to children living with PHIV. Participants noted that because children are unaware of their status, the likelihood of further transmission is heightened.

> ***Participant 8, professional nurse:*** *"One thing I can tell you is that delaying disclosure leads to very bad circumstances. Most of the elderly women that are on ART medication on our database have contracted the virus from the children in their care. This is because most biological parents die without informing their family members of their own HIV status and leave children in the care of their grandmothers. Now, because most of these grandmothers have little knowledge of HIV and its modes of transmission, such as touching open wounds, they care for these children nonchalantly with little to no speculation of HIV. As a result, they fall ill and come to the clinic to simultaneously learn of their own HIV status and that of the children left in their care. It is devastating really."*

Suicidal ideation

Participants exposed suicide ideation amongst children and adolescents living with PHIV as one of the negative outcomes of delayed disclosure of HIV status.

> **Participant 2, lay counsellor:** *"Quite a number of children contemplate suicide after discovering their status during adolescence. Most of them are of the belief that they have nothing to live for, that they are worthless and different so they there is no point in being alive. Delayed disclosure really messes up with a child mentally."*

> **Participant 11, community healthcare worker:** *"This thing of not telling children their status when they are younger is problematic. I was once called to a school regarding a child who learned of her status by overhearing peers discuss her in class. The news spread like wildfire and this child was mocked. She was so depressed, she wanted to kill herself. I did everything in my power to link her with the social worker and our government psychologist. This thing is more serious than people think."*

According to the South African Disaster Management Act (South Africa, 2002), a disaster causes disruption and can be continuous. It can cause injury, disease and even death. The above responses prove this definition true. They exemplify that delayed disclosure contributes to the aggravation and proliferation of the HIV/AIDS pandemic. Delayed disclosure intensifies vulnerability by placing the lives of the children concerned and those of significant others, at continued risk of further infection, reinfection and premature death.

Positive experiences with early disclosure

Contrary to the abovementioned negative experiences with delayed disclosure, participants revealed that in their experiences as HCWs at Hoekfontein (Mmakau) clinic, early disclosure has over the years to date, yielded better health and behavioural outcomes than non-disclosure or delayed disclosure of HIV status to children.

Improved adherence to ART

Participants revealed that children who learn of their HIV status early fare better on ART than those who are uninformed or learn of their HIV status in their late adolescence.

> **Participant 7, assistant nurse:** *"In my experience over the years, children who were told earlier, say 11 or 12 years or so, take their pills more consistently than those who are not told at an early age. Children who know their status rarely give us challenging problems such as defaulting and being lost to follow-up. The problem is with these ones that don't know what their medication is for."*

> ***Participant 1, lay counsellor:*** *"ART adherence is number one! Children who know their status take their treatment regime seriously, more than those that those that are confused and told untruths by their parents or guardians."*

Safe sexual practices and access to SRH services

Participants expressed that adolescents who were disclosed to at an early stage often feel empowered and are transparent enough to ask about delicate matters such as sex and pregnancy. They can seek guidance as opposed to those who do not know their HIV status.

> ***Participant 2, lay counsellor:*** *"I have facilitated many sessions and I can tell you that early disclosure is more beneficial, more so with adherence to ART and safe sexual practices. Most of the adolescents that I have helped know about terms such Pre-Exposure Prophylaxis, Post-Exposure Prophylaxis, and Undetectable=Untransmittable. They know that they can practice safe sex with HIV-negative partners and not transmit the virus if their viral load is suppressed. Those who are not informed on time, miss such opportunities and fall behind. They are at danger because the truth is that these children have sex whether we like it or not."*

> ***Participant 10, professional nurse:*** *"I had a patient once; she is now a young adult. I helped her mother disclose to her when she was still a child. That patient has to this day been consistent with her medication, she even has an HIV-negative child because she listened and she came in for PMTCT and SRH consultations. Early disclosure is better."*

Fetches own medication and asks questions about health

Early disclosure promoted autonomy amongst children and adolescents living with PHIV, while delayed disclosure obstructed this ability.

> ***Participant 4, professional nurse:*** *"What I like about children who learnt of their HIV status earlier is that they are more confident and free to ask questions. They are more accepting of who they are regardless of their diagnosis. Most of them fetch their own medication and never miss appointment dates because they know what will happen if they start slacking."*

> ***Participant 8, professional nurse:*** *"Children who know their status are more independent to a point that even when they miss school due to a scheduled appointment at the clinic or to collect medication, they are able to ask for a letter to*

> *submit to their teachers at school. They even inform their teachers about their HIV status for additional support."*

Voluntary engagement in support groups

Participants held that early disclosure, unlike delayed disclosure, encourages additional support from other meso-systems surrounding the child.

> ***Participant 12, community healthcare worker:*** *"What I have observed at our clinic and at the NGO nearby the clinic is that most of the children who know their status come for peer support with lay counsellors because some of their friends from school also take pills like them."*

> ***Participant 5, lay counsellor:*** *"What's nice about early disclosure is that it gives children the chance to seek support. Some of these children don't have parents and only have their grandparents to talk to when they get home, so at least when they are here in support groups, we educate them and meet them at their level. They are free to ask questions without feeling ashamed."*

Based on the aforementioned responses, disclosing the HIV status of children at an earlier stage of their childhood is more beneficial than delaying or not disclosing their HIV status. In the context of disaster management, early disclosure allows children to exploit the capacity (resources) available at their disposal, such as the above-mentioned support groups. This results in reduced vulnerability and risk of further transmission and defaulting. Furthermore, practising safe sex, accessing SRH and PMTCT programmes, mirror preparedness and mitigation. By accessing these programmes head-on, children and adolescents do not only protect themselves, but they also protect others from potential harm. The joining of support groups also serves as a phase of recovery because children are better able to receive psychosocial support, which in turn helps them accept their PHIV status and subsequently make informed health decisions that promote longevity.

6.4.2 Experiences of non-disclosed primary caregivers

Barriers to timely disclosure

During the interviews, participants revealed that although they had intentions to disclose and knew that their children deserved to know their HIV statuses, they were unable to do so due to several internal and personal struggles. Studies embarked on by Kiwanuka et al. (2014) and Manye and Madiba (2015) revealed similar findings.

Lack of readiness and skill to disclose

Participants expressed that they were not yet ready to disclose the HIV status of their children because they had little to no skill to carry out the process.

> ***Participant 14, grandmother of a 16-year-old girl:*** *"Even though I want to tell her, I honestly don't know where to start. I am old and have no knowledge of this disease. I fear telling her and having no answers for her. I mean, her mother died without even telling me, her own mother, about her own HIV status."*

> ***Participant 17, biological mother of a 13-year-old girl:*** *"I have a burning desire to tell her, but feel unready and unskilled to initiate the process. Perhaps if I can get someone to help me, maybe a nurse or social worker, then maybe I could try."*

Unacceptance of own HIV status

During the interviews, most primary caregivers, biological caregivers, in particular, expressed that they were unable to disclose to their children because they had not come to terms with their own HIV status, hence the delay.

> ***Participant 16, biological mother of a 14-year-old boy:*** *"I haven't accepted my HIV status and have not forgiven his father for infecting me. I am still angry at myself for trusting him with my life. Now, I have infected my child and I am struggling to live with that. I need counselling, to heal, maybe thereafter, I'll have courage to tell him."*

Guilt of vertical transmission, fear, blame and rejection

Participants explained that they feared disclosing because they felt guilty for having infected their children. They also feared the possibility of being blamed and rejected by their children following disclosure.

> ***Participant 28, biological father of a 17-year-old girl:*** *"I feel so guilty for having infected my own child. I think she might not see me the same after I tell her; she will blame me. Her mother died about two years ago and she was traumatised. I fear that she will think that she will also die."*

> ***Participant 29, biological mother of a 12-year-old girl:*** *"I feel like I have failed her. I should have known better, done better and not mixed fed her. She was actually born negative, but I didn't take my medication well and transmitted the virus as a result. This haunts me, she might blame me and I can't live with that."*

Fear of stigma and socio-cultural beliefs

As mentioned by Gyamfi et al. (2017), societal stigma from the community (exo-system) plays a substantial role in delayed disclosure of HIV status to children and adolescents living with PHIV. Likewise, participants in this study revealed socio-cultural beliefs and stigma as some of the factors contributing to their inability to disclose to their children.

> ***Participant 30, biological mother of an 11-year-old boy:*** *"I know that I should start telling him, but I haven't even told my own parents (his grandparents) about my own HIV status. We all live together in the same household, but they don't know anything. I tell them the pills help with respiratory problems, a condition I painted so that I wouldn't be judged. My parents are quite old and very traditional. They are still of the mentality that HIV is a disease caused by promiscuity."*

Child is still young

Notions that children were too young to be informed of their HIV status also arose in the interviews. Participants believed that the children in their care did not possess sufficient maturity to understand HIV and its complexities.

> ***Participant 15, aunt of a 15-year-old girl:*** *"I just feel that she's still too young, maybe when she's 17, I'll tell her. For now, I just want her to focus on her books, telling her will just disturb her, she won't cope well with the news."*

Time considered suitable for disclosure

Participants noted disclosure as an uneasy and complicated venture that ought to take place during a suitable and enabling time.

When I have first accepted my own status

Most biological caregivers expressed acceptance of their own status as an enabler to disclosure.

> ***Participant 16, biological mother of a 14-year-old boy:*** *"I think I will only be able to disclose once I have accepted my own status. For now, I am still uncomfortable, though I know disclosure is the right thing to do."*

When the child is mature enough (late adolescence)

Most participants regarded late adolescence as the most appropriate time to disclose the HIV status of their children. They stated that it is only then, that their children will be mature enough to handle the true nature of their illness.

> ***Participant 15, aunt of a 15-year-old girl:*** *"I will tell her when she is 17; she'll be able to handle this matter then and will be a bit more mature than she is now."*

When the child asks questions about sexual orientation

Participants also revealed that they would only disclose once their children began asking questions related to sexual practices. They viewed these questions as indicators of maturity.

> ***Participant 29, biological mother of a 12-year-old girl:*** *"I think I will tell her when she starts asking me about boys and relationships, you know, sex and so on. This to me will be an indication that she is mature enough to understand HIV."*

When the child starts taking ART irregularly or defaults

Of concern, some participants voiced that they would only disclose when their children start taking ART medication irregularly. They viewed such behaviour as an indication that their children are now ready to know the truth about their illness.These findings were consistent with studies conducted by Appiah et al. (2019) and Torani et al. (2019).

> ***Participant 14, grandmother of a 16-year-old girl:*** *"Till now she hasn't given me any problems with medication, but if for some reason she stops taking medication, I will tell her that she will die. I have heard from foster parents like myself who live in the village that these children have a tendency to stop taking medication when they start getting older and getting influenced by their friends."*

Many of the above responses exemplify the often-overlooked dangers of delayed disclosure. The notion that a child first has to take medication irregularly or default on treatment to be told of his or her HIV status, is hazardous and imposes great risk on the well-being of the child. Lentoor (2017) and Mengesha et al. (2018) inform that the more a child misses treatment, the more such a child will develop increased viral load concentration and an even weaker immune system. Furthermore, such a child may become resistant to medication and may even end up dying.

Disclosure might ruin the child-primary caregiver relationship

Most participants, who had not disclosed, explained that they feared that disclosure might ruin the relationship that they have with their children.

Child might withdraw and become hostile

Participants revealed that they particularly feared that following disclosure, their children would become hostile and withdraw from socialising and engaging with them altogether.

> ***Participant 15, aunt of a 15-year-old girl:*** *"I really fear telling her now because you know how teenagers are; they become moody and don't want to talk when they are angry. I think she will stop talking to me and give me problems in the house."*

> ***Participant 14, grandmother of a 16-year-old girl:*** *"Raising a teenager at my age is hard, I sometimes don't understand her. Sometimes when she misses her parents she doesn't talk to anyone, so if I tell her that she actually got HIV from them, she might really pull away and I really won't have the ability to handle her moods."*

Child might start misbehaving at home and school

Many participants upheld that if they disclosed, their children may start presenting behavioural problems both at home and at school, which will affect the nature of their relationships and overall performance.

> ***Participant 16, biological mother of a 14-year-old boy:*** *"My child is already struggling at school you know, he grasps slowly, so imagine telling him?! He will definitely give his teachers grief and start performing even poorer. He will be angry and shout at me as well. This will not be good for our relationship."*

> ***Participant 17, biological mother of a 13-year-old girl:*** *"She tends to be cheeky sometimes, backchats, and that alone is a lot to handle. If I tell her this, she might throw tantrums and lose control. I really don't think I'm ready to deal with that."*

Brown et al. (2011) enlighten that primary caregivers tend to have preconceived ideas of how children will react and these ideas are often misconstrued. Research studies have shown that children mainly get angry at not being told earlier of their status, and hardly at the parent or caregiver. They accept and recover quicker if they are told of their HIV status earlier and truthfully (Gitahi et al., 2020).

Delayed disclosure influences the psychosocial functioning of children

Participants attested that although they feared disclosing, they were not oblivious to the potential harm that delayed disclosure has or may have on the psychosocial functioning of their children.

Leads to accidental disclosure

In the interviews, most participants attested that delay in informing children of their status has the potential to lead to harmful accidental or inadvertent disclosure. It can also cause confusion, leading to children not knowing who or what to believe due to different narratives.

> ***Participant 14, grandmother of a 16-year-old girl:*** *"The child is in boarding school, one day she came home and told me that a nurse at the school said she had HIV, all the while I kept telling her that she suffers from lung problems. I told her that the teacher doesn't know what she is talking about, that she musn't believe that. I could tell that she was confused and disturbed, but I felt that I had to protect her. I still maintain the lung story; I am so scared of telling her I lied and that her teacher was actually right. She won't cope with this after all these years."*

Incorrect information disturbs a child's mental health and treatment regimen

Participants also acknowledged that delaying disclosure through myths and untruths about their health status could greatly affect a child's overall well-being.

> ***Participant 16, biological mother of a 14-year-old boy:*** *"My child has been asking me when he is going to stop taking these pills, he is tired of them. I told him he will stop when he is about 18, now he cannot wait to reach 18. I told him these pills are just temporary, they are for lung problems. He really hates them and sometimes does not want to take them; it is a struggle. Not telling children the whole truth really plays tricks on their minds because they have hope, I know it is wrong, but I just don't want to hurt his feelings you know."*

> ***Participant 17, biological mother of a 13-year-old girl:*** *"She asks, she asks a lot and she gets extremely annoyed because I sometimes ignore her questions. You can tell that there is a bit of confusion and speculation, you can tell that she has an idea of some sort and that stresses her out from time to time."*

> ***Participant 15, aunt of a 15-year-old girl:*** *"She sometimes takes her medication at 6 in the evening, other times at 8, very indecisive and that is not good. Because she doesn't really know what the pills are for, she tends to be casual about them. She really does not like them; I have to remind her every day to take them."*

The above responses resonate with statements made by Simoni et al. (2007) who stipulated that there is a clear distinction between disclosure and deception. Deception distorts children's views and dilapidates their mental health and overall psychosocial functioning, while disclosure promotes truth and gradual adjustment to the diagnosis.

6.4.3 Experiences of primary caregivers who had already disclosed

Factors promoting disclosure

During the interviews, participants described that their decision to disclose was influenced by behavioural changes observed in their children over time. The possible risks that could occur when their children grew older, also influenced the participants' decision to disclose.

Child asked too many questions

A majority of the participants voiced that they opted to disclose when their children began asking too many questions about their illness and their medication.

> ***Participant 13, biological mother of a 14-year-old boy:*** *"I decided to tell him because he was going on and on asking me about the pills. I learned then that children are not as clueless as we parents tend to think. I had to tell him to reduce the constant asking, it gets tiring after a while."*
>
> ***Participant 25, biological mother of a 16-year-old girl:*** *"I fully disclsosed when the child was still young, about 12. She had started asking way too many questions and I knew then that I had to tell her because she would not stop."*

Child started defaulting on ART

Many participants declared that they decided to disclose when they saw that their children were inconsistent with their ART regimen.

> ***Participant 21, biological sister of a 15-year-old girl:*** *"She started giving us problems in the house, and did not want to take her pills as per usual. She started acting differently, asking religiously about the pills, so I had to do it otherwise she would die like our mother."*
>
> ***Participant 26, biological mother of a 17-year-old girl:*** *"Just last year, my child started drinking pills in front of me, only to take them out of her mouth and hide them*

> *in the pockets of some of her jackets and jerseys. I would find these as I cleaned her room. This shook me completely, I had to tell the truth, there was no way out."*

Child started displaying signs and symptoms

During the interviews, many participants informed that they disclosed the status of their children when they saw signs and symptoms such as weight loss and skin rashes. This alarmed them and propelled them to disclose.

> ***Participant 20, grandmother of an 18-year-old girl:*** *"I disclosed very early, when she was still young, maybe 12. Her mother died without telling us that she was HIV-positive, so as time went, the child got really sick with bad skin rash and we took her to the clinic. It was only then that we learnt of her HIV status, she was about 10 then. I waited a two more years for her to heal and be a bit smarter and then told her."*

> ***Participant 23, aunt of a 15-year-old boy:*** *"I told him this year, at age 15. He had started losing a lot of weight, so I got worried and told him the truth. I was scared he would die."*

Child learned status accidentally

Some participants shared that they were compelled to disclose because their children had already learned of their status elsewhere without their consent. This bred anger in children, forcing the truth out of their primary caregivers.

> ***Participant 18, aunt of a 15-year-old boy:*** *"I was forced to tell him because he confronted me in fury. He visited his paternal side of the family for the school holidays last year and overheard his aunt talk about him and his illness with his grandmother and uncle. When he came back, he wanted the whole truth, I had no choice, I told him, unprepared as I was. I wish I told him earlier."*

Child reached the age of sufficient maturity

Some participants disclosed when their children reached the age of sufficient maturity.

> ***Participant 24, biological mother of a 15-year-old boy:*** *"My child is a smart child; he understands everything we teach him almost immediately, so I knew that he would get this one as well. I told him at 11, he was already mature enough to remember his pills without being reminded. There is a programme on TV, "Skeem Saam", it plays from 6:30–7:00 p.m., and so every time at 7:00, he immediately*

> *jumps off the chair to get his bottle and a glass of water. Telling him on time was one of the best decisions of my life."*

> ***Participant 27, biological mother of a 15-year-old girl:*** *"I thought she was old enough and ready, so I just told her. They teach us when we attend parents meetings and when fetch their reports at school that these children are smart and we must not take that for granted."*

Feared child would infect another

Other participants disclosed because they feared that their children would one day grow up, infect other people, and subsequently blame them for such repercussions.

> ***Participant 22, aunt of an 18-year-old girl:*** *"I saw that she was growing older so I started considering things like puberty and romantic partners. You know how children are, they like to experiment with a lot of things, like sex and alcohol, I didn't want to find myself in a position of regret should she have sex and infect other children unknowingly."*

Ran out of ways to falsify illness

A majority of the participants elucidated that they decided to disclose when they realised that they could no longer keep misinforming their children about their diagnosis.

> ***Participant 21, biological sister of a 15-year-old girl:*** *"It gets exhausting you know, the lying. It works on your conscience as well. When the child gets older, the questions increase and you basicially find yourself backed into a little corner with nowhere to run."*

> ***Participant 26, biological mother of a 17-year-old girl:*** *"I got tired, really tired because we're human remember, sometimes you forget what you initially told the child, so the story becomes inconsistent and dodgy. I then decided to just stop and tell the truth even though it was hard."*

Feared prospect of accidental disclosure

Many participants stated to have disclosed due to fear of accidental disclosure. They feared that if they did not tell their children earlier, someone else would, and this would harm their children's well-being.

> ***Participant 25, biological mother of a 16-year-old girl:*** *"I've heard from some mothers at the clinic while in the waiting line that some of their children discover their HIV status at school and sometimes from neighbours. This scared me and I did not want that for myself or my child. The thought of it made me tell her early on."*

Experienced frequent anxiety and stress

Most of the participants indicated that they felt obliged to disclose because delaying the process led to them experiencing constant anxiety and stress.

> ***Participant 23, aunt of a 15-year-old boy:*** *"Not telling him used to stress me a lot. I would feel burdened and stressed. You even get headaches and things like that, not a nice feeling at all. It was only after telling him that I felt a bit of relief even though it was not an easy thing to do."*

> ***Participant 22, aunt of an 18-year-old girl:*** *"You know how secrets are, they are heavy, and this one is no different. I had to let it go because it was stressing me physically and emotionally."*

> ***Participant 13, biological mother of a 14-year-old boy:*** *"The thought of my child dying early and leaving me here in guilt, didn't sit well with my spirit. I decided there and then to do it. When you hear of stories here in the village about children who stop taking medication and killing themselves because they were not told of their status, you have to act and you have to act fast as a parent, it is stressful."*

From the abovementioned responses, it can be deduced that participants who reported to have disclosed earlier, experienced more positive outcomes than participants who disclosed later when their children were in middle (15-17) and late adolescence (18-19) phases. Detrimental outcomes such as accidental disclosure and abandonment of ART were more likely to occur when disclosure was delayed. Similar to findings made by Vreeman et al. (2015) and Madiba and Mokgatle (2017), the results of this study also revealed that delaying the process of disclosure not only affects the child but also places physical and mental strain on the primary caregiver. From this, it can be reiterated that primary caregivers also need counselling, support and education so that they may be able to relieve some of the burdens they carry.

Reactions after disclosure

Participants expressed that following disclosure, their children reacted differently to the news of their diagnosis. Some children showed little to no emotion, while others were enraged.

Shocked and sad, but subsequently understood

Most participants who fully disclosed to their children at an early age (11–12), expressed that their children were initially shocked and sad, but consequently came to terms with their illness.

> ***Participant 27, biological mother of a 15-year-old girl:*** *"She was sad in the beginning, but really came around after like a week or so. She was so moody and antisocial at first. About a week later, she spoke more and played more."*

Angry, wish was told earlier

Participants who disclosed in middle (15-17) and late (18-19) adolescent stages alluded to their children being livid and wishing they had been informed earlier of their HIV status.

> ***Participant 23, aunt of a 15-year-old boy:*** *"He really didn't take the news well at all, he was outraged. He said that he didn't understand why he wasn't told sooner. He told us he would have accepted the news better, in pinches of salt, now his life is upside down because his own family kept him in the dark, yet they all knew."*

No reaction or emotion, understood and accepted swiftly

Some participants reported little to no reaction or emotion in their children following disclosure. They stated that their children understood and accepted their status without hassle.

> ***Participant 19, aunt of a 16-year-old girl:*** *"Because she was still so young, she barely showed emotion. She didn't even cry, she just acknowledged the outcome and knew that she wasn't supposed to miss any dosage of her pills, ever. This stuck with her to date, she is a pleasant child."*

Angry, felt betrayed by falsification of status

Participants, who had repeatedly falsified the diagnosis of their children, reported that when they eventually decided to disclose to their children, their children reacted angrily and felt betrayed by the misguidance.

> ***Participant 14, biological mother of a 17-year-old girl:*** *"My child was so angry, she still is to some extent. I remember that day like it was yesterday. Over and above everything, she was infuriated by the false information that we initially gave her. This just made things worse for us as a family, she was angry at everyone who participated in this. She felt backstabbed, really angry. She just wanted the truth and we failed her because we were fearful. Fear can really blind you sometimes."*

The reactions to the above responses also reflect some of the reactions given by children and adolescents in studies conducted by Vreeman et al. (2015) and Lawan et al. (2016). The scholars found that children who learn of their status early tend to display emotions such as shock or sadness following disclosure. These emotions are often short-lived and consequently replaced by acceptance, especially if a child is supported at home. Children, who are not told on time, however, are more inclined to display emotions of anger such as those described in the responses above. These outcomes further divulge that early disclosure is more advantageous than delayed disclosure.

Changes in a child-primary caregiver relationship

A majority of the participants who disclosed early, reported improvement in the relationship with their children. They noted more openness and transparency following disclosure. Participants who delayed disclosing to their children, expressed changes in their relationship; they also noted changes in their social behaviour.

Child withdrew and became antisocial

Most participants who had delayed disclosure stated that the children in their care became antisocial.

> ***Participant 22, aunt of an 18-year-old girl:*** *"She withdrew, stopped playing with friends and even slept early just to avoid everyone at home. This was a very tough time in our family because we just didn't know how to make it better. It took a long time for her to come around, we are still working on fixing things, and it is a long process. We have to rebuild that trust again since she now knows that it is HIV and*

> *not the fabricated illness that we had come up with. I wish we did better as a family, I wish we had told her much earlier."*

Child started misbehaving

Delayed disclosure also contributed to children's misbehaviour. Participants reported disrespect, defaulting from treatment and poor school attendance as some of the behavioural changes following disclosure.

> ***Participant 18, aunt of a 15-year-old boy:*** *"After I told him, things took a turn for the worst. He defaults on treatment so much so that I get calls from the clinic to ask why he doesn't come to collect medication and draw blood. It is so bad at home, he doesn't talk; he is just angry and comes home late. Schoolwork has also been affected because he just gave up. I also think he is drinking alcohol. I don't know how to get through to him, even his uncles tried. I really wish I told him sooner."*

Improved support and transparency in a relationship

Most of the participants who had disclosed early reported improvement in their relationship with their children. They admitted that they were better able to discuss matters concerning HIV/AIDS without fear or shame.

> ***Participant 13, biological mother of a 14-year-old boy:*** *"What I like about our relationship now is that it is very open and supportive. My child is able to ask me questions and I am not afraid to answer him. We even have our alarms ready each evening so that we take medication at the same time. We remind each other, we are friends and I love that. I am so glad I made the decision when I did, it worked out well for us."*

The above results are a further indication that children and adolescents do not take well to the nature of their illness being hidden or delayed. It affects their mental health and overall psychosocial functioning. Based on these results, it becomes increasingly evident that training HCWs on child disclosure services is pivotal and necessary. If more HCWs are trained, more primary caregivers can be supported and educated on the importance of early disclosure. Mitigation can also be done on some of the dangers and challenges brought by delayed disclosure and how such disclosure affects the child holistically.

6.4.4 Suggestions to promote early disclosure of HIV status

Participants expressed that for early disclosure to be normalised and delayed disclosure to be lessened in Mmakau village, they need substantial support and team effort. They suggested the following:

Counselling and support groups for primary caregivers

> **Participant 16, biological mother of a 14-year-old boy:** *"I know for sure that there are people out there somewhere who like me, are battling to accept themselves. They need someone to talk to, they need to be listened to and not judged. I really think increased counselling for us as parents is also important, it is not just about children. If we get help, we can be able to tell our children and families on time, without fear or shame. I think this will save a lot of children from being rebelious."*

Education on child disclosure processes

> **Participant 6, professional nurse:** *"The issue of training cannot be stressed enough, we need to be educated; all of us need to have some basic understanding of disclosure. If we are educated, then we will implement those guidelines confidently and reduce the negative outcomes brought by delayed disclosure. We will be able to help more children around the village and refer them for further intervention because honestly, this thing of children not knowing why they take pills is physically and mentally challenging."*

Increased health talks during waiting periods

> **Participant 4, professional nurse:** *"We do a lot of health talks on HIV/AIDS, but hardly touch on the subject of early disclosure and its significance in the care and management of children living PHIV. I think if we maybe use waiting periods as some kind of platform to tell parents about the importance of disclosure, it might change some of their minds, some may even spread the message when they get home or when they are with their friends and neighbours. They sometimes wait for a long time in the queues so we might as well educate them while they are waiting to be called in."*

Preparation of new mothers living with HIV during antenatal and postnatal care

> **Participant 3, lay counsellor:** *"The sooner we prepare these mothers, the better. We need to start early by informing new mothers who are HIV-positive that there will*

> *come a time where they will need to disclose to their children about their status. Mothers who are HIV-negative must also be encouraged to stay that way and to protect themselves and their children to avoid having to go through this as this is a difficult process; hence so many mothers can't do it."*

Awareness campaigns and community dialogues to reduce stigma

> ***Participant 12, community healthcare worker:*** *"What could also help is getting trained so that we can be able to impart some of the benefits of disclosure during awareness campaigns with other stakeholders in the community. Beyond the clinic, we can use platforms such as schools and community halls to hold dialogues and outreaches. Even during our household visits, we can do some kind of information session. If more adults become sensitized about disclosure, they can seek help and learn strategies on how to reduce rates of delayed disclosure in Mmakau village."*

6.5 Summary of the research findings

This section of the chapter presents a summary of the research findings based on the study's objectives. The research study was driven by six key objectives, all of which were successfully met.

Objective 1, which served as the main objective of the research study, aimed to analyse the impact that delayed disclosure of HIV status has on the psychosocial functioning of children and adolescents living with PHIV in Mmakau village. The results of the research study revealed that delayed disclosure of HIV status contributed to hazardous conditions such as children and adolescents defaulting on ART and unwittingly transmitting HIV to others. Other harmful conditions included suicidal ideation, misbehaviour, poor performance at school and mental degradation.

The NDOH (2016) states that HCWs play a critical role in ensuring that disclosure is facilitated at an age-appropriate time, however most HCWs are not adequately skilled to facilitate the process. The lack of skills contributes to disclosure being delayed, leading to consequences such as those highlighted in objective 1 above. **Objective 2** therefore aimed to evaluate how skilled HCWs designated at Hoekfontein (Mmakau) clinic are in facilitating the disclosure process with primary caregivers and their HIV positive children. The results revealed that albeit all (100%) HCWs knew and understood the concept of child disclosure, and deemed it a necessary practice, many were still uncertain of how to go about putting theory into practice. A majority of the HCWs (33.3%) disagreed with having adequate professional skills to carry out the process. A further 16.7% strongly disagreed with possessing sufficient skills to facilitate disclosure. Only 16.7% of the HCWs agreed that they had skills to facilitate disclosure with primary caregivers and their children. These findings revealed the need for more capacitation of HCWs on disclosure practices in order to reduce the impact of delayed disclosure.

The WHO (2011) maintains that primary caregivers are responsible for initiating age-appropriate disclosure to avoid risks associated with delayed disclosure as mentioned in objective 1. Despite these identified risks, delayed disclosure remains prevalent in most communities. As such, **Objective 3** aimed to determine possible factors inhibiting primary caregivers of Mmakau village to disclose the HIV status of their HIV positive children at an age-appropriate time. The results revealed that most primary caregivers participating in the study delayed disclosing to their children because they had not yet accepted their own HIV status and were as a result, unready to initiate the process. Harmful practices such as fabricating diagnosis due to lack of knowledge and skill to disclose were some of the key findings amongst participants. Some participants delayed disclosure because of societal influences such as stigma and socio-cultural belief systems. Others were of the perception that their children were still too young to comprehend the nature and intricacy of their illness. Biological caregivers, in particular, feared disclosing because they felt guilty for having vertically transmitted the virus to their children. These findings were consistent with previous and present-day studies conducted by scholars such as Kiwanuka et al. (2014), Manye and Madiba (2015) and De Silva et al. (2018). The findings moreover revealed the need to educate and support primary caregivers in overcoming these inhibitions so that they may be able to alleviate delayed disclosure and the impact it has on the psychosocial functioning of their children.

Objective 4 aimed to determine whether HCWs designated at Hoekfontein (Mmakau) clinic could carry out the process of disclosure appropriately and professionally as per relevant guidelines and legislation. The results revealed that despite the existence of the well-acclaimed HIV child disclosure guidelines as developed by the WHO and the succeeding child and adolescent disclosure guidelines advanced by the NDOH, many HCWs at Hoekfontein (Mmakau) clinic as in many parts across sub-Saharan Africa, remain unfamiliar with their establishment and as a result, do not implement them as recommended. In this study, only 58.3% claimed to have been aware of their existence while an even lower 25% affirmed implementation of the guidelines. Some HCWs claimed to rely on their professional intuition when carrying out the disclosure process. Others claimed to refer patients in need of disclosure, to other professionals such as social workers as they are considered more knowledgeable and skilled to facilitate the process.

Furthermore, various factors stemmed as root causes to poor implementation of existing guidelines. Of prominence, a majority of HCWs (66.7%) stated to have never received any formal or informal training on the guidelines. They motioned lack of training and tangible resources such as reading material as the biggest barriers to effective implementation of the guidelines. The findings hereof reflected those of many studies conducted internationally, regionally and nationally by scholars such as Sariah et al. (2016), Busza et al. (2016) and Madiba and Diko (2021).

Objective 5 aimed to evaluate whether HCWs receive ongoing training on child disclosure and its importance on the well-being of children and adolescents living with PHIV. The results revealed notable discrepancies. The majority (75%) stated that they had never received any follow-up training on child disclosure guidelines, while 25% attested to have received follow-up training. The HCWs reiterated the critical need for the NDOH to prioritise and standardise national training amongst all personnel involved in HIV disclosure services. Some participants revealed inequality in training opportunities and distribution of resources. They expressed that some HCWs receive more training than others do, which creates rigidity and confusion amongst healthcare teams. This finding is consistent with that of Watermeyer (2015).

Objective 6 explored perceptions and experiences of HCWs with disclosure and non-disclosure of HIV status to propose possible strategies aimed at improving child disclosure services at Hoekfontein (Mmakau) clinic. A majority of HCWs conveyed that they struggle to assist children living with PHIV with disclosure because some of their primary caregivers do not accompany them to the clinic. Other barriers to assisting primary caregivers to successfully disclose to their children included overwhelming workload, lack of child-friendly spaces and the shortage of skilled staff. Notwithstanding these barriers, the majority of HCWs who had assisted primary caregivers and children with disclosure expressed that in their experience, early disclosure has been a more beneficial approach than delayed disclosure. They upheld early disclosure as a noteworthy promoter of adherence to ART and access to SRH services. Suggested strategies and recommendations to improve disclosure services at Hoekfontein (Mmakau) clinic are detailed in Chapter 7.

6.6 Chapter summary

This chapter presented the quantitative and qualitative data obtained during the one-on-one semi-structured interviews with the participants. The chapter provided the socio-demographic information of the participants. It moreover interpreted the perceptions of participants with disclosure and non-disclosure of HIV status to children and adolescents living with PHIV. Experiences of participants with disclosure and non-disclosure of HIV status were thoroughly discussed. Data were presented using graphs, tables and themes, and were interpreted to meet the study’s objectives. The findings of the research answered all research questions and met the objectives of the study. The next chapter presents the conclusion and recommendations of the study.

Chapter 7
CONCLUSION AND RECOMMENDATIONS

7.1 Introduction

This chapter presents the conclusion and recommendations of the research study. It first outlines the summary of the research study and subsequently deals with the conclusion of the study, which is consistent with the research findings. The last section of the chapter discusses the recommendations, all of which stem from the research findings and draw on the conclusion.

7.1.1 Summary of the research study

The research study was based on the premise that delayed disclosure of HIV status affects the psychosocial functioning of children and adolescents living with PHIV. The study also notioned that delayed disclosure stems from various factors such as lack of training and skills of HCWs and primary caregivers to disclose the HIV status of children and adolescents living with PHIV, hence its prevalence in rescource limited settings such as Mmakau village. To ascertain this, various perceptions and experiences of HCWs providing HIV/AIDS-related services at Hoekfontein (Mmakau) clinic in the Bojanala District, North West province, South Africa, were explored. The study also included primary caregivers of children and adolescents concerned to explore their perceptions and experiences with disclosure and non-disclosure of PHIV status. The study adopted the mixed methods design and used interview guides as data collection tools during semi-structured interviews. The targeted readers of this study are individuals in the public health sector, government sector, private sector and the general public. The study aimed to add to the existing literature by providing possible intervention strategies to mitigate the prevalence and perpetuation of delayed disclosure in Mmakau village and communities alike.

7.2 Conclusion

The study employed the PAR and the Ecological model (main theoretical framework) to demonstrate how delayed disclosure of HIV status to children living with PHIV impacts their psychosocial functioning, and how the delay is as a result of factors such as lack of knowledge, training and skills to disclose on the part of HCWs and primary caregivers of the children and adolescents concerned. The findings revealed that delayed disclosure impacted the psychosocial functioning of most children by leading to various problems such as children unknowingly transmitting HIV to others, defaulting on ART, attempting suicide, performing poorly at school and disobeying their primary caregivers at home.

The findings of the study moreover uncovered that HCWs designated at Hoekfontein (Mmakau) clinic, although fully cognisant of the concept of child disclosure, are not adequately skilled to facilitate the disclosure process with children and their primary caregivers as per existing guidelines. Many HCWs were not aware of the existence of both the longstanding WHO guidelines and the recent South African guidelines; hence, the lack of skills to facilitate child disclosure practices at the clinic. The lack of skills to facilitate disclosure amongst most of the HCWs resulted in implementation being poor, contributing to the prevalence of delayed disclosure in Mmakau village.

Factors inhibiting primary caregivers to disclose the HIV status of their children were also explored. The study discovered that primary caregivers mainly delayed disclosing to their children because they lacked the skills to initiate the process. Other factors included guilt of vertical transmission and fear of rejection from children if they were to disclose at an age-appropriate time. Primary caregivers living with HIV particularly delayed disclosing because they had not yet found the innate courage to accept their own health status. As a coping mechanism, most primary caregivers concealed the diagnosis of their children by falsifying its true nature. Illnesses such as lung problems, respiratory problems and eye deficiencies were some of the conditions used to defer children who asked questions about their health status. These concealments led to children being furious with their primary caregivers once they learned the true nature of their diagnosis. As a result of this, some children defaulted on ART while others withdrew from societal enagements.

The study also found that delayed disclosure prevailed because child and adolescent disclosure guidelines were not effectively implemented at the clinic. This was mainly due to a lack of training and resources such as manuals and booklets. Most HCWs stressed that they had never received any formal or informal training on the guidelines and oftentimes relied on their professional instinct when assisting children and primary caregivers during disclosure. Ongoing training was also inconsistent. A majority of the HCWs claimed to have never received ongoing or follow-up training, only a few stated to have received such training. HCWs contended that the NDOH provides unequal training opportunities to staff, alluding to the observation that some HCWs are trained several times on one aspect, while others are not. This was one of the barriers impeding optimum service delivery at the Hoekfontein (Mmakau) clinic.

Furthermore, perceptions and experiences of HCWs with disclosure and non-disclosure of HIV status were explored. Most HCWs upheld that in their experience at Hoekfontein (Mmakau) clinic, many children who were informed of their HIV status at an age-appropriate time adhered better to ART and practiced safer sexual intercourse as opposed to their peers who were not disclosed to. The HCWs revealed that most children who experienced delayed disclosure neglected their ART medication, attempted suicide and engaged in risky behavioural practices such as unprotected sexual intercourse. Through the perceptions and experiences of HCWs, the findings further confirmed that delayed disclosure has an effect on the psychosocial functioning of children and adolescents living with PHIV. Although the HCWs acknowledged the importance of disclosure in the care and management of HIV, they also noted constraints such as shortage of skilled staff and lack of child-friendly spaces as some of the supplementary barriers to successful facilitation of disclosure sessions at Hoekfontein (Mmakau) clinic. Practical suggestions aimed at improving implementation of existing child and adolescent guidelines are discussed in the recommendations section.

7.3 Recommendations

7.3.1 The South African Department of Health and relevant stakeholders

In line with the research findings, this study recommends for the NDOH to nationalise and standardise training in all district and sub-district public health facilities in the North West province, as well as in all other provinces across South Africa. Training should accommodate all HCWs eligible to provide HIV services to children and adolescents living with HIV. This way, skill, growth and implementation of the above-said guidelines will be honed. Training all eligible personnel will aid in reducing disparities and will enhance performance and capacity – ultimately reducing the level of vulnerability resulting from delayed disclosure.

It is further recommended that attendees of such training receive tangible resources such as manuals, booklets and brochures that contain information needed to implement disclosure services. Training should also be frequent or ongoing to monitor and evaluate the progress and effectiveness of the guidelines. Evident in literature, knowledge and information surrounding HIV/AIDS is not stagnant; it constantly evolves. Therefore, refresher courses and in-service training, for example, are suggested to ensure that all role players and officials involved keep abreast with current and impending vicissitudes of the HIV/AIDS pandemic.

More health talks, awareness programmes and community dialogues should be held. The HCWs suggested that over and above the clinical focus on HIV/AIDS such as adherence to ART, patients should also be informed about the psychosocial impact of the illness. During health talks and waiting periods at the clinic, patients could be informed about disclosure and its importance in the care and management of HIV/AIDS. In this way, more patients can be aware of the advantages and disadvantages of disclosure and be able to seek appropriate counsel. The HCWs suggested that if they are trained and adequately skilled to facilitate disclosure sessions, they would be in a better and more confident position to create awareness and dialogue on disclosure. These dialouges could be initiated in the community using platforms such as community forums, halls and schools. The HCWs also indicated that if they adequately trained on disclosure, they will be able to conduct early prevention by informing new mothers caring for newborn babies living with PHIV about the necessity of disclosure as their children transition. If this kind preparation is done early on, mothers will be able to understand the necessity of age-appropriate disclosure as as well as the consequences of delayed disclosure on the psychosocial functioning of their chidren. Through such education, precarious decisions such as primary caregivers concealing their children’s diagnosis, can be alleviated. This will aid in reducing the prevalence of delayed disclosure and the impact it has on children and adolescents living with PHIV.

The HCWs also made a recommendation for provision of child-friendly spaces. They expressed the crucial need for a room that allows patient confidentiality as they have a confined clinic facility with limited space available to counsel patients. A more child-friendly room can help normalise disclosure and gradually ease children and their primary caregivers into the process. The HCWs furher communicated that they were more often than not, overwhelmed with work due to the high influx of patients on a daily basis. It was as such, recommended that the NDOH employ more skilled staff such as clinical social workers and counsellors to help facilitate disclosure sessions. The addition of such staff will help identify primary caregivers and children eligible for assistance with disclosure sessions. This will ensure that more primary caregivers are supported in disclosing the HIV status of their children at an age-appropriate time, thus reducing rates of delayed disclosure in Mmakau village.

Moreover, Enabler 1 of the NDMF (South Africa, 2005b) concedes disaster management as a collaborative process that requires collaboration among all spheres of government. This collaboration includes, but is not limited to government, NGOs and the private sector. Likewise, the findings of this research study suggested collaboration amongst local stakeholders. Participants noted the crucial need for strengthened referral and linkage coordination between departments, in particular, the DSD. They recommended increased visibility of area social workers in the vicinity as they are sometimes faced with challenges that are beyond their jurisdiction.

The DSD are custodians of orphans, vulnerable children and the youth. Most of the children receiving ART medication at Hoekfontein (Mmakau) clinic are either single or double orphaned due to HIV/AIDS. This implies that some of them are already registered on the DSD database as foster care recipients. This means that they already have case managers (social workers) responsible for their foster care placements and overall psychosocial functioning. As such, if the NDOH and the DSD could strengthen their working relationship by improving their referral and linkages systems, more children and adolescents could receive a holistic package of services. For example, during disclosure counselling sessions at the clinic, some children reveal that they default on treatment because they only receive their daily meals at school and hardly ever eat at home due to lack of food or access to social grants. They as a result, default because they fear that by taking their medication on an empty stomach, they will hurt their gut. It is when such complex issues arise at the clinic that HCWs engaging with such children, can refer and link them with the relevant social workers at the DSD for services such as in-depth counselling and provision of food parcels. Such referrals can aid in alleviating other socio-economic issues attached to the child. The primary caregivers of the children concerned can also be referred to area social workers employed by the DSD for in-depth counselling and psychosocial support. This will help address and reduce factors inhibiting them to disclose the HIV status of their children at an age-appropriate time. This kind of collaboration between HCWs and social service providers can help reduce rates of delayed disclosure in Mmakau village and Bojanala district as a whole.

7.3.2 Suggestions for future research

This study only explored perceptions and experiences of HCWs and primary caregivers, and not of the children and adolescents in question. As such, more research is necessary in South Africa to explore perceptions and experiences of children and adolescents living with PHIV so that their views can be considered when modifying policies and guidelines regarding their health and psychosocial well-being.

7.4 Concluding remarks

It can be concluded that delayed disclosure of HIV status to children living with PHIV, contributes to the longstanding disaster that is the HIV/AIDS pandemic. Failure to inform children and adolescents of their HIV status not only places their lives at risk, but also places the lives of others at risk of further transmission and reinfection. To mitigate the furtherance of this hazardous cycle, the adoption of a risk-avoidant culture as mentioned in Enabler 2 of the NDMF (South Africa, 2005b), is needed. A lack of training and education on guidelines amongst HCWs designated to provide HIV services to children living with HIV reflects a lack of preparedness, and thus needs to be prioritised. Enabler 2 of the NDMF (South Africa, 2005b) calls for all role players and officials involved in disciplines associated with disaster management to be trained on programmes that aim to reduce and manage disaster risk. As such, through the provision of adequate training, HCWs will be able to offer a well-informed response when assisting primary caregivers to disclose to their children. Such collaboration will not only lead to the reduction of children's vulnerability to probable risk, it will also help improve their coping capacity.

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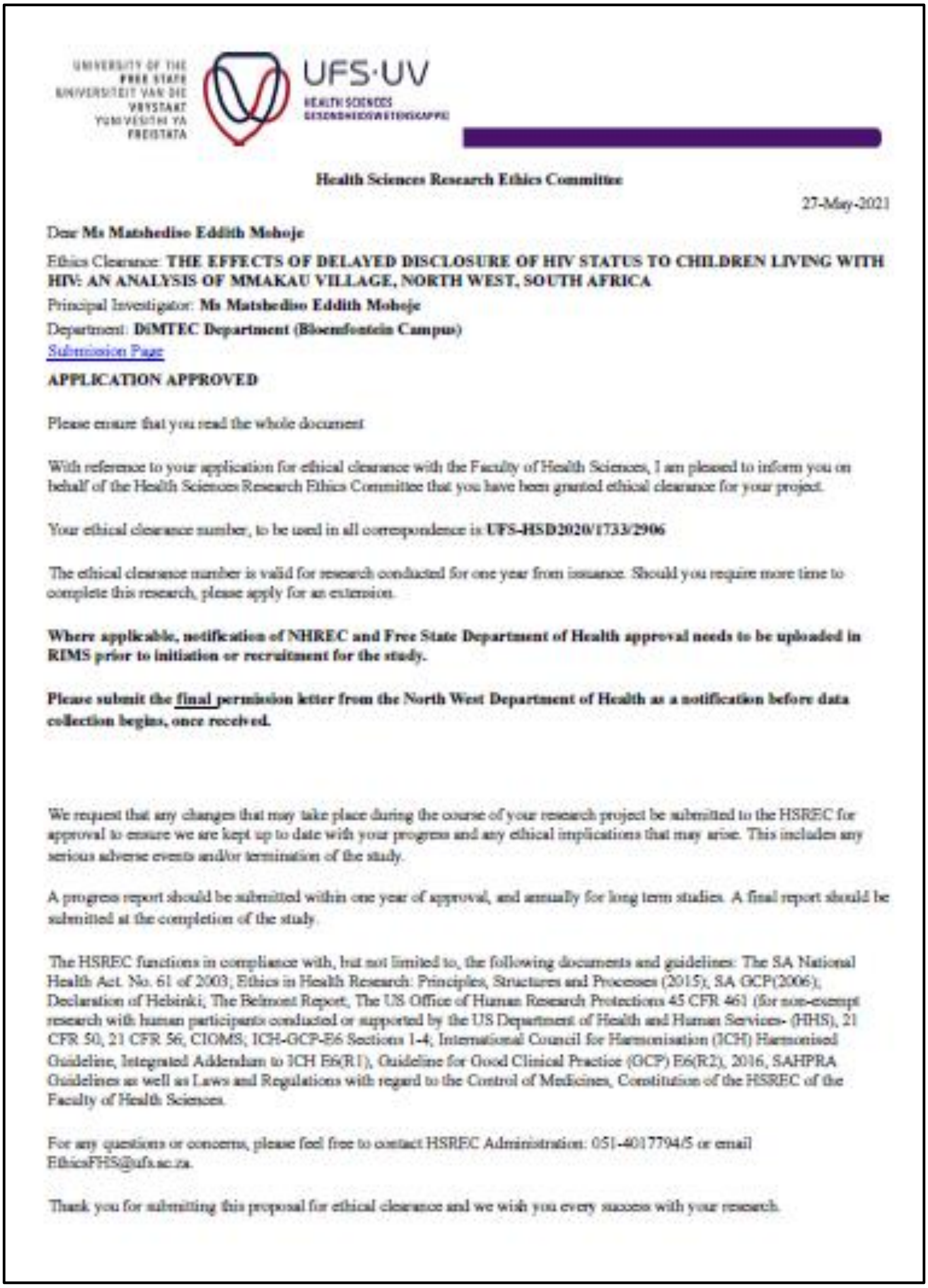
APPENDIX A:
ETHICAL CLEARANCE LETTER FROM THE HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



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HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

Health Sciences Research Ethics Committee

27-May-2021

Dear **Ms Matshediso Eddith Mohoje**

Ethics Clearance: **THE EFFECTS OF DELAYED DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV: AN ANALYSIS OF MMAKAU VILLAGE, NORTH WEST, SOUTH AFRICA**

Principal Investigator: **Ms Matshediso Eddith Mohoje**

Department: **DiMTEC Department (Bloemfontein Campus)**

Submission Page

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is **UFS-HSD2020/1733/2906**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

Where applicable, notification of NHREC and Free State Department of Health approval needs to be uploaded in RIMS prior to initiation or recruitment for the study.

Please submit the final permission letter from the North West Department of Health as a notification before data collection begins, once received.

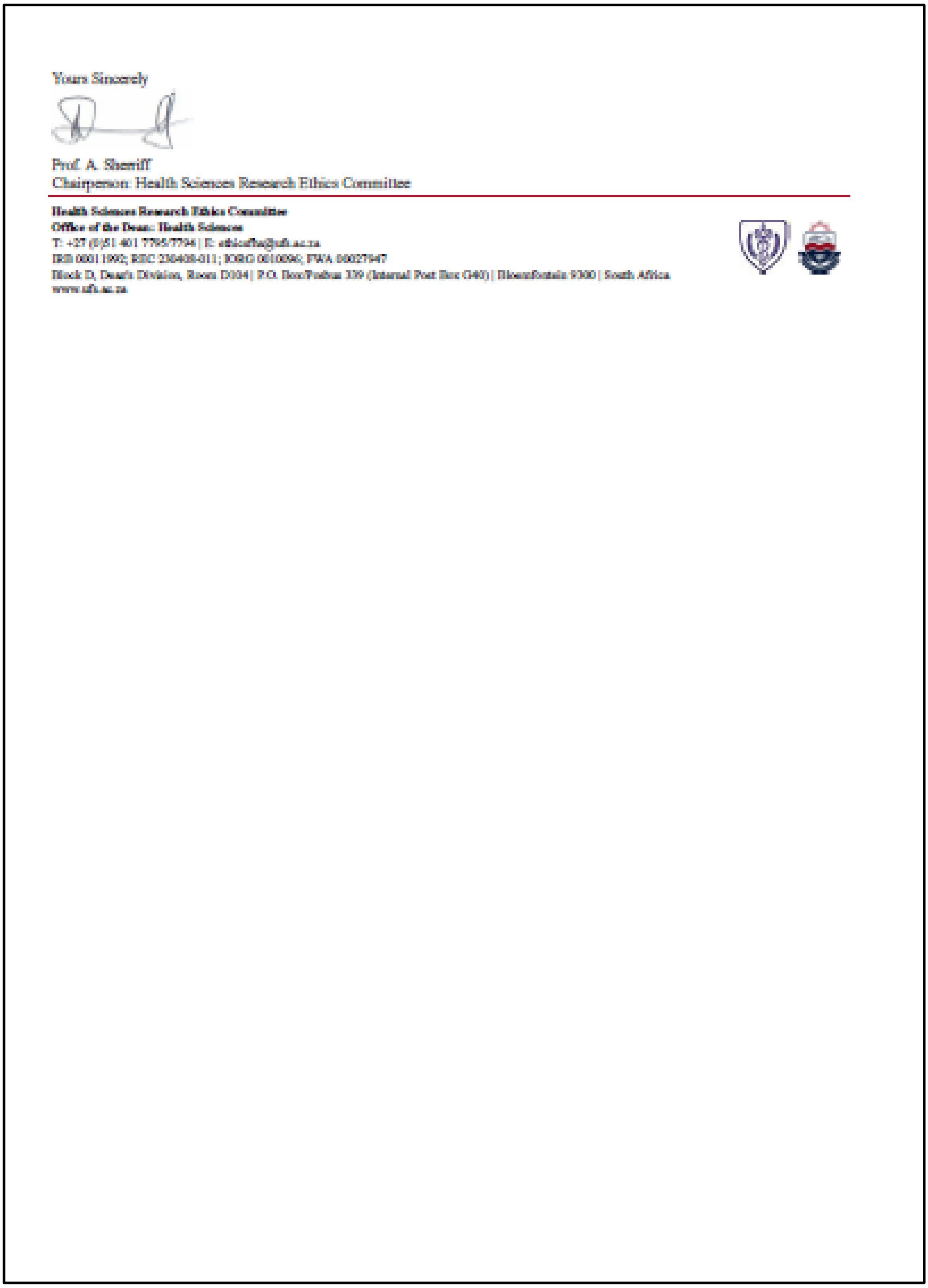
We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; International Council for Harmonisation (ICH) Harmonised Guideline, Integrated Addendum to ICH E6(R1), Guideline for Good Clinical Practice (GCP) E6(R2), 2016, SAHPRA Guidelines as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.



Yours Sincerely

Prof. A. Sherriff
Chairperson: Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee
Office of the Dean: Health Sciences
T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za
IRB 00011992; REC 230408-011; IORG 0010096; FWA 00027947
Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa
www.ufs.ac.za

APPENDIX B:
INFORMATION SHEET AND CONSENT FORM FOR PRIMARY CAREGIVERS

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA
UFS UV

THE EFFECTS OF DELAYED DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV: AN ANALYSIS OF MMAKAU VILLAGE, NORTH WEST, SOUTH AFRICA

PART A: INFORMATION SHEET

My name is Matshediso Mohoje and I am presently studying towards a Master's degree in Disaster Management at the University of the Free State. I am conducting research on "The effects of delayed disclosure of HIV status to children living with HIV: an analysis of Mmakau Village, North West, South Africa". The purpose of this study is to gain better understanding on the perceptions and experiences of primary caregivers with regard to disclosure of HIV status to children perinatally infected with HIV. In particular, the researcher would like to explore some of the factors or challenges that influence your decision to disclose or not disclose to your child about his or her HIV status. The researcher hopes that the findings obtained in the interviews conducted will help inform gaps identified in research and also improve disclosure services offered to primary caregivers and their HIV infected children.

Procedure: If you decide to take part in this research study, it will be required of you to undergo a one-on-one interview session that will take approximately 30 minutes. The researcher will conduct the interview in either English or Setswana depending on your language of preference. Kindly be informed that the interviews will be tape recorded in order to assist the researcher to capture all information needed. The tape recorder is also used to help revisit the conversation at any given time should the researcher miss any valid points made during the interview. All tape recordings and written information will be kept in a safe and confidential cabinet that only the researcher has access to.

Voluntary participation: Your participation in this study is completely voluntary. You will not be forced to answer any question that you may feel uncomfortable to answer. You are as such, free to change your mind at any stage of the study. If you choose to leave the study, you are welcome to do so at any point in time, you do not have to provide reasons for your decision. Your decision to participate or not participate in the research study will not affect the care and treatment that you, your child or family receive at Hoekfontein (Mmakau) clinic. Furthermore, if you choose to leave the study, your relationship with the University of the Free State or any other organisation will also not be affected.

Confidentiality: All interviews will be conducted in a private room at the clinic, at a scheduled date and time. The researcher will ensure that all COVID-19 protocols are observed. Masks will be worn at all times, hands will be consistently sanitized and social distancing (1 m spacing) will be maintained. The information acquired during the interviews will be handled with utmost confidentiality. All tape recordings, interview sheets and transcripts will not reveal your real name(s), the researcher will instead make use pseudonyms to protect and respect your identity. No report or publication on this research study will in any way identify you.

Possibility of risk: Please note that there is a possibility that you will undergo some emotional discomfort when taking part in this research study. You are not obligated to answer any question that makes you feel uncomfortable during the interview. Should you feel overwhelmed during the session and need to speak to a qualified social worker or trained counsellor, you will be granted the opportunity to do so.

Compensation: You will not be compensated to take part in this research study; the researcher will however provide you with refreshments during the interview session**.**

Should you have any questions or concerns about this research study, please feel free to contact the following persons:

Study supervisor: Dr Alice Ncube

Contact details: 051 401 2721 or 051 401 9701

Email address: NcubeA@ufs.ac.za

Researcher: Matshediso Mohoje

Contact details: 071 906 8612

Email address: MatshedisoMohoje@gmail.com

Health Sciences Research Ethics Committee (HSREC)

Office of the Dean: Health Sciences:

Contact details: 051 401 7795/7794

Email: ethicsfhs@ufs.ac.za

PART B: CONSENT FORM

I have read and understood the abovementioned information. I have also been presented with an opportunity to ask questions which have been answered satisfactorily. I hereby grant consent to voluntarily partake in this research study.

Name of participant: ____

Signature of participant: _____________________ **Date:** _____________________

If participant is illiterate or unable to write

I confirm that the contents on the information sheet have been read and thoroughly explained to me as a participant in the study. I have been given an opportunity to ask relevant questions and they have all been answered to my satisfaction. I therefore grant consent to participate voluntarily in the research study.

Thumb print of participant: __________________

Name of witness: __________________________

Signature of witness: _______________________ **Date:** ____________________

Name of researcher:

____

Signature of researcher: ____________________ **Date:** ____________________

LETLAPE LA KETELOPELE LE FOROMO YA GO NEELANA KA TUMELLANO LE BATLHOKOMEDI BA BANA

DITLAMORAGO TSA GO DIYEGA GO ITSISE BANA BAO BA TSHELANG LE KOKWANATLHOKO YA HIV KA BOTENG BA YONA MO GO BONA: PATLISISO KA MOTSE WA MMAKAU KO BOKONE BOPHIRIMA, AFORIKA BORWA

KAROLO A: KETELETSOPELE

Nna ke le, Matshediso Mohoje, moithuti wa dikerii ya Master's mo seritweng sa Disaster Management ko Yunibesiti ya Foreisetata ke dira dipatlisiso ka setlhogo se "Ditlamorago tsa go diyega go itsise bana bao ba tshelang le kokwanatlhoko ya HIV ka boteng ba yona mo go bona: Patlisiso ka motse wa Mmakau ko Bokone Bophirima, Aforika Borwa". Maikemisetso a dipatlisiso tse ke go batla go utlwisisa botoka go tswa mo batlhokomeding ba bana gore bone ba bona jang le gona gore ba itemogetse eng ka taba ya gore bana ba itsisiwe gore ba tsetswe ba na le yona kokwanatlhoko ya HIV. Ka go kgetholla mmatlisisi o batla go itse ditshusumetso le ona mabaka ao a dirang gore o tseye tshweetso ya go itsise kgotsa go ose itsese ngwana ka boemo ba gagwe ba HIV. Mmatlisisi o tshepa gore dipolelo tsa dipuisano tseo di tlabeng di dirilwe di tla thusa go neela tshedimosetso mo diphatleng tseo di fitlhelletsweng ebile di boele di ntlafatse ka moo batlhokomedi ba bana moogo le bana bao ba nang le kokwanatlhoko ba neelwang tshebeletso ya go buisana ka boemo ba HIV ka teng.

Tsamaiso: Fa o tsaya tshweetso ya go nna karolo ya dipatlisiso tse, o tlile go tswanela ke go nna le puisano le mmatlisisi nako e e ka nnang kana ka metsotso e e masome a mararo (30 min). Puisano e tla tsamaisiwa ka Setswana kgotsa Sekgowa go ya ka moo o thabelang ka teng. Itse gee gore puisano e tlile go gatisiwa ka setsaya mafoko lebaka e le gore mmatlisisi a tle a kgone go ya go kwala ditaba ka moo di boilweng ka teng le go direla gore a kgone go boela mo go yona leng kapa leng fa go na le dintlha tsa botlhokwa tseo di ka tswang di lebetswe ka nako ya puisano. Mafoko a a gatisitsweng, mmogo le tsona ditaba tse di kwadilweng di tlile go bolokiwa felo fa go fitlhegileng ebile go bolokegile foo go tla fitlhelelwang ke mmatlisisi fela.

Boithaopi go tseyeng karolo: Go tseya karolo mo dipatlisisong tsena ke ka mokgwa wa go ithaopa. Ga o kitla o patelediwa go araba dipotso tse o sa ikutlweng sentle go ka di araba. Ka moo o lokologile go ka fetola monagano wa gago nako enngwe le enngwe mo tsamaisong ya dipatlisiso. Fa o kgetha go itokolla mo dipatlisisong o dumelletswe leng kgotso leng ntle le gore o neelane ka mabaka. Tshweetso ya gago gore aa o tsaya karolo kgotsa nnya ga e kitla e ama ka moo o tla tshwarwang ka teng le go bona tirelo wena, ngwana wa gago kgotso lelapa la gago mo kliniking ya Mmakau. Go feta moo, ge o kgetha go tlogela dipatlisiso seo ga se kitla se ama dikgolagano tsa gago le Yunibesiti ya Foreisetata kgotsa mekgatlo e meng ya ditshebeletso.

Sephiri: Dipuisano tsotlhe di tlile go diragala ka fa teng ga kamore e e ikgethileng teng fa kliniking ka letsatsi le nako tse di rulagantsweng. Mmatlisisi o tla netsefatsa gore o latela melao e e beilweng ya COVID-19. Setswala nko le molomo se tla aparwa ka dinako tsotlhe, diatla di ditlapiwe ebe go katoganwe sebaka sa metara (1 m). Ditaba tse di fitlhelletsweng di tla bolokiwa e le sephiri. Diphatlhalatso tsa dipatlisiso tsena ga di kitla di go tlhagisa jang kapa jang.

Kgonagalo ya kotsi: Itse gore go na le kgonagalo ya gore o ka amega maikutlo ka nako eo o leng karolo ya dipatlisiso tsena. Ga gona se se go gapelatsang go araba potso e e go dirang gore o seke wa iketla ka nako ya dipuisano. Fa o ikutlwa o imetswe ka nako ya dipuisano ebile o tlhoka go buisana le modirela loago kapa motho yo a ithutetseng go dira ka maukutlo a batho, teng o tla neelwa monyetla wa go dira jalo.

Dituelo: Ga o kitla o duelelwa go tsaya karolo dipatlisisong tsena, efela mmatlisisi o tla neelana ka sengwenyana sa go isa maleng ka nako ya puisano

Fa o na le dipotso kgotsa tsona dingwaego ka dipatlisiso tsena, o seke wa tshaba go golagana le ba ba latelang:

Mooetapele wa dithuto: Dr Alice Ncube

Nomoro ya mogala: 051 401 2721 or 051 401 9701

Aterese ya e-mail: NcubeA@ufs.ac.za

Mmatlisisi: Matshediso Mohoje

Nomoro ya mogala: 071 906 8612

Aterese ya e-mail: MatshedisoMohoje@gmail.com

Health Sciences Research Ethics Committee (HSREC)

Office of the Dean: Health Sciences:

Nomoro ya mogala: 051 401 7795/7794

Aterese ya e-mail: ethicsfhs@ufs.ac.za

KAROLO B: FOROMO YA TUMELLANO

Ke buisitse le go utlwisisa ditaba tse di fa godimo. Ke ile ka neelwa le monyetla wa go botsa dipotso tseo di arabilweng go nkgotsofatsa. Ke neelana ka tumellano ya gore ke ithaopa go tsaya karolo mo dipatlisisong tsena.

Leina la Motsayakarolo: ____

Tshaeno ya motsayakarolo: _________________ **Letlha:** _____________________

Fa motsayakarolo a sa kgone go bala le go kwala

Ke dumela gore ke buiseditswe keteletsopele le go neelwa ka tlhalosetso jaaka motsayakarolo mo dipatlisisong tsena. Ke ile ka neelwa le monyetla wa go botsa dipotso tseo di arabilweng go nkgotsofatsa. Ka moo, ke neelana ka tumellano ya gore ke ithaopa go tsaya karolo mo dipatlisisong tsena.

Kgatiso monwana wa motsayakarolo: __________________

Leina la paki: __________________________

Tshaeno ya paki: _______________________ **Letlha:** __________________

Leina la mmatlisisi:

____

Tshaeno ya mmatlisisi: ___________________ **Letlha:** _________________

APPENDIX C: INFORMATION SHEET AND INFORMED CONSENT FORM FOR HEALTHCARE WORKERS

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA
UFS
UV

THE EFFECTS OF DELAYED DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV: AN ANALYSIS OF MMAKAU VILLAGE, NORTH WEST, SOUTH AFRICA

PART A: INFORMATION SHEET

My name is Matshediso Mohoje and I am presently studying towards a Master's degree in Disaster Management at the University of the Free State. I am conducting research on "The effects of delayed disclosure of HIV status to children living with HIV: an analysis of Mmakau Village, North West, South Africa". The purpose of this study is to gain better understanding on the perceptions and experiences of healthcare workers with regard to disclosure and non-disclosure of HIV status to children perinatally infected with HIV. The researcher hopes that the results obtained from the interviews conducted will help inform gaps identified in research and also improve disclosure services offered by healthcare workers to primary caregivers and their HIV infected children.

Procedure: If you decide to take part in this research study, it will be required of you to undergo a one-on-one interview session that will take approximately 30 minutes. The researcher will conduct the interview in either English or Setswana depending on your language of preference. Kindly be informed that the interviews will be tape recorded in order to assist the researcher to capture all information needed. The tape recorder is also used to help revisit the conversation at any given time should the researcher miss any valid points made during the interview. All tape recordings and written information will be kept in a safe and confidential cabinet that only the researcher has access to.

Voluntary participation: Your participation in this study is completely voluntary. You will not be forced to answer any question that you may feel uncomfortable to answer. You are therefore free to change your mind at any stage of the study. Your decision to participate or not participate in the research study will not affect your relationship with the University of the Free State or your employment at Hoekfontein (Mmakau) clinic.

Confidentiality: All interviews will be conducted in a private room at the clinic, at a scheduled date and time. The researcher will ensure that all COVID-19 protocols are observed. Masks will be worn at all times, hands will be consistently sanitized and social distancing (1 m spacing) will be maintained. The information acquired during the interviews will be handled with utmost confidentiality. All tape recordings, interview sheets and transcripts will not reveal your real name(s), the researcher will instead make use pseudonyms to protect and respect your identity. No report or publication on this research study will in any way identify you.

Possibility of risk: Please note that there is a possibility that you will undergo some emotional discomfort when taking part in this research study. You are not obligated to answer any question that makes you feel uncomfortable during the interview. Should you feel overwhelmed during the session and need to speak to a qualified social worker or trained counsellor, you will be granted the opportunity to do so.

Compensation: You will not be compensated to take part in this research study; the researcher will however provide you with refreshments during the interview session**.**

Should you have any questions or concerns about this research study, please feel free to contact the following persons:

Study supervisor: Dr Alice Ncube

Contact details: 051 401 2721 or 051 401 9701

Email address: NcubeA@ufs.ac.za

Researcher: Matshediso Mohoje

Contact details: 071 906 8612

Email address: MatshedisoMohoje@gmail.com

Health Sciences Research Ethics Committee (HSREC)

Office of the Dean: Health Sciences:

Contact details: 051 401 7795/7794

Email: ethicsfhs@ufs.ac.za

PART B: CONSENT FORM

I have read and understood the abovementioned information. I have also been presented with an opportunity to ask questions which have been answered satisfactorily. I hereby grant consent to voluntarily partake in this research study.

Name of participant: ____

Signature of participant: ______________________ **Date:** ___________________

Name of researcher: ____

Signature of researcher: _____________________ **Date:** ___________________

LETLAPE LA KETELOPELE LE FOROMO YA GO NEELANA KA TUMELLANO LE BADIREDI BA BOPHELO BO BONTLE

DITLAMORAGO TSA GO DIYEGA GO ITSISE BANA BAO BA TSHELANG LE KOKWANATLHOKO YA HIV KA BOTENG BA YONA MO GO BONA: PATLISISO KA MOTSE WA MMAKAU KO BOKONE BOPHIRIMA, AFORIKA BORWA

KAROLO A: KETELETSOPELE

Nna ke le, Matshediso Mohoje, moithuti wa dikerii ya Master’s mo seritweng sa Disaster Management ko Yunibesiti ya Foreisetata ke dira dipatlisiso ka setlhogo se “Ditlamorago tsa go diyega go itsise bana bao ba tshelang le kokwanatlhoko ya HIV ka boteng ba yona mo go bona: Patlisiso ka motse wa Mmakau ko Bokone Bophirima, Aforika Borwa”. Maikemisetso a dipatlisiso tse ke go batla go utlwisisa mo go badiredi ba tsa bophelo bo bontle gore bone ba bona jang le gona gore ba itemogetse eng mo tirong ya bona ka taba ya gore bana ba itsesiwe kapa gone go se itsisiwe gore ba tsetswe ba na le yona kokwanatlhoko ya HIV. Mmatlisisi o tshepa gore dipolelo tsa dipuisano tseo di tlabeng di dirilwe di tla thusa go neela tshedimosetso mo diphatleng tseo di fitlhelletsweng ebile di boele di ntlafatse ka moo badiredi ba tsa bophelo ba neelang batlhokomedi ba bana moogo le bana bao ba nang le kokwanatlhoko tshebeletso ya go buisana ka boemo ba HIV.

Tsamaiso: Fa o tseya tshweetso ya go nna karolo ya dipatlisiso tse, o tlile go tswanela ke go nna le puisano le mmatlisisi nako e e ka nnang kana ka metsotso e e masome a mararo (30 min). Puisano e tla tsamaisiwa ka Setswana kgotsa Sekgowa go ya ka moo o thabelang ka teng. Itse gee gore puisano e tlile go gatisiwa ka setsaya mafoko lebaka e le gore mmatlisisi a tle a kgone go ya go kwala ditaba ka moo di boilweng ka teng le go direla gore a kgone go boela mo go yona leng kapa leng fa go na le dintlha tsa botlhokwa tseo di ka tswang di lebetswe ka nako ya puisano. Mafoko a a gatisitsweng mmogo le tsona ditaba tse di kwadilweng di tlile go bolokiwa felo fa go fitlhegileng ebile go bolokegile foo go tla fitlhelelwang ke mmatlisisi fela.

Boithaopi go tseyeng karolo: Go tseya karolo mo dipatlisisong tsena ke ka mokgwa wa go ithaopa .Ga o kitla o patelediwa go araba dipotso tse o sa ikutlweng sentle go ka di araba. Ka moo o lokologile go ka fetola monago wa gago nako enngwe le enngwe mo tsamaisong ya dipatlisiso. Tshweetse ya gago gore a naa o tsaya karolo kgotsa nyaa mo dipatlisisong ga e kitla e ama dikgolagano tsa gago le Yunibesiti ya Foreisetata kgotsa tiro ya gago mo kliniking ya Hoekfontein (Mmakau).

Sephiri: Dipuisano tsotlhe di tlile go diragala ka fa teng ga kamore e e ikgethileng teng fa kliniking ka letsatsi le nako tse di rulagantsweng. Mmatlisisi o tla netsefatsa gore o latela melao e e beilweng ya COVID-19. Sethiba nko le molomo se tla aparwa ka dinako tsotlhe, diatla di ditlapiwe ebe go katoganwe sebaka sa metara (1 m). Ditaba tse di fitlhelletsweng di tla bolokiwa e le sephiri. Diphatlhalatso tsa dipatlisiso tsena ga di kitla di go tlhagisa jang kapa jang.

Kgonagalo ya kotsi: Itse gore go na le kgonagalo ya gore o ka amega maikutlo nako eo o tsayang karolo ya dipatlisiso tsena. Ga gona se se go gapelatsang go araba potso e e go dirang gore o seke wa iketla ka nako ya dipuisano. Ge o ikutlwa o imetswe ka nako ya dipuisano ebile o tlhoka go buisana le modirela loago kapa motho o a ithutetseng go dira ka maukutlo a batho, teng o tla neelwa monyetla wa dira jalo.

Dituelo: Ga o kitla o duelelwa go tsaya karolo dipatlisisong tsena, efela mmatlisisi o tla neelana ka sengwenyana sa go isa maleng ka nako ya puisano.

Fa o na le dipotso kgotsa tsona dingwaega ka dipatlisiso tsena, o seke wa tsaba go golagana le ba ba latelang:

Mooetapele wa dithuto: Dr Alice Ncube

Nomoro ya mogala: 051 401 2721 or 051 401 9701

Aterese ya e-mail: NcubeA@ufs.ac.za

Mmatlisisi: Matshediso Mohoje

Nomoro ya mogala: 071 906 8612

Aterese ya e-mail: MatshedisoMohoje@gmail.com

Health Sciences Research Ethics Committee (HSREC)

Office of the Dean: Health Sciences:

Nomoro ya mogala: 051 401 7795/7794

Aterese ya e-mail: ethicsfhs@ufs.ac.za

KAROLO B: FOROMO YA TUMELLANO

Ke buisitse le go utliwisisa ditaba tse di fa godimo. Ke ile ka neelwa le monyetla wa go botsa dipotso tseo di arabilweng go nkgotsofatsa. Ke neelana ka tumellano ya gore ke ithaopa go tsaya karolo mo dipatlisisong tsena.

Leina la motsayakarolo: ____

Tshaeno ya motsayakarolo: ________________ **Letlha:** ____________________

Leina la mmatlisisi: ____

Tshaeno ya mmatlisisi: ___________________ **Letlha:** ____________________

APPENDIX D:
INTERVIEW GUIDE FOR PRIMARY CAREGIVERS

UNIVERSITY OF THE
FREE STATE
UNIVERSITEIT VAN DIE
VRYSTAAT
YUNIVESITHI YA
FREISTATA

UFS
UV

You have been asked to participate in a research study. Please note that by partaking in this interview, you are voluntarily agreeing to participate in this research study. The results of the study may be published for academic purposes, therefore, as a means to protect your identity, the researcher will assign you with a fictional name (pseudonym) to safeguard that the information you provide during the interview is kept confidential and treated with utmost respect. You are not in any way compelled to participate in this study; you may withdraw at any given moment during the interview should you feel uncomfortable to continue. The aim of this interview guide is to provide primary caregivers with an opportunity to express their perceptions and experiences with child disclosure and non-disclosure of HIV status as far as possible. Thus, the questions below have been developed to help enable and navigate dialogue between the researcher and the primary caregivers participating in the research study.

SECTION A: SOCIO-DEMOGRAPHIC INFORMATION

1. What is your gender?

☐ Male ☐ Female

2. How old are you?

☐ 18–29 years ☐ 30–39 years ☐ 40–49 years ☐ 50–59 years ☐ 60+ years

3. What is your level of education?

1	No formal education	
2	Primary education	
3	Secondary education	

4	TVET college	
5	University education	
6	Postgraduate education	
7	Other (Please specify)	

4. What is your relation to the perinatally infected child(ren)?

☐ Biological caregiver ☐ Non-biological caregiver

5. Have you disclosed the HIV status to your child(ren)?

☐ Yes ☐ No

6. How old is the child(ren) in your care?

	Child 1	Child 2	Child 3
Age 6–8			
Age 9–11			
Age 12–14			
Age 15–17			
Age 18–19			

7. Who else lives with you and your child(ren)? (You can select more than one option)

1	Mother	
2	Father	
3	Aunt	
4	Uncle	
5	Grandfather	

6	Grandmother	
7	Stepfather	
8	Stepmother	
9	Siblings	
10	Nephews	
11	Nieces	
12	Cousins	
13	Other (Specify)	

8. Does the person or persons residing with you and your child(ren) know of the child(ren)'s HIV status?

   ☐ Yes ☐ No

9. Do people outside of your household or family know of your child (ren)'s HIV status?

   ☐ Yes ☐ No

SECTION B: EXPERIENCES WITH CHILD DISCLOSURE AND NON-DISCLOSURE OF HIV STATUS

Please note that the following questions are relevant to primary caregivers who have not yet disclosed to their child (ren): <u>Answered No in Question 5.</u>

10. What would you say discourages you from telling your child(ren) about his or her HIV status?

    ____

    ____

    ____

11. When do you consider it the right time to tell your child(ren) about his or her HIV status?

    ____

    ____

12. At what age do you think a child(ren) that has been perinatally infected with HIV should be told of his or her HIV status?

____

13. Do you think telling your child(ren) about his or her HIV status will affect the nature of your relationship?

____

____

____

14. Do you think that non-disclosure of HIV status can have an impact on the psychosocial functioning of your child(ren)?

____

____

____

15. Do you think the responsibility to disclose lies with you or with the healthcare worker?

____

____

16. Any other comments regarding the disclosure or non-disclosure of HIV status to children living with HIV?

____

____

____

Please note that the following questions are relevant to primary caregivers who have already disclosed to their child(ren): <u>Answered Yes in Question 5.</u>

17. When did you disclose to your child(ren) about his or her HIV status?

____

____

____

18. At what age did your child(ren) learn of his or her HIV status?

____

19. What are the main reasons for informing your child(ren) about his or her HIV status?

____

____

____

____

20. Can you provide me with some of the challenges that you were faced with when you were disclosing to your child(ren)?

____

____

____

____

21. Do you think the responsibility to disclose lies with you or with the healthcare worker?

____

22. What was your child(ren)’s reaction after being told of his or her HIV status?

____

____

____

23. Was the relationship with your child(ren) affected after disclosure?

____

____

____

____

24. Any other comments regarding the disclosure of HIV status to children living with HIV?

____

____

____

Thank you for your time and participation.

TATAISO YA PUISANO LE BATLHOKOMEDI BA BANA

Maikemisetso a tataiso ya puisano ena ke go neela batlhokomedi ba bana monyetla wa gore ba tlhagise ka moo ba bonang ebile ba itemogetseng ka teng mo tabeng ya gore ngwana a ka itsisiwe kgotsa nyaa ka boemo ka gagwe ba HIV. Ke ka moo dipotso tse di latelang di rulagantswe go kgontsha le go tsamaisa ngangisano magareng a mmatlisisi le motsayakarolo e leng motlhokomedi wa ngwana mo dipatlisisong tsena. Go na le kgonagalo ya gore dipoelo tsa dipatlisiso di ka phatlhalatswa ka lebaka la tsa dithuto, ka moo, mmatlisisi ga a kitla a tlhagisa leina la gago le gore o mang, o tla go neela leina la maiketsetso e le go sireletsa ditaba tsa puisano ya gago le go di boloka di fitlhegile ebile di tlhomphegile. Ga go na mokgwa o o go pateletsang gore o tseye karolo mo dipatlisisong tseno, o lokologile gore o ka boela morago ka nako efe kapa efe ya dipuisano fa o ikutlwa o sa lokologa go tswelela pele.

KAROLO A: KITSISO YA LOAGO LA DIPALOPALO TSA BAAGI

1. Bong ba gago?

   ☐ Monna ☐ Mosadi

2. Dilemo tsa gago?

   ☐ Dilemo tse 18–29 ☐ Dilemo tse 30–39 ☐ Dilemo tse 40–49

   ☐ Dilemo tse 50–59 ☐ Dilemo tse 60+

3. Dithutho tsa gago?

1	Ga ke a tsena sekolo	
2	Thuto e kwa tlase (Primary)	
3	Sekolo se segolo (Sekontari)	

4	Thuto e godimo ya TVET college	
5	Thuto e godimo ya Yunibesithi	
6	Dikerii ya tlaleletso	
7	Se sengwe (Tlhalosa)	

4. O amana jang le ngwana a tsetsweng gotsa bana ba tsetsweng a/ba tshwaetsegile ka kokwanatlhoko ya HIV?

☐ Ka tsalo ☐ Ga gona kamagano

5. O setse o itsisitse ngwana/bana ka boemo ba gagwe/bona ba HIV?

☐ Eya ☐ Nyaa

6. O tlhokomela ngwana/bana o/ba nang le dilemo tse kae?

	Ngwana1	Ngwana 2	Ngwana 3
Dilemo 6–8			
Dilemo 9–11			
Dilemo 12–14			
Dilemo 15–17			
Dilemo 18–19			

7. Ke bo mang ba ba tshelang le lona mo ntlung? (O ka dira ditlhopa tse di fetang nngwe)

1	Mme	
2	Ntate	
3	Mmane/Rakgadi	
4	Malome/Rangwane	
5	Ntatemogolo	
6	Nkoko	

7	Rre o e seng wa madi	
8	Mme o e seng wa madi	
9	Dikgaitsedi	
10	Motlogolo wa mosimane	
11	Motlogolo wa mosetsana	
12	Motswala	
13	Ba bang (Tlhalosa)	

8. A naa batho ba ba tshelang le lona ba itse ka boemo ba ngwana /bana ba HIV?

☐ Eya ☐ Nyaa

9. A naa batho ba kwa ntle ga lelapa la lona ba na le kitso ka boemo ba ngwana/bana ba HIV?

☐ Eya ☐ Nyaa

KAROLO B: BOITEMOGELO KA GO ITSISE KGOTSA GO SE ITSISE NGWANA KA BOEMO BA GAGWE BA HIV

Ela tlhoko gore dipotso tse di latelang di maleba go batlhokomedi ba bana bao ba iseng ba ba itsise ka boemo ba bona ba HIV: <u>O arabile nnyaa mo potso 5.</u>

10. O kare ke eng se se go ntshitseng mo mogopolong wa go bolella ngwana/bana ka boemo ba gagwe/bona ba HIV?

____

____

____

11. O bona nako e e maleba e le efeng ya go itsise ngwana/bana wa/ba gago ka boemo ba gagwe/bona ba HIV?

____

____

12. Ke ka dilemo difeng mo o nagang gore ngwana/bana oo/bao a/ba tsetsweng a/ba na le kokwanatlhoko ya HIV gore a/ba ka itsisiwe ka boemo ba gagwe/bona?

____

13. A o nagana gore fa o ka itsise ngwana/bana wa/ba gago ka boemo ba gagwe/bona ba HIV go tla ama dikamano tsa lona?

____

____

14. A o nagana gore go se itsisiwe ka boemo ba HIV go ka nna le ditlamorago tsa ka moo ngwana/bana a/ba tshelang mo monaganong le sechabeng?

____

____

15. O nagana maikarabelo a go itsise ka boemo ba HIV a magetleng a gago kgotsa a modiredi wa tsa bophelo bo bontle?

____

____

16. Tlhagiso e nngwe ka taba tsa go itsise kgotsa go se itsise bana ka boemo ba bona ba HIV?

____

____

____

Ela tlhoko gore dipotso tse di latelang di maleba go batlhokomedi ba bana bao ba setseng ba itsisitse bana ba bona ka boemo ba bona ba HIV: <u>O arabile eya mo potso 5.</u>

17. O itsisitse ngwana/bana wa/ba gago leng ka boemo ba gagwe/bona ba HIV?

____

____

____

18. Ngwana/bana wa/ba gago o/ba ne a/ba na le dilemo tse kae fa a/ba ne a/ba utlwa ka boemo ba gagwe/bona ba HIV?

____

____

____

19. Mabaka magolo e ne e le a feng gore ngwana/bana a/ba istsisiwe ka boemo ba gagwe/bona ba HIV?

____

____

____

20. O ka neela ka dikgwetlho tse o kopaneng le tsona fa o ne o itsise ngwana/bana ka boemo ba gagwe /bona ba HIV?

____

____

____

21. O nagana maikarabelo a go itsise ka boemo ba HIV a magetleng a gago kgotsa a modiredi wa tsa bophelo bo bontle?

____

____

22. Ngwana/bana o/ba ile a/ba nna jang morago ga gore a/ba bollellwe ka boemo ba gagwe/bona ba HIV?

____

____

____

23. Morago ga gore ngwana/bana a/ba itsisiwe ka boemo ba gagwe/bona ba HIV, a seno se kile sa ama dikamano tsa lona?

____

____

____

24. Tlhagiso e nngwe ka taba tsa go itsise kgotsa go se itsise bana ka boemo ba bana ba HIV?

____

____

____

Ke lebogela nako ya gago le go tsaya karolo.

APPENDIX E:
INTERVIEW GUIDE FOR HEALTHCARE WORKERS

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA
UFS
UV

You have been asked to participate in a research study. Please note that by partaking in this interview, you are voluntarily agreeing to participate in this research study. The results of the study may be published for academic purposes, therefore, as a means to protect your identity, the researcher will assign you with a fictional name (pseudonym) to safeguard that the information you provide during the interview is kept confidential and treated with utmost respect. You are not in any way compelled to participate in this study; you may withdraw at any given moment during the interview should you feel uncomfortable to continue. The aim of this interview guide is to provide healthcare workers with an opportunity to express their perceptions and experiences with child disclosure and non-disclosure of HIV status as far as possible. As such, the questions below have been developed to help enable and navigate dialogue between the researcher and the healthcare workers participating in the research study.

SECTION A: GENERAL QUESTIONS

1. What is your gender?

   ☐ Male ☐ Female

2. How old are you?

   ☐ 18–29 years ☐ 30–39 years ☐ 40–49 years ☐ 50–59 years ☐ 60+ years

3. What is your profession?

   ____

4. How long have you been under the employ of the South African Department of Health?

   ☐ 1–5 years ☐ 6–10 years ☐ 11–15 years ☐ 16–20 years ☐ 21–25 years

   ☐ 26–30 years ☐ 30+ years

5. What is your role or responsibility at the clinic?

____

____

6. Do you know what child disclosure is?

☐ Yes ☐ No

7. If yes, can you briefly explain?

____

____

8. Are you aware of the existing child and adolescent disclosure guidelines that have been developed by the South African Department of Health?

☐ Yes ☐ No

9. Do you implement these guidelines?

☐ Yes ☐ No

10. If no, what are the possible reasons?

____

____

____

SECTION B: PERCEPTIONS AND EXPERIENCES ON DISCLOSURE AND NON-DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV

11. How often do you receive training on child and adolescent disclosure guidelines?

Monthly	
Quarterly	
Half yearly	
Once a year	
Never	

12. Do you think training is necessary?

☐ Yes ☐ No

13. Do you ever receive follow-up training on child and adolescent disclosure guidelines?

    ☐ Yes ☐ No

14. Is there any monitoring and evaluation done in your facility to ensure that the guidelines are implemented?

Yes	
No	
I am not sure	

15. Would you say you are adequately skilled to facilitate the disclosure process as per the child and adolescent disclosure guidelines?

Strongly agree	
Agree	
Neither agree or disagree	
Disagree	
Strongly disagree	

16. What according to you limits successful child disclosure at Hoekfontein (Mmakau) clinic? (E.g. time constraints, lack of skills or resources at facility, heavy workload etc.)

    ____

    ____

    ____

17. What do you think can be done to enhance your knowledge on child disclosure and the implementation thereof?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
Frequent trainings on child disclosure guidelines					
Provision of tangible resources (e.g. manuals)					
Allocation of child friendly spaces					
Increased time allocation for disclosure services					
Employment of more skilled personnel					
Strengthen referral and linkages systems amongst stakeholders					

18. Can you tell me about any of your negative or positive experiences with child disclosure services since you have been in practice?

____

____

____

____

19. At what age do you think a child should be informed about his or her HIV status?

____

20. Do you think a child has the right to know his or her HIV status?

☐ Yes ☐ No

21. Whose responsibility do you think it is to disclose to a child (ren) that has been perinatally infected with HIV? Yours or the child (ren)'s primary caregiver?

____

____

22. Any other comments on the issue of primary caregivers disclosing HIV status to their children?

____

____

____

Thank you for your time and participation.

UNIVERSITY OF THE
FREE STATE
UNIVERSITEIT VAN DIE
VRYSTAAT
YUNIVESITHI YA
FREISTATA

UFS
UV

TATAISO YA DIPUISANO LE BADIREDI BA TSA BOPHELO BO BONTLE

Maikemisetso a tataiso ya puisano ena ke go kgontsha badiredi ba tsa bophelo bo bontle ka monyetla wa gore ba tlhagise ka moo ba bonang ka teng ebile ba itemogetse mo tabeng ya gore ngwana a ka itsisiwe kgotsa nyaa ka boemo ka gagwe ba HIV. Ke ka moo dipotso tse di latelang di rulagantswe go re di kgontshe le go tsamaisa ngangisano magareng a mmatlisisi le motsayakarolo e leng modiredi wa tsa bophelo bo bontle mo dipatlisisong tsena. Go na le kgonagalo ya gore dipoelo tsa dipatlisiso di ka phatlhalatswa ka lebaka la tsa dithuto, ka moo, mmatlisisi ga a kitla a tlhagisa leina la gago le gore o mang, o tla go neela leina la maiketsetso e le go sireletsa ditaba tsa puisano ya gago le go di boloka di fitlhegile ebile di tlhomphegile. Ga go na mokgwa o o go pateletsang gore o tseye karolo mo dipatlisisong tseno, o lokologile gore o ka boela morago ka nako efe kapa efe ya dipuisano fa o ikutlwa o sa lokologa go tswelela pele.

KAROLO A: DIPOTSO TSA KAKARETSO

1. Bong ba gago?

☐ Monna ☐ Mosadi

2. Dilemo tsa gago?

☐ Dilemo tse 18–29 ☐ Dilemo tse 30–39 ☐ Dilemo tse 40–49 ☐ Dilemo tse 50–59 ☐ Dilemo 60+

3. Tiro ya gago ke eng?

____

4. Ke sebaka se se kae o direla Lefapha la Bophelo Bo Bontle mo Aforika Borwa?

☐ Dilemo tse 1–5 ☐ Dilemo tse 6–10 ☐ Dilemo tse 11–15 ☐ Dilemo tse 16–20

☐ Dilemo tse 21–25 ☐ Dilemo tse 26–30 ☐ Dilemo 30+

5. O tsaya karolo efeng kgotsa maikarabebelo a gago ke afeng mo kliniking?

____

____

6. O na le kitso ka go tlhagisa boemo mo ngwaneng?

☐ Eya ☐ Nyaa

7. Fa karabo e le eya, a o ka tlhalosa?

____

____

8. A naa o itse fa go na le tsamaiso ya go bua le bana kgotsa batsha ka HIV eo e thailweng ke Lefapha la Bophelo Bo Bontle mo Aforika Borwa?

☐ Eya ☐ Nyaa

9. A o dirisa ditsamaiso keletso?

☐ Eya ☐ Nyaa

10. Fa karabo e le nnyaa, ekaba mabaka ke afe?

____

____

____

KAROLO B: PONO LE MAITEMOGELO KA GO ITSESE LE GO SE ITSESE KA BOEMO BA HIV MO BANENG BA BA TSHELANG LE KOKWANATLHOKO YA HIV

11. O bona kwetliso ka ditsamaiso keletso mabapi le go tlhagisa boemo mo ngwaneng makga a makae

Ka kgwedi	
Kgweding dingwe le dingwe tse tharo	

Ga bedi mo ngwageng	
Gangwe mo ngwageng	
Ga gona motlhang	

12. A o agana gore tlhatlhello e botlhokwa?

☐ Eya ☐ Nyaa

13. A naa le fiwa tlhatlhello eo e latedisisa kapa tsona dikopano tsa thuto moo go tlhatlhobiwang tswelopele kapa go se be teng ga tswelopele ya tshebetso ya go itsise ngwana ka boemo ba gagwe ba HIV mo tirelong ya lona?

☐ Eya ☐ Nyaa

14. A naa lefelo tirelo la gago le na le go latedisisa le go tlhatlhoba gore a naa ditsamaiso keletso tsa go tlhagisa boemo baneng di a diragatswa?

Eya	
Nnyaa	
Ga ke na bonnete	

15. A naa o kare o tlhatlhegile go lekane gore o ka tsamaisa ditaba tsa go tlhagisa boemo go latela ka moo di beilweng mo tsamaisa keletsong ya go tlhagisa boemo?

Ke dumela ka matla	
Ke a dumela	
Ga ke dumele kgotsa gona go ganetsana	
Ke a ganetsana	
Ke ganetsana ka matla	

16. Go ya ka wena, ke eng e e dirang gore kliniki ya Hoekfontein (Mmakau) e seke ya bona phunyeletso mo tshebeletsong ya go itsise ngwana ka boemo ba gagwe ba HIV?

____

____

____

17. O nagana gore go ka dirwa eng go matlafatsa kitso ya gago ka go tlhagisa boemo mo ngwaneng le tshebetso ya teng morago?

	Ke dumela ka matla	Ke a dumela	Ga ke dumele kgotsa gona go ganetsana	Ke a ganetsana	Ke ganetsana ka matla
Dikwetliso tsa kgafetsa ka go tlhagisa boemo mo ngwaneng					
Go neelwa didiriswa tsa go ikwetlisa (e.g. dibukana)					
Go neelwa ka sebaka sa tshebeletso sa boemo bo bo tshwanetseng bana					
Kokeletso ya nako eo e beetsweng tshebeletso ya go tlhagisa boemo					
Kgiro ya basebeletsi ba ba tlhatlhegeleng					
Tiiso ya tirisano mmogo					

magareng a mafapha					

18. A o ka mpollela ka maitemogelo a gago e le a mantle kgotsa a a bosula ka go itsise ngwana ka boemo ba gagwe ba HIV mo tshebeletsong ya gago?

____

____

____

____

19. O nagana gore ngwana a ka itsisiwe ka boemo ba gagwe ba HIV a le dilemo tse kae?

____

20. O nagana gore ngwana o na le tokelo ya go itse boemo ba gagwe ba HIV?

____

____

____

21. O nagana gore ke maikarabelo a mang go itsise ngwana yoo a tsetsweng a na le kokwanatlhoko ya HIV? Wena kgotsa motlhokomedi wa ngwana?

____

____

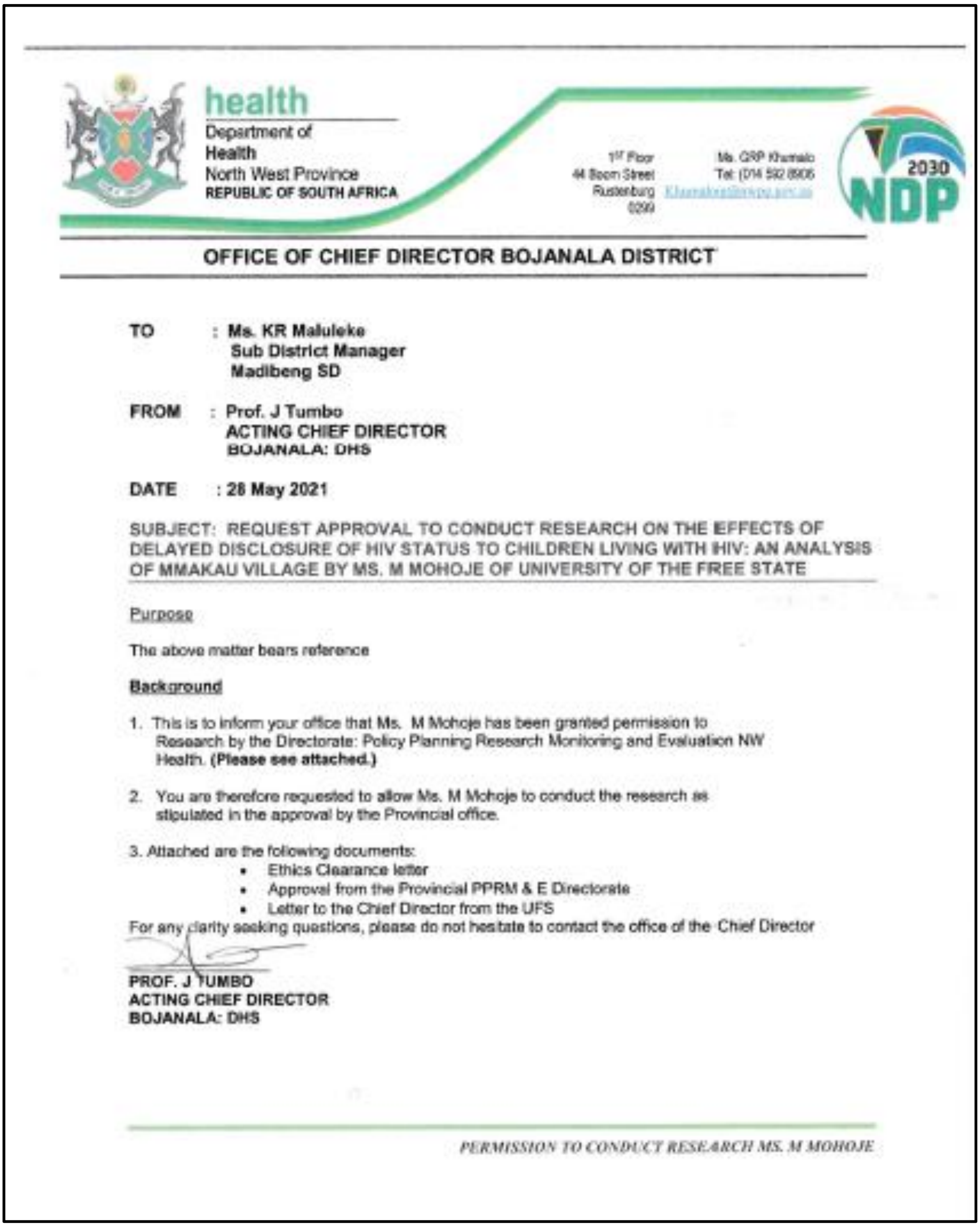
22. Tshwaelo e nngwe ka taba ya gore motlhokomedi wa ngwana a itsise ngwana ka boemo ba gagwe ba HIV?

____

____

Ke lebogela nako ya gago le go tsaya karolo.

APPENDIX F:
FINAL PERMISSION LETTER FROM NORTH WEST DEPARTMENT OF HEALTH



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

1ST Floor
44 Boom Street
Rustenburg
0299

Ms. GRP Khumalo
Tel: (014 592 8906
[illegible]

OFFICE OF CHIEF DIRECTOR BOJANALA DISTRICT

TO : **Ms. KR Maluleke**
Sub District Manager
Madibeng SD

FROM : **Prof. J Tumbo**
ACTING CHIEF DIRECTOR
BOJANALA: DHS

DATE : **28 May 2021**

SUBJECT: REQUEST APPROVAL TO CONDUCT RESEARCH ON THE EFFECTS OF DELAYED DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV: AN ANALYSIS OF MMAKAU VILLAGE BY MS. M MOHOJE OF UNIVERSITY OF THE FREE STATE

Purpose

The above matter bears reference

Background

1. This is to inform your office that Ms. M Mohoje has been granted permission to Research by the Directorate: Policy Planning Research Monitoring and Evaluation NW Health. **(Please see attached.)**

2. You are therefore requested to allow Ms. M Mohoje to conduct the research as stipulated in the approval by the Provincial office.

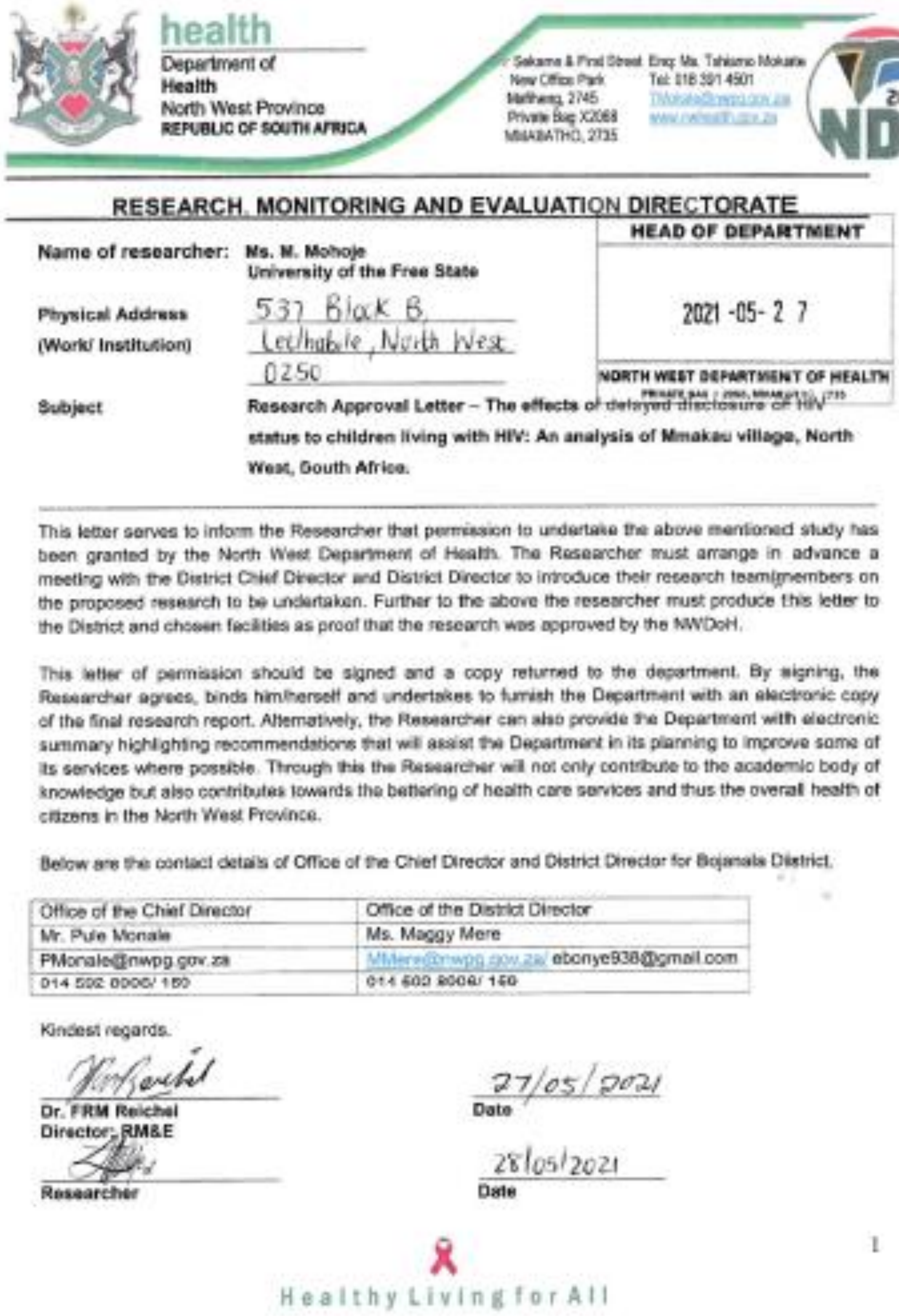
3. Attached are the following documents:
    - Ethics Clearance letter
    - Approval from the Provincial PPRM & E Directorate
    - Letter to the Chief Director from the UFS

For any clarity seeking questions, please do not hesitate to contact the office of the Chief Director

PROF. J TUMBO
ACTING CHIEF DIRECTOR
BOJANALA: DHS

PERMISSION TO CONDUCT RESEARCH MS. M MOHOJE

APPENDIX G:
RESEARCH APPROVAL LETTER FROM NORTH WEST DEPARTMENT OF HEALTH



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

Sekame & First Street
New Office Park
Mafikeng, 2745
Private Bag X2068
MMABATHO, 2735

Enq: Ms. Tshiamo Mokate
Tel: 018 391 4501
[illegible]
www.nwhealth.gov.za

RESEARCH, MONITORING AND EVALUATION DIRECTORATE

HEAD OF DEPARTMENT
2021 -05- 2 7
NORTH WEST DEPARTMENT OF HEALTH
PRIVATE BAG X2068, MMABATHO, 2735

Name of researcher: **Ms. M. Mohoje**
University of the Free State

Physical Address (Work/ Institution)
537 Block B,
Letlhabile, North West
0250

Subject **Research Approval Letter – The effects of delayed disclosure of HIV status to children living with HIV: An analysis of Mmakau village, North West, South Africa.**

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher must arrange in advance a meeting with the District Chief Director and District Director to introduce their research team/members on the proposed research to be undertaken. Further to the above the researcher must produce this letter to the District and chosen facilities as proof that the research was approved by the NWDoH.

This letter of permission should be signed and a copy returned to the department. By signing, the Researcher agrees, binds him/herself and undertakes to furnish the Department with an electronic copy of the final research report. Alternatively, the Researcher can also provide the Department with electronic summary highlighting recommendations that will assist the Department in its planning to improve some of its services where possible. Through this the Researcher will not only contribute to the academic body of knowledge but also contributes towards the bettering of health care services and thus the overall health of citizens in the North West Province.

Below are the contact details of Office of the Chief Director and District Director for Bojanala District.

Office of the Chief Director	Office of the District Director
Mr. Pule Monale	Ms. Maggy Mere
PMonale@nwpg.gov.za	MMere@nwpg.gov.za/ ebonye938@gmail.com
014 592 0006/ 150	014 600 8008/ 150

Kindest regards.

Dr. FRM Reichel
Director: RM&E

27/05/2021
Date

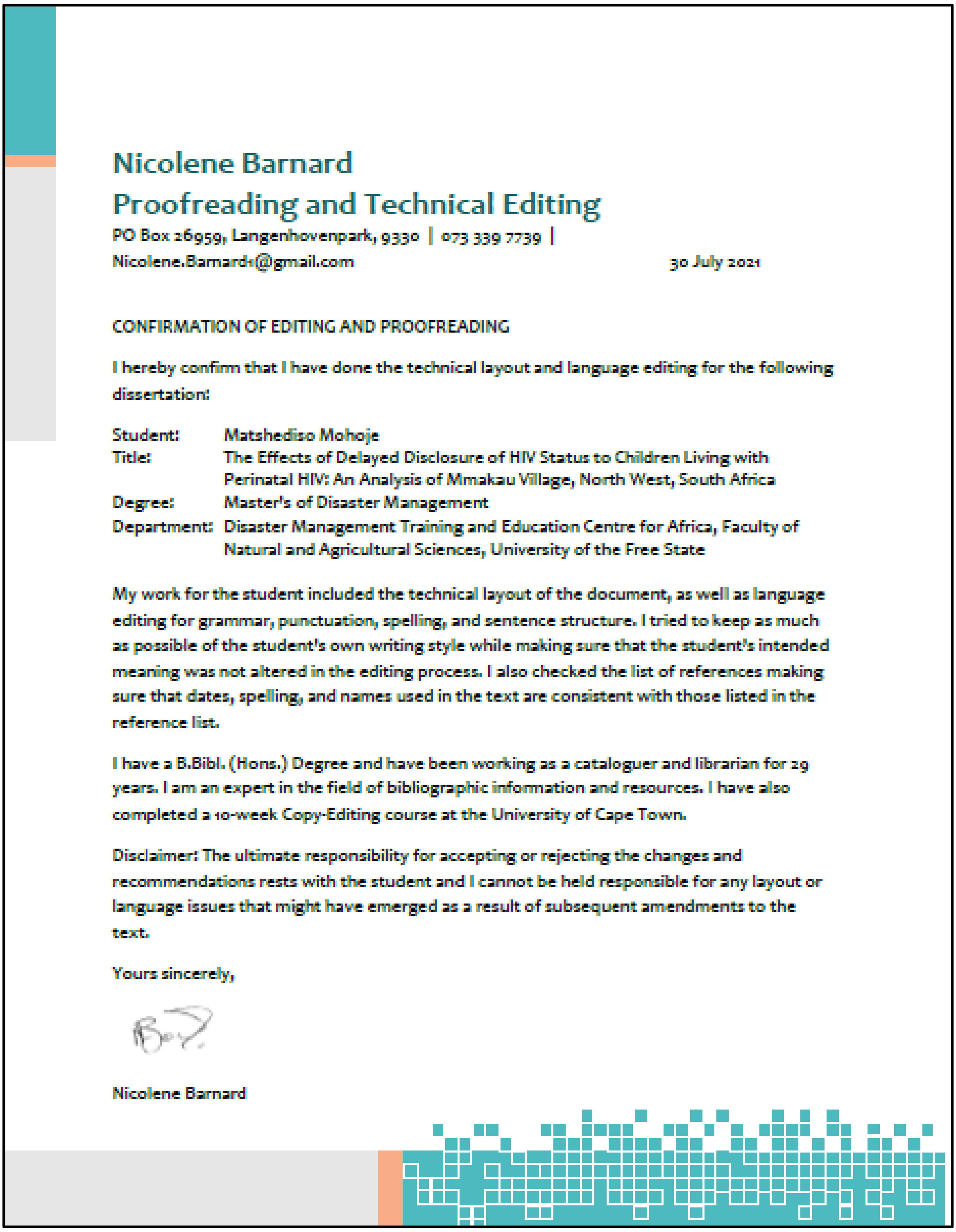
Researcher

28/05/2021
Date

1

Healthy Living for All

APPENDIX H: CONFIRMATION OF EDITING



Nicolene Barnard
Proofreading and Technical Editing
PO Box 26959, Langenhovenpark, 9330 | 073 339 7739 |
Nicolene.Barnard1@gmail.com

30 July 2021

CONFIRMATION OF EDITING AND PROOFREADING

I hereby confirm that I have done the technical layout and language editing for the following dissertation:

Student: Matshediso Mohoje
Title: The Effects of Delayed Disclosure of HIV Status to Children Living with Perinatal HIV: An Analysis of Mmakau Village, North West, South Africa
Degree: Master's of Disaster Management
Department: Disaster Management Training and Education Centre for Africa, Faculty of Natural and Agricultural Sciences, University of the Free State

My work for the student included the technical layout of the document, as well as language editing for grammar, punctuation, spelling, and sentence structure. I tried to keep as much as possible of the student's own writing style while making sure that the student's intended meaning was not altered in the editing process. I also checked the list of references making sure that dates, spelling, and names used in the text are consistent with those listed in the reference list.

I have a B.Bibl. (Hons.) Degree and have been working as a cataloguer and librarian for 29 years. I am an expert in the field of bibliographic information and resources. I have also completed a 10-week Copy-Editing course at the University of Cape Town.

Disclaimer: The ultimate responsibility for accepting or rejecting the changes and recommendations rests with the student and I cannot be held responsible for any layout or language issues that might have emerged as a result of subsequent amendments to the text.

Yours sincerely,

Nicolene Barnard