EXPLORING THE PSYCHO-SOCIAL FACTORS THAT INFORM HIV POSITIVE STATUS DISCLOSURE TO CHILDREN BETWEEN THE AGES OF 7-14 BY THEIR PARENTS AND CAREGIVERS IN NKANGALA DISTRICT OF MPUMALANGA, SOUTH AFRICA

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DECLARATION

I, Mrs Constance Thuli Mashile, declare that I wrote this dissertation, titled EXPLORING THE PSYCHO-SOCIAL FACTORS THAT INFORM HIV-POSITIVE STATUS DISCLOSURE TO CHILDREN BETWEEN THE AGES OF 7-14 BY THEIR PARENTS AND CAREGIVERS IN NKANGALA DISTRICT OF MPUMALANGA, SOUTH AFRICA. I have noted and credited any sources that I have used.

This study treatise is my own original work, and it has never been evaluated by another university. I accept full responsibility for any editorial, grammatical, or structural faults in this content.

28/03/2024

Ms C.T. Mashile **Date**

DEDICATION

I sincerely dedicate my dissertation to the Almighty God in gratitude for the perfect health and clear mind he bestowed upon me in order for this task to be completed.

This research is also dedicated to my mother, Ms Christina Nkosi, whose unending love, support, and prayers gave me the strength, courage, and confidence to pursue my dreams with zeal.

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“For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you, plans to give you a hope and a future” (Jeremiah 29:11).

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ABSTRACT

The majority of human immunodeficiency virus (HIV) disclosure research in South Africa has focused on spouses and sexual partners. Few studies have researched how parents and caregivers disclose children’s HIV-positive status to them. Most parents and caregivers of children living with HIV still struggle with status disclosure, which has a negative impact on treatment adherence and the children’s mental and physical health. Understanding the motivations for and against disclosure, as well as how these reasons differ depending on the disclosure target, is crucial for effective preventative actions, such as the tools or practical information parents need. This study explored the social and psychological impacts of HIV-status disclosure to children between the ages of seven and 14 by their parents and caregivers. A qualitative, research design was adopted to achieve the goal of the study. Data were collected through in-depth face to face interviews with 12 participants who were purposefully chosen to participate in the study. Goffman’s stigma theory and literature on parental disclosure of HIV status to children were employed to navigate how stigma contributes to HIV non-disclosure to children by their parents and caregivers and the challenges faced by parents in terms of HIV-status disclosure. The research findings identified three themes: Is it important to disclose, reasons for non-disclosure, and the motivation and procedure for disclosure. Based on the findings, recommendations were developed to assist healthcare providers and policymakers to help parents and caregivers to disclose their children’s HIV-positive status to them. The study’s findings include a consistent pattern of when, how, and what information to convey during disclosure, as described by the parents and caregivers of HIV-positive children who participated in this study.

Keywords: HIV-positive status; non-disclosure; disclosure; child; childhood caregiver(s); parent(s); impact of HIV; South Africa; social; psychological

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Anti-retroviral treatment
ARV	Antiretroviral
COVID-19	Coronavirus disease on 2019
DoH	Department of Health
HIV	Human immunodeficiency virus
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure prophylaxis
RSA	Republic of South Africa
TB	Tuberculosis
TLD	Tenofovir, Lamivudine, and Dolutegravir
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children’s Fund
USA	United States of America
WHO	World Health Organization

CHAPTER 1:

A STUDY OF CHILDREN'S HUMAN IMMUNODEFICIENCY VIRUS (HIV)-POSITIVE STATUS DISCLOSURE

1.1 INTRODUCTION

According to recent statistics, approximately 270 000 children and adolescents in South Africa live with HIV and are on antiretroviral treatment (ART) (Joint United Nations Programme on HIV/AIDS [UNAIDS] 2021:2). South Africa's ART programme is reported to be one of the largest HIV programmes in the world. Globally, approximately 91% of children living with HIV have access to ART (World Health Organization [WHO] 2023:17). In South Africa, between 2014-2018, new HIV infections among children have decreased as a result of the success of the prevention of mother-to-child transmission and the availability of ART (UNAIDS 2018:34). Even if there are fewer new infections, which are mainly due to the rollout of the ART programme, South Africa has experienced challenges regarding the disclosure of children's HIV-positive status to them by their parents (WHO 2020:32). HIV disclosure involves discussing a potentially life-threatening, stigmatized, and contagious condition (WHO 2020:71). Madiko and Diko (2020) argue that parents and caregivers tend to provide unclear information about the disease and treatment to HIV-positive children, which affects adherence to treatment as a result. Other parents and caregivers are unsure of the best times, methods, and details to disclose the HIV status to the infected child (Madiko & Diko 2020). As such, this study sought to explore HIV-positive status disclosure to children between the ages of seven and 14 by their parents and caregivers in the Nkangala District of the Mpumalanga province in South Africa.

Adding to the above challenges is the COVID-19 pandemic, which has hampered efforts to sustain progress made in the fight against HIV. Lockdowns, curfews, and fear of catching the virus that causes COVID-19 prevented people, especially mothers and children, from getting the treatment they need (United Nations Children's Fund [UNICEF] 2020:10). As a result, the number of patients attending HIV treatment clinics, especially women and children, declined during the pandemic (UNICEF 2020:10). According to a recent survey by UNICEF (2020:11), children between the ages of 0 and 14 living with and being vulnerable to HIV experienced a 10% decline in HIV treatment. This global picture demonstrates poor adherence to ART due to a lack of information as to why the children are on treatment, resulting in an estimation of 310 children and adolescents dying from illnesses related to acquired immunodeficiency syndrome (AIDS) every day (WHO 2020:54); hence the significance of this study, which sought to investigate parents' and guardians' experiences of disclosing an HIV-positive status to their children.

Madiko and Diko (2020) argue that antiretrovirals (ARVs) increase the life expectancy of HIV-positive children, so much so that they become adults who are well informed about the disease and treatment. The increased life expectancy of children beyond teenage years to adulthood due to ART access confirms that parents indeed need to disclose children's HIV status to ensure that these infected children adhere to their treatment (WHO 2020:23). Disclosure of HIV status to children by their parents is important as this helps them to adhere to treatment and take charge of their own health (Madiko & Diko 2020; Klutsey, Amankwah-Poku & Asante 2021:3). According to Statistics South Africa (2020), in 2020 alone, approximately 688 girls between the age of nine and 10 gave birth. The statistics demonstrate the need for children to be aware of their HIV status from a young age since they may engage in sexual intercourse, either voluntarily or involuntarily.

It is against this backdrop that this study sought to explore children's HIV-positive status disclosure to them by their parents and caregivers and the implications that disclosure have for children between the ages of seven and 14 in the Nkangala District of Mpumalanga. There is limited literature on parents and caregivers disclosing their children's HIV-positive status to them in South African rural communities. This study sought to fill this gap by exploring the extent of HIV-positive status disclosure in rural areas and the support that parents and caregivers in these areas receive in the process of disclosing to their children. The study further sought to explore some of the strategies that rural parents and guardians adopt in disclosing the children's HIV-positive status to them. The research provides insight into the disclosure of HIV-positive status to children and will likely lead to the identification of support and skills or information that parents and caregivers may require in tackling the sensitive issue of HIV-status disclosure. This study is important since the results will further knowledge of HIV disclosure and non-disclosure, as well as parents' and children's views on and experiences with HIV disclosure, as well as their knowledge of ARV and ART. The findings will also aid in understanding adherence to treatment and will be helpful in creating interventions that will consider the difficulties faced by children living with HIV and receiving ARVs at a public hospital in Mpumalanga.

1.2 HISTORY OF HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) IN SOUTH AFRICA

HIV is a subgroup of retro-viruses that attacks the cells that help the body to fight infections. Over time it causes AIDS (Kumar 2012:147). The transmission of HIV occurs through breastfeeding and the exchange of vaginal fluid, pre-ejaculate fluid, semen, and blood (Cunningham, Donaghy, Harman, Kim & Turville 2010:524). HIV infects vital cells in the human immune system. Infected cells are directly killed by the virus and infected CD4+T cells are also killed by cytotoxic lymphocytes, both of which contribute to low levels of CD4+T cells (Cunningham *et al* 2010:524). If left untreated, this can develop into AIDS. As the immune system gradually fails, life-threatening opportunistic infections and cancers can flourish in people with the illness known as AIDS (Doitsh, Nicole, Geng, Yang, Monroe, Zepeda, Hunt, Hatano, Sowinski, Munoz-Arias & Greene 2014:509).

In 1983, two homosexual men in South Africa were diagnosed with AIDS, which marked the country's first cases of the disease, and the first AIDS-related death occurred the same year (Van Dyk, Tlou & Van Dyk 2015:56). Similar to the United Kingdom and the United States of America (USA), in South Africa only homosexual men, haemophiliacs, and those who received blood transfusions were previously thought to be the only carriers of HIV and AIDS in South Africa (Van Dyk, Tlou & Van Dyk 2017:57). It was verified that HIV had entered the heterosexual community by the end of 1989, and the virus expanded quickly in the early 1990s (UNAIDS 2010:32). In 1993, almost 1% of South Africans had AIDS and the number increased to 3% by 1995 (Zhang, Zhou, Groppelli, Pellegrino, Williams, Borrow, Chain & Jolly 2015:2). Although HIV rates had climbed by 30% by the late 1990s, the South African government was still taking its time in responding to the public health emergency that was developing (Van Dyk *et al* 2017:88). Former president Nelson Mandela did not address the government's neglectful attitude toward the crisis until the late 1990s. At that point, South Africa had the largest HIV-positive population in the world (UNAIDS 2010:55).

With an estimated 3.5 million new infections happening globally in 1996, the spread of HIV reached its peak. Although many South Africans were aware of HIV and AIDS and the preventative measures, it was difficult for them especially women to put that knowledge into practice because of factors such as incorrect cultural practices which include sex-based distinction of difference in physique age group, poverty, stigma, non-disclosure, and lack of education (Van Dyk *et al* 2017:44). HIV- positive women have historically and currently been perceived as immoral and promiscuous due to their unequal power relationships with men. Although males who are HIV positive are seen as normal guys who have several sexual partners, women still face HIV and deal with stigma and marginalization that is exacerbated by cultural norms, sexual assault, and a lack of rights (UNAIDS 2018:31). Throughout the centuries, women and children have been mistreated and socially disadvantaged, living in the shadows, especially in third world countries including South Africa (Van Dyk *et al* 2017:56).

Although HIV and AIDS are presently remains some of humanity's most serious health challenges, many successful interventions have been achieved through global solidarity against the virus (Pinzón-Irequi, Beck-Sagué & Malow 2013). It would be inaccurate to suggest that South Africa's future is bleak. One of its first significant achievements was in 1998 when South Africa introduced the prevention of mother-to-child transmission (PMTCT) programme. With better monitoring of prophylactic HIV medication at antenatal clinics, the rate of mother-to-child transmission decreased from 8% in 2008 to 2.7% in 2012 and, as a result, children's HIV death rates decreased by 20% in 2015 (Van Dyk, Tlou & Van Dyk 2015:107). In the study conducted by Van Dyk *et al* (2015:77) on HIV and AIDS education, care, and counselling, it is stated that on World AIDS Day in 2009, South Africa's former president, Jacob Zuma, announced a number of critical interventions to improve the access to special groups such as pregnant women, children, and patients with HIV/tuberculosis (TB) co-infection, to antiretroviral therapy. The main aim of these interventions was not only to decrease the disease's burden, but also to improve life expectancy and at the same time address child and maternal mortality.

In December 2015, South Africa became the first country in sub-Saharan Africa to fully approve pre-exposure prophylaxis (PrEP) for HIV prevention for all citizens who were HIV negative (WHO 2015:44). In 2019, it was estimated that between 23 000 and 24 000 people were using PrEP in ongoing and planned projects across South Africa

(WHO 2019:32). South Africa has made improvements in getting people to test for HIV in recent years and has met the first of the 90-90-90 targets, with 90% of people infected with HIV being aware of their HIV status in 2018 (WHO 2018).

In December 2019, South Africa introduced an affordable, cutting-edge new drug as the fastest way to reduce the HIV viral load known as Tenofovir, Lamivudine, and Dolutegravir (TLD). The health department has started rolling out the advanced pill (UNAIDS 2019). The new three-in-one pill, developed with the financial backing of global health development organisation, Unitaid[1], bands together the drugs tenofovir disoproxil fumarate, lamivudine, and dolutegravir (UNAIDS 2019). With its great suppression of HIV, minimal toxicity, and convenience of use, the pill is administered as a first-line treatment with the expectation that it will make it easier for individuals to stay on treatment for the rest of their lives and will lower the likelihood that ARV resistance will emerge (UNAIDS 2019).

In 2020, South Africa was making significant progress to reach its campaign targets, which include diagnosis targets, viral suppression targets, and disclosure (Van Schalkwyk, Seatlhodi, Velasquez, Feizzadeh, Johnson & Leigh 2021:25). That was until the COVID-19 pandemic hit the world in early 2020, which necessitated the so-called lockdowns. The lockdowns and government efforts to fight the pandemic posed serious challenges in reaching the 90% ART target because the healthcare focus shifted from this target to fighting the COVID-19 pandemic. With many mothers and children being unable to access the care they needed, the number of people attending HIV treatment clinics, especially women and children, declined (Van Schalkwyk *et al* 2021:25). It is crucial to provide a historical overview of HIV and AIDS in South Africa because it serves as the basis for the study and helps to identify the gaps in how HIV disclosure to children has been managed to potentially assist medical staff in identifying possible areas of advocacy regarding parental disclosure of HIV status in children.

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[1] Unitaid is an international organisation that invests in new ways to prevent, diagnose, and treat HIV/AIDS, TB, and malaria.

1.3 BACKGROUND OF THE STUDY

The South African Department of Health (DoH 2019:119) has made significant strides to reduce HIV prevalence among children and young adults by increasing the number of facilities that provide medical interventions to HIV-positive patients, PMTCT, and rolling out a national ARV programme. In addition, President Cyril Ramaphosa in 2018 called for increased testing and treatment and noted that two million South Africans, especially children and young adults, should be tested by December 2020. However, due to the COVID-19 pandemic, there has been a reversal of many critical gains made in terms of HIV and AIDS (UNICEF 2020:13). UNAIDS (2020:86) states that between the months of April and May 2020 there was an interruption in the delivery of services for HIV testing and treatment for children and women, which is the period during which South Africa was in hard lockdown. The lockdown restrictions led to supply chain disruptions and redeployment of healthcare workers to primarily focus resources on the fight against COVID-19 (UNICEF 2020:18). Aggravating the circumstances, some unwillingness by parents to disclose the HIV status to their children resulted in the virus spreading among children, as well as to ART non-adherence (UNICEF 2020:22). Some parents fear that if their children’s HIV status is disclosed, their children will be stigmatised (Madiko & Diko 2021:15). In their qualitative study in South Africa, Madiko and Diko (2021) found that parents keep their children’s HIV-positive status a secret because they want to protect them from being isolated since there are people who still believe, for example, that they cannot share food with someone who is HIV positive. Similarly, a study conducted by Vreeman, Scanlon, Tu, Slaven, McAteer, Aluoch, Ayaya and Nyandiko (2019:09) in western Kenya found that parents and caregivers worry that the children would reveal their HIV status to others, which could subject the child and the entire family to stigma and social exclusion. Disclosing a child’s HIV status may be perceived as an easy process by other people; however, these findings are evidence that it remains a challenge for parents to disclose it.

Children in South Africa have had a decrease in new infections, from 28 000 in 2010 to 14 000 in 2018 (UNAIDS 2018:12). This milestone is attributed to the PMTCT programme (UNAIDS 2018:12). Even though South Africa managed to decrease new HIV infections by 50%, 14 000 is a significant number and still concerning. While the researcher is cognisant of the fact that new HIV infections are on the decline, she argues that this study is important since parental disclosure of HIV status to children between seven and 14 years of age is a crucial process in the attempt to prevent the spread of the virus and reduce HIV infections among the youth. Lindberg, Zimet and Marcell (2019:170) argue that children as young as 13 are having sex and that children as young as five years are directly or indirectly exposed to sexual activities. Moreover, children as young as nine years are engaging in unprotected sex, with their peers who are living with HIV; thus causing HIV to potentially spread if there has been no HIV-positive status disclosure (Lindberg *et al* 2019:172). UNAIDS (2018:87) states that children need to be taught from a young age about HIV treatment and how to take care of their health. One of the ways of ensuring that these children take care of themselves is for their parents and caregivers to disclose their HIV-positive status to them and teaching them about the importance of adhering to treatment and protecting themselves.

A quantitative study conducted by Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa and Mupepi (2018:18) on HIV diagnosis disclosure to infected children and adolescents in Ghana discovered that parental non-disclosure led to children who are on ARV treatment for HIV not taking their medication as prescribed, which resulted in treatment failure, high viral loads, a risk of early disease progression and/or dramatic changes in the clinical course of HIV infection, and ultimately a shorter life expectancy for these children. According to Lyimo, De Bruin, Van den Boogaard, Hospers, Van der Ven and Mushi (2018:534), it is important to identify and address the challenges faced by parents and caregivers in order to complete the process of disclosure and adherence when children start on ART, since disclosure of HIV and adherence are vital parts of the treatment programme. UNAIDS (2020:98) argues that should non-disclosure by parents to their HIV-positive children continue in South Africa, the entire nation would have a negative impact as these children will grow into adolescents and spread the virus unintentionally. Lack of disclosure will result in poor treatment and non-compliance, which could increase the risk of new HIV infections in the general population. This illustrates the significance of this study, which brings attention to children’s HIV-positive status disclosure in especially South African rural communities.

1.4 PROBLEM STATEMENT AND RATIONALE FOR THE STUDY

Globally, 39 million people live with HIV, of whom an estimated 2.1 million are children (0 to 14 years). Of the 2.1 million children, 270 000 live in South Africa (WHO 2023:

9). Johnson, Van Rensburg, Govathson and Meyer-Rath (2019:13) explain that in 2018, less than 20% of children in South Africa who received treatment were aware of their HIV status. Additionally, Van Elsland, Peters, Grobbelaar, Ketelo, Kok, Cotton, and Van Furth (2019:14) argue that the lack of disclosure by parents to children negatively affects treatment plans. While disclosure is identified as important in the prevention of new infections, globally only 50% of children know their HIV status (UNAIDS 2015:69-71). Van Dyk *et al* (2017:529) argue that the unwillingness of parents to disclose the HIV-positive status to these children results in virus spreading among children and this hampers global efforts to end HIV/AIDS.

According to the National Institute for Communicable Diseases (2021:6), a number of children below the age of 18 who were admitted to hospitals and died during the so-called third wave of the COVID-19 pandemic were also HIV positive. Moreover, some of these children defaulted on their ARVs because their statuses were never revealed to them and they did not know the importance of adhering to their ARVs. The issue of disclosure by parents to their HIV-positive children is important in order for the children to take control of their treatment earlier in their lives and not depend on their parents. Available research on the social and psychological impacts of HIV in South Africa has paid attention to the stigma attached to HIV, depression, and anxiety, but neglected the important topic of parents or guardians disclosing a child's HIV-positive status (Rasoolinajad, Abedinia, Noorbala, Mohraz, Badie, Hamd & Sahebi 2018; Van Dyk *et al* 2017; Van Elsland *et al* 2019). As a result of limited research, little knowledge is available about children's HIV-positive status disclosure in South African rural and disadvantaged communities, particularly how parents and caregivers navigate the issue of disclosure. This limits the support and interventions that are necessary to assist them. This study therefore aimed to contribute to addressing this gap in this field of knowledge by exploring HIV-status disclosure by parents and caregivers to children between the ages of seven and 14 and the aspects that hamper disclosure. Additionally, this study explored the skills and information that parents and caregivers need to navigate the issue of disclosure.

1.5 RESEARCH PURPOSE, OBJECTIVES, AND QUESTIONS

1.5.1 Purpose of the study

Working from the premise that the majority of children who live with HIV do not know their status, as per various studies cited above, including that of Hayfron-Benjamin *et al* (2018:366), the main purpose of this study was to explore the disclosure of HIV-positive status to children between the ages of seven and 14 by their parents and caregivers in the Nkangala District in Mpumalanga, South Africa. This is so that possible recommendations can be suggested to public health clinics in the Nkangala District, as well as support groups for parents, caregivers, community training teams, and various other interest groups on how to best equip parents and caregivers with information and skills to navigate disclosure and to understand the positive effects of such disclosure.

1.5.2 Objectives of the study

A research objective is an end goal that is specific and measurable (Brink, Van der Walt & Van Rensburg 2018:84).

The objectives of this research were as follows:

- To explore the social and psychological impacts of disclosing children’s HIV-positive status on parents and caregivers and the infected children in the Nkangala District in Mpumalanga;
- To explore the support and knowledge that parents and caregivers receive for the disclosure of an HIV-positive status to children between the ages of seven and 14 in the Nkangala District in Mpumalanga; and
- To explore the skills and information needed by parents and caregivers to address HIV-status disclosure to children between the ages of seven and 14 in the Nkangala District in Mpumalanga.

1.5.3 Research questions

This study’s primary research question is: How do parents and caregivers navigate the social and psychological factors that influence the disclosure of the children HIV positive statuses?

The following specific questions are based on the main research question mentioned above:

- What are the challenges faced by parents and caregivers in the disclosure of an HIV-positive status to their infected children in the Nkangala District in Mpumalanga?
- What are the social and psychosocial impacts of HIV-positive status disclosure on parents and caregivers and their children in the Nkangala District in Mpumalanga?
- What kind of assistance do parents and caregivers need in order for them to be fully equipped to disclose the status of their HIV-positive children to them in the Nkangala District in Mpumalanga?

1.6 DEFINITION OF KEY CONCEPTS

The following key concepts are used throughout this thesis:

1.6.1 Child

According to UNICEF (2010), a person under the age of 18 is considered a child, unless the applicable laws specify an earlier age. In the South African context, the Children’s Act, No. 38 of 2005, defines a child as any person under the age of 18 (Republic of South Africa [RSA] 2005).

1.6.2 Childhood

According to United Nations Committee on the Rights of the Child (2021:13), childhood is a term usually applied to the phase of human development between infancy and adulthood. For this study’s purposes, it is the time during which human beings develop their physical bodies and their mental abilities.

1.6.3 Parent

A parent is a biological mother or a biological father to a child (Lekganyane & Alpaslan 2019:4). For this study’s purposes, a parent is a person who is entrusted with providing primary care to a child under their care. This also includes caregivers who may or may not be biological parents.

1.6.4 Caregiver

A caregiver is anyone who takes care of or is responsible for young children, in any setting (Lekganyane & Alpaslan 2019:4). In this study, a caregiver is defined as a person who voluntarily offers to raise an HIV-positive child in the absence of biological parent(s).

1.6.5 Guardian

According to the Children's Act of 2005, a guardian means a parent or other person who has guardianship of a child (RSA 2005:12). The term "guardianship" in this study refers to the legal authority and duty to provide for a child's upbringing, care, and decision making regarding the child.

1.6.6 HIV status

HIV status refers to the confirmed result of HIV that indicates if a person is HIV negative or positive (Act Against AIDS HIV Testing Campaigns 2018:23). HIV is the virus that causes infection (WHO 2021:77).

1.6.7 HIV-positive status

HIV-positive status refers to having received a positive result on a blood test for HIV (Act Against AIDS Testing Campaigns 2018:23). An HIV-positive status means there are traces of HIV in the body that are detected by a rapid, standard, or laboratory test (WHO 2021:78).

1.6.8 Disclosure

Disclosure is the act of revealing someone's HIV-positive status (Van Elsland *et al* 2019:17). For the purposes of this study, disclosure to children refers to their parents or caregivers disclosing the child's HIV status to them (Van Elsland *et al* 2019:17).

1.7 METHODOLOGICAL UNDERPINNINGS

A qualitative hermeneutical method was applied in this study, where 12 in depth face-to-face interviews were conducted with parents and caregivers of HIV positive children. The hermeneutical method was used for this study to describe, explore, and interpret the social and psychological impacts on parents and caregivers of disclosing an HIV-positive status to their children.

The in-depth face-to-face interviews provided the researcher with an opportunity to explore the participants' experiences in depth and where necessary to probe for more information and seek clarity. All the research questions were formulated in English; however, some participants preferred to used their native languages, which were siSwati and isiNdebele. The translation of these interviews and the audio recordings of the research interviews was performed by a professional translator. Thematic analysis method was used in this study to identify themes and subthemes. The ethical principles of informed consent and voluntary participation, privacy and confidentiality, autonomy, beneficence and non-beneficence were followed throughout the study.

1.8 OUTLINE OF CHAPTERS

This thesis contains the following chapters:

Chapter 1 outlined the study, with a particular focus on the background, problem statement, and purpose of the study. The aims, objectives, and research questions of the study were outlined. The chapter concluded with a brief summary of the research design and some of the methodological choices made, as well as an outline of the chapters of the thesis.

Chapter 2 examines existing international and South African literature on the topic of HIV-status disclosure. Literature from the Global North and the Global South is taken into consideration to identify common themes and gaps in existing knowledge. Furthermore, this chapter establishes the theoretical framework of the study, namely Goffman's (1963) stigma theory and the socio-ecological theory.

Chapter 3 presents the methodological approach employed, as well as the qualitative research design that was followed. The data-collection tools and method of analysis are discussed in this chapter to indicate how data were collected, processed, and used. The honesty and trustworthiness of the collected data and findings are expounded on, followed by the ethical guidelines adhered to in ensuring that the study was conducted in an ethical manner.

Chapter 4 explores stigma as a barrier to disclosure and discusses how parents and caregivers in this study navigate HIV-related stigma in their rural communities. The chapter establishes how stigma facilitates the disclosure of children's HIV-positive status to them.

Chapter 5 presents an analysis of the collected data and discusses the findings of the study, with a particular focus on three themes, namely is it important to disclose, reasons for non-disclosure, and disclosure motivation and procedure.

Chapter 6, as the final chapter, provides a critical engagement of the findings presented in Chapters 4 and 5, followed by recommendations for the healthcare sector and future research. This is followed by concluding remarks.

1.9 CONCLUSION

This chapter started by providing background on the study, followed by a detailed discussion of the problem statement, which suggests that disclosure of their HIV-positive status to children is vital because it is the first step towards treatment adherence. However, the prevalence of disclosure of HIV status by parents to their children is very low, which is very concerning as non-disclosure is linked to poor adherence to treatment, which leads to treatment failure and results in the virus spreading among children and thus hampering global efforts to fight HIV/AIDS. The key concepts used in the study were defined. The research purpose, and objectives were also discussed in this chapter, and the main research question and secondary research questions were presented. An outline of the thesis' chapters was also provided.

CHAPTER 2:
HIV STIGMA AND DISCLOSURE: A LITERATURE REVIEW

2.1 INTRODUCTION

In order to locate this study in terms of previous research on the disclosure of an HIV-positive status to children between the ages of seven and 14 by their parents and caregivers, this chapter reflects on a number of studies in international, local, and online publications and academic journals, including relevant theoretical perspectives. This chapter seeks to review available literature on HIV-related stigma and disclosure to children by parents and caregivers. This chapter starts with a detailed discussion of disclosure to HIV-positive children. The subsequent section presents an in-depth exploration of the legal framework and rights pertaining to HIV disclosure for South African children. Within this context, the chapter delves into the multifaceted impact of HIV disclosure to children and examines distinct patterns observed in how parents and caregivers disclose such information. Moreover, barriers to the disclosure of children's HIV-positive status are thoroughly analysed. Contrary to viewing HIV disclosure as a singular event, this study critically examines it as a dynamic process shaped by parental actions over time. The concluding segment of this chapter concentrates on elucidating the various stages involved in HIV disclosure to children, grounded in a comprehensive theoretical framework. Specifically, this study adopted the socio-ecological theory and Goffman's stigma theory to underpin the exploration of this critical aspect.

2.2 THE DISCLOSURE OF CHILDREN'S HIV-POSITIVE STATUS

Disclosure to children is a process of informing perinatally infected children, adolescents, and young adults of their HIV-positive status (Mokganyetji 2023:20). There is qualitative and quantitative evidence of the beneficial impacts of disclosure on behavioural risk reduction, follow-up to care, ART adherence, and reduced mental illness (Mutumba, Bauermeister, Musiime, Byaruhanga, Francis, Snow & Tsai 2015; Bernays, Tshuma, Willis, Mvududu, Chikeya, Mufuka, Cowan & Mavhu 2020; Mokganyetji 2023). Child HIV disclosure is a significant milestone in paediatric care and adherence to ART. Despite the advantages of disclosing HIV status in low- and middle-income countries, the rate of disclosure at a suitable age is still comparatively low (Mutumba *et al* 2015; Bernays *et al* 2020). According to a qualitative study conducted by Hazra, Siberry and Mofenson (2010:169) in the USA on growing up with HIV among children, adolescents, and young adults with perinatally acquired HIV infection, in the early years of the HIV epidemic, HIV-positive children had a short life expectancy due to a lack of treatment, which is popularly known as PMTCT. Children's HIV-positive status was not paid sufficient attention by health authorities in the US (Hazra *et al* 2010:169). Over time, the human race faced challenges from other chronic diseases such as cancer, which necessitated adults to realise the beneficial nature of full disclosure for medical treatment (WHO 2015:136). The WHO (2015) emphasises that the disclosure of HIV-positive status to infected children is the gateway to treatment adherence. Quantitative study conducted by Michaud, Suris, Thomas, Kahlert, Rudin and Cheseaux (2009) in the USA on to disclose or not and Lee and Oberdorfer (2009) in Thailand on risk-taking behaviours among vertically HIV-infected adolescents found that, even though parents and caregivers are urged to disclose to their children, many families continue to struggle with disclosure because parents occasionally delay the procedure. The various difficulties that parents and caregivers may face during this process must be acknowledged. Many people have the misconception that contracting HIV is the result of being cursed or punished for engaging in promiscuous behaviour (Pantelic, Boyes, Cluver & Meinck 2017:98). The decision of whether parents and caregivers eventually disclose their children's status is often influenced by maternal guilt and worrying about unfavourable effects from the disclosure. Since they fear being criticised and blamed for the illness, biological parents are frequently ashamed to disclose the HIV status to their children (Krauss, Letteney, De Baets, Baggaley & Okero 2013; Mutumba *et al* 2015; Gachanja & Burkholder 2016). It is within this context that disclosure of HIV positive status to infected children by their parents is considered a major issue in the level of disclosure and the care and management of HIV-infected children (Hayfron-Benjamin *et al* 2018; Mutumba *et al* 2015). The next section discusses the laws and rights regarding disclosure in terms of South African children.

2.3 LAWS AND RIGHTS REGARDING DISCLOSURE IN TERMS OF SOUTH AFRICAN CHILDREN

The Constitution of the Republic of South Africa and the United Nations' (UN) Convention on the Rights of the Child (hereafter referred to as "the UN Convention"), the latter of which South Africa became a signatory to on 16 June 1995, provide protection for South African children. Additionally, the Children's Act of 2005, as amended in 2007, guarantees the basic rights of children. In accordance with the UN Convention as related to HIV and COVID-19, in 2021, South Africa adopted a rights-based approach to HIV. The UN Convention, which states in Article 17 that every child should have "access to information and material from a diversity of national and international sources, especially those aimed at promoting his or her social, spiritual, and moral well-being and physical and mental health", is generally regarded as establishing disclosure as a legal right for children (Britto, Mehta, Thomas & Shet 2016:23).

The UN (2021:5) Convention on rights related to disclosure details that children have the right to access healthcare and information and to enjoy privacy and dignity, including making decisions about their lives. According to Section 130(1) of the Children's Act of 2005, no child may be tested for HIV unless it is in their best interest and consent was granted in accordance with Section 130(2) of the Act. This also applies if the test is required to determine whether a healthcare worker or any other individual may have become infected with HIV as a result of coming into contact with any substance from the child's body that may transmit the virus.

Furthermore, Section 130(2)(a) of the Act and the UN (2021:5) Convention state that children above the age of 12 and those deemed to be "sufficiently mature" can consent to HIV testing, a treatment plan, and full disclosure. The following individuals may consent on behalf of a child under the age of 12 who is not mature enough to understand the benefits, risks, and social effects of the test: the provincial head of the Department of Social Development, a designated child protection organisation that is arranging the child's placement, or the superintendent or person in charge of a hospital if the child is a minor and has no parent or caregiver and no designated child protection organisation that is arranging for the child's placement (Section 130(2)(a)-(d)). Consent may only be granted by the Children's Court if the consent granted by the role players mentioned above and in Section 130(2)(a) to (d) of the Children's Act is unreasonable or if the child, parent, or caregiver is unable to give consent.

The Children's Act No 38 of 2005 also guarantees the confidentiality of information regarding a child's HIV and AIDS status and mandates counselling both before and after testing. A child under the age of 12 cannot grant permission for someone to reveal their HIV-positive status, according to Section 133 of the Children's Act of 2005. Section 130 of the Act provides for the *mutatis mutandis* provision of consent on behalf of the child by the parent or caregiver, a recognised child protection organisation arranging the child's placement, the superintendent or person in charge of a hospital, and the Children's Court. Disclosing a child's HIV status is allowed when it falls within the parameters of a specific individual under the Children's Act or any other law that requires it, or when it is required to carry out the Act's provisions, to comply with a court order, or to serve as part of legal proceedings. The Children's Act is silent with regard to the treatment of minors, especially for HIV and AIDS. However, it is comforting to note that Section 39(4)(b) of the repealed Child Care Act of 1983 did make specific provisions for treatment and consent for children living with HIV.

Additionally, according to the WHO's published standards, school-age children should be told of their HIV-positive status, with younger children receiving information gradually as they get older (Lorenz, Grant, Muyindike, Maling, Card, Henry & Nazarali 2016:77). Moreover, the Children's Act states that when dealing with children, the best interest of the child must be at the centre of all decisions made about the child's life and wellbeing (RSA 2005:32).

The UN Convention clearly states that children have the right to the best healthcare possible and that they should have information about how to stay safe and healthy; however, parents and caregivers in South Africa find it difficult to discuss an HIV-positive status with their children and they are confused as to which age is considered safe and legal to disclose the child's HIV status to the child. These legal frameworks are relevant to this study because they serve as a starting point to develop an understanding of children's rights when it comes to health-related issues. The frameworks were useful in exposing the gap that exists between general children's rights and the rights of children who are living with HIV and AIDS. Using these frameworks assisted in developing an understanding of how health professionals are guided in handling HIV disclosure to children by parents and how these frameworks have shaped the process.

2.4 HIV AND AIDS DISCLOSURE TO CHILDREN GLOBALLY

Globally, researchers from various health disciplines have conducted research on HIV-status disclosure; thus providing insight into the implications of non-disclosure (Lyimo *et al* 2018:534; Madiko & Diko 2021:15; Lindberg *et al* 2019:170). The availability of ART over the past few years has greatly improved the lifespan of both HIV-positive adults and children (Madiko & Diko 2021:21). However, the challenges around HIV disclosure to children by parents and caregivers exist. Some parents are still reluctant to disclose the HIV status to their children due to fearing blame, negative judgement, stigma and discrimination, resentment, and lack of proper disclosure information (O’Malley, Beima-Sofie, Ferris, Shepered, Hamunime, Steward, Tjituka & Brandt 2015; Sabhyta, Mitchell & Fan 2018; Madiko & Diko 2021). As indicated in Chapter 1, it is evident that the disclosure of an HIV-positive status to children by parents is a vital part of treatment. It is therefore important to identify and address the challenges faced by parents and caregivers in an effort to achieve full disclosure globally.

In a qualitative study conducted by Armoon, Fleury, Bayat, Fakhri, Higgs, Moghaddam and Gonabadi-Nezhad (2022:1001) in Canada on the prevalence, socio-demographics, and service use determinants associated with the disclosure of HIV/AIDS status to infected children, it was found that 75% of the 340 infected children had been informed of their HIV status. There were, however, few specifics regarding when complete disclosure took place, what was said, and how frequently they talked to the child about it. The American Academy of Pediatrics (1999) suggests that all children and adolescents should be informed of their HIV status, and that disclosure to those of school age is considered appropriate. However, the American Academy of Pediatrics (1999) does not offer many specific recommendations to help parents and caregivers through the process of HIV disclosure, including when and how to disclose, how to make decisions, and how to assess the psychological impacts of disclosure (Vaz, Eng, Maman, Tshikandu & Behets 2010). Vaz *et al* (2010) argue that in order to encourage parental disclosure of HIV status to infected children, healthcare providers may need to take a leading role.

Similarly, a qualitative study conducted by Jantarapakde *et al* (2019:4) in Thailand on an integrated approach to HIV-status disclosure for HIV-affected families found that 50% of the interviewed parents had not disclosed the HIV status to their children as they lacked assistance and support from healthcare providers regarding the disclosure. Jantarapakde *et al* (2019:5) argue that there is a lack of awareness and communication regarding HIV treatment and disclosure among children, and that healthcare professionals should assist parents in informing children of the diagnosis, treatment, and disclosure of HIV. Jantarapakde *et al* (2019:5) stress the importance of equipping parents and caregivers with practical knowledge so that they can identify opportunities to start the disclosure process as soon as possible.

In line with Jantarapakde *et al*'s (2019) research, a qualitative study conducted by Sabhyta *et al* (2018:7) in the USA on whether there should be a disclosure mandate for physicians caring for perinatally infected adolescents who do not know their HIV serostatus found that of 146 youths living with HIV between the ages of 13 and 18, 44% have had unprotected sexual intercourse in the previous three months but did not report their HIV serostatus to their partners since their parents had never informed them of their own HIV status. Even though most parents and caregivers understand that the disclosure of an HIV-positive status to infected children plays a crucial role in child health and wellbeing, they still delay the disclosure (Appiah, Ivanova, Hoelscher, Kroidl & Dapaah 2021:4). Sabhyta *et al* (2018:78) argue that adolescents who are properly informed of their own status are more likely to receive emotional support and follow preventative practices to reduce risks for themselves and others. Sabhyta *et al* (2018:11) state that despite the fact that there are over 67 laws in the USA that govern HIV disclosure, it is obvious that guidelines alone are not sufficient to persuade parents and caregivers to inform their children of their HIV status. Parents need additional, practical assistance from healthcare professionals to address issues associated with child HIV-status disclosure in order to prevent future HIV infections (Sabhyta *et al* 2018:15).

Similar to research from the Global North and Asian countries, a qualitative study by John-Steward, Wariua, Beima-Sofie, Richardson, Farquhar, Maleche-Obimbo, Mbori-Ngacha and Wamalwa (2013:85) in Kenya on the prevalence, perceptions, and correlation of paediatric HIV disclosure in a treatment programme found that parents and caregivers believed that children should know their HIV-positive status; however, the prevalence of disclosure of the HIV status to children by their parents was very low. John-Steward *et al* (2013) further found that the main reasons for non-disclosure were the children's cognitive development level, not knowing how to disclose, fear of the child disclosing their status to their friends, fear of discrimination, and parents being blamed for their children's HIV-positive status by their children.

Similarly, a study conducted in Zimbabwe by Finnegan, Langhaug, Schenk, Puffer, Rusakaniko, Choi, Mahaso and Green (2019:56) on the prevalence and process of paediatric HIV disclosure to children between the ages of nine and 15 found that only 26% of children knew their HIV status, how they were infected, what was expected of them to not pass the virus on to others, and how to take their medication. A similar study conducted in eSwatini by Dlamini and Matlakala (2020) on the disclosure of HIV status to children found that parents believed that disclosure is important and that measures should be put in place to equip them on how to disclose to their children and assist the children to understand their HIV status. In support of Finnegan *et al* (2019) and Dlamini and Matlakala (2020), a qualitative study conducted by Appiah *et al* (2021:21) in Ghana on disclosure of HIV/AIDS status to infected children revealed that only 8% of 25 955 children younger than 15 years did not know their HIV status even though they were on ART. A lack of knowledge of one's HIV-positive status has the propensity to increase new HIV infection rates. The study by Appiah *et al* (2021:23) further states that the current guidelines that are used by healthcare professionals globally have been revised; however, HIV disclosure to children by their parents and caregivers is mentioned only in passing, with no specific references, while emphasis was placed on sexual partner disclosure.

Kalembo, Kendall and Chimwaza (2019) conducted a qualitative study in Malawi and found that eight out of every 10 children who were on ART were not aware of their HIV-positive status. Kalembo *et al* (2019:37) argue that this is because eight out of every 10 healthcare workers are not trained on disclosure, and the absence of disclosure tools is a major barrier. The study further revealed that parents and caregivers keep their children's HIV-positive status a secret because they are scared of dealing with the issues involving disclosure, such as stigma, discrimination, and blame. These will have a negative impact on the child's life because as they grow older, information about their disease will encourage them to make safe and healthy life choices about sex and relationships (Kalembo *et al* 2019:44).

2.5 HIV AND AIDS DISCLOSURE TO CHILDREN IN SOUTH AFRICA

An essential step in the progression of parents' and caregivers' HIV care is disclosing perinatal HIV-positive children's status to them. In order for children to adhere to their treatment regimens, accept their HIV status, be healthy, and actively participate in their own health management, it is imperative that they are informed of their HIV status (Madiba & Diko 2021:8). The WHO (2011) recommends informing children of their HIV status in a way that is developmentally appropriate, whereby partial disclosure is initiated at the age of six years, with full disclosure occurring by the child's 12th birthday.

A qualitative study conducted by Madiba and Diko (2021:11) in the Eastern Cape province of South Africa on telling children with perinatal HIV about their HIV serostatus found that the disclosure of HIV status to children and adolescents in South Africa is remains low. This is despite children's frequent clinic attendance and lifetime ART use. Parental and caregiver perspectives on when, how, and who should disclose to children vary in South Africa, which has an impact on when and how information is shared with children (Madiba and Diko 2021:11). The parents and caregivers are the ones who have the primary responsibility to disclose the HIV status to the child, according to the South African Department of Health's (2016:38) guidelines; however, parents often find the disclosure process challenging in South Africa, which delays disclosure to children.

Similarly, a qualitative study conducted by Joyce, Ramsammy, Gavin, Leshabane, Liberty, Otwombe, Buckley, Milovanovic and Violari (2022) in the Gauteng province of South Africa found that a lack of awareness regarding how and when to address the issue of disclosure is one of the significant factors that delay disclosure. Joyce *et al* (2022:3) explain that many children are unaware of their HIV status and that their parents and caregivers are reluctant to disclose it to them due to their personal experience in the environment and the attitudes of those around them.

Likewise, a quantitative study conducted by Van Elsland *et al* (2019) in Cape Town in the Western Cape province of South Africa on disclosure of HIV status to children found that children above the age of 12 years who have educated parents and caregivers are more likely to be informed of their HIV status than younger children and those whose parents are uneducated. Van Elsland *et al* (2019:21) explain that parents and caregivers feel less pressure to reveal the child's HIV-positive status when the child responds well to ART. In order for the disclosure of an HIV-positive status to children to be valuable, it is crucial that it be handled thoughtfully and proactively in the long-term management of the disease, as this will present an opportunity for future intervention (Van Elsland *et al* 2019:22). A qualitative study conducted by Naidoo and McKerrow (2015) in the KwaZulu-Natal province of South Africa on current practices around HIV disclosure to children on highly active ART found that despite national and international norms, HIV disclosure to children receiving ART is still not adequate. Fear (Van Elsland *et al* 2019) and unruly behaviour were cited by parents as the main reasons for non-disclosure . Naidoo and McKerrow (2015) note that the parents' and caregivers' educational attainment and the child's repeated hospital admissions are factors that are linked to disclosure. A qualitative study conducted by Naidoo and McKerrow (2015), found that of the children who were aware of their status, 76.9% had already thought they might be HIV positive (Naidoo and McKerrow 2015).

A quantitative study conducted by Madiba and Mokgatle (2015) in the Mpumalanga province of South Africa on healthcare workers' perspectives of disclosure to HIV-infected children found that 89.3% of the 206 medical professionals surveyed expressed concern about the high number of children receiving ART without being aware of their HIV status. While all medical professionals who formed part of the study agreed that children should be informed of their HIV status, they could not agree on the exact age at which disclosure should occur (Madiba and Mokgatle 2015). Some participants advised between the ages of 11 and 18, while others recommended between the ages of 10 and 15. Madiba and Mokgatle (2015:13) state that the medical professionals asserted that their capacity to engage completely in disclosure to children is impacted by the absence of policies and recommendations on disclosure counselling for children. In order to support, encourage, and help parents and caregivers in disclosing their HIV status to their children, the health experts underlined the necessity of adopting the WHO's (2011) HIV disclosure guidelines for children and tailoring them to local cultural and community contexts.

Despite the favourable health benefits of HIV-status disclosure by parents to their children being highlighted, there is still a low level of HIV-positive status disclosure to children (Madiba & Mokgatle 2015). This is consistent with earlier research that found that HIV disclosure is low in many countries and should the lack of HIV disclosure to children persist, numerous countries, South Africa included, will have many young adults and adolescents who are not aware of their HIV status. Given that some parents and caregivers are aware of the significance of HIV disclosure, it is evident that the reviewed literature is relevant in the context of this study. However, despite this, some parents and caregivers choose to withhold or delay HIV disclosure to the greatest extent possible due to the challenges associated with disclosure, including stigma, fear of being blamed, and lack of information and support from healthcare professionals.

2.6 IMPACT OF HIV DISCLOSURE ON THE CHILD

Evidence from different studies conducted on HIV disclosure shows that telling children about their HIV status has a positive influence psychologically, socially, and clinically (Hayfron-Benjamin *et al* 2018; Madiba & Mokgatle 2015; Namukwaya, Paparini, Seeley and Bernays 2017). A qualitative study conducted by Madiba (2016) in South Africa on telling children with perinatal HIV about their HIV serostatus found that children who experienced full disclosure became self-motivated, were more likely to adhere to treatment, and easily overcame challenges that come with the treatment. Madiba (2016) is supported by Hayfron-Benjamin *et al* (2018:7), who argue that disclosure is very crucial as it serves as a starting point in meeting the educational needs of children and young people living with HIV, specifically in their daily lives and how it influences the decisions they make in their social lives, health management, disclosing their HIV status to their partners, and making sexual choices. Children’s treatment effectiveness depends on HIV disclosure and ART since it enhances their quality of life. However, for the ART to be successful, full disclosure and optimum adherence are needed (Hayfron-Benjamin *et al* 2018:8).

Similarly, studies conducted by Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal and Ross (2014), Dusabe-Richards, Rutakumwa, Zalwango, Asiimwe, Kintu, Ssembajja and Seeley (2016), Namukwaya *et al* (2017), Madiba and Mokgatle (2017), and Gyamfi, Okyere, Enoch and Appiah-Brempong (2017) found that children whose status was revealed to them took charge of their healthcare, went to the hospital by themselves, and ensured that they took their medication on time. Children also talked openly about their physical health, felt free to ask questions, and could obtain assistance from caregivers (Namukwaya *et al* 2017:34).Adolescents whose HIV-positive status was disclosed to them were found to have increased access to adherence assistance and various forms of psychosocial support from both peers and family. Moreover, the disclosure of children's HIV status played a pivotal role in enabling them to devise strategies for concealing both the disease and ART from unfamiliar individuals (Namukwaya *et al* 2017; Madiba & Mokgatle 2017). Additionally, compelling evidence emerged from a qualitative study undertaken by Sweeney, Gray, Purcell, Sewell, Babu, Tarver, Prejean and Mermin (2017:1484) that investigated the correlation between HIV diagnosis rates and laws criminalising HIV exposure in the USA. The findings indicated that children whose parents and caregivers had disclosed their HIV status to them exhibited lower levels of aggression and enhanced self-esteem compared to their counterparts who had not been informed. Furthermore, a noteworthy observation surfaced, namely that family cohesion among those who engaged in disclosure was markedly higher than among those who chose not to disclose (Sweeney et al. 2017).

Contrary to the studies mentioned above, Newman et al. (2016) and Murnane et al. (2017) observe that when a child's HIV-positive status is revealed, they often have tremendous emotional reactions, anxiety, depression, fear, and self-blame. They also occasionally experience disruptive adolescent sexual encounters. While the non-disclosure of HIV status to children has been identified as one of the barriers to optimum ART adherence, Hayfron-Benjamin *et al* (2018:18) found that children who are not told about their HIV-positive status eventually become aware of their status through extended family members, but they are too scared to confront their parents or caregivers, which leads to feelings of loneliness, sadness, lack of trust, and depression. Additionally, children who unintentionally learned their status from healthcare providers or other sources other than their parents experience unfavourable outcomes from such disclosure, such as being furious and slowly developing anger and lack of trust towards their elders (Doat, Negarandeh & Hasanpour 2019; Dusabe-Richards *et al* 2016; Mburu *et al* 2016). In order to eliminate the negative feelings stated above, it is crucial to gradually introduce the stages of disclosure to children.

2.7 PATTERNS OF HIV DISCLOSURE TO CHILDREN BY THEIR PARENTS OR CAREGIVERS

Disclosure is a process rather than a single event where partial information is provided to the child prior to full disclosure (UNAIDS 2016:86). A study conducted by Marinda et al. (2020:29) on achieving the 90-90-90 HIV targets in South Africa showed that nearly 41% of children below the age of 14 years in 2017 were unaware of their HIV-positive status and an undisclosed number of children above the age of 15 had received partial, inaccurate, or no information from their parents or caregivers. The premise of the 90-90-90 notion is that by 2020, 90% of people who are HIV-positive will be diagnosed, 90% of those who were diagnosed will begin treatment, and 90% of those who started treatment will see viral load suppression. When the amount of virus in the blood of an HIV-positive person is lowered to an undetectable level, this state is known as viral suppression (UNAIDS 2014:1). The 90-90-90 method is illustrated in Figure 2.1.

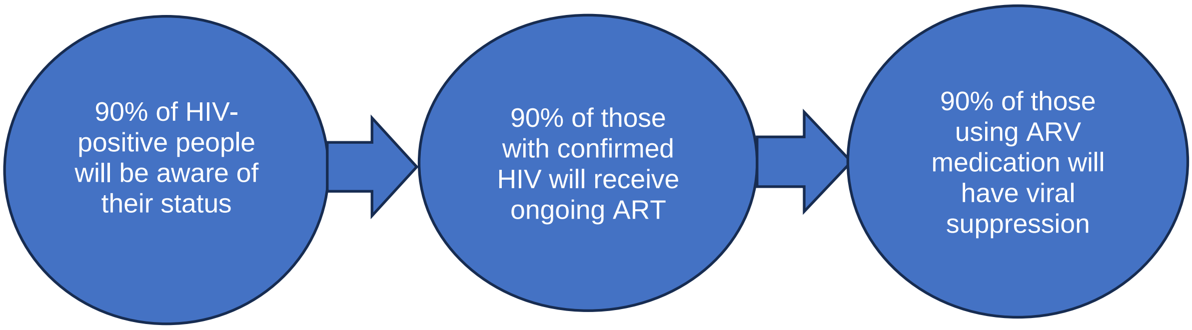

Figure 2.1: The 90-90-90 concept

Source: UNAIDS (2014:1)

The 90-90-90 concept was developed to assist all health sector role players in understanding the strategy designed by UNAIDS. South Africa has made significant advancements in the management of two epidemics, namely AIDS and TB, which together accounted for the majority of the nation's deaths when it adopted the 90-90-90 plan in December 2014 (Health Systems Trust 2015:4).

Dlamini and Matlakala (2020:1) argue that disclosure occurs in various patterns. The patterns of disclosure are a procedure used to communicate HIV information to HIV-positive children, including when, how, and by whom (Dlamini & Matlakala 2020; Hayfron-Benjamin *et al* 2018; Britto *et al* 2016). This information has an impact on understanding HIV-disclosure patterns and provides greater insight into the therapeutic relationship between parents and caregivers with their HIV-positive children. These patterns of disclosure range from complete non-disclosure, deception, partial disclosure, to full disclosure (Dlamini & Matlakala 2020; Britto *et al* 2016). Complete non-disclosure has to do with keeping the child's HIV status secret or not telling the truth about the diagnosis (Britto *et al* 2016:12). Britto *et al* (2016) and Dlamini and Matlakala (2020) describe deflected disclosure as a strategy of deception that parents and caregivers frequently use by replacing the word "HIV" with unrelated conditions such as cancer. For example, linking ART to TB treatment, in most cases, is done deliberately by parents. According to Hayfron-Benjamin *et al* (2018:13), deception is frequently coupled with non-disclosure. Partial disclosure involves providing information based on the age and cognitive development of the child. In partial disclosure, parents tell the child the truth but not the whole truth, and without mentioning the word "HIV". It is usually the first step towards full disclosure. Additionally, Britto *et al* (2016:13) argue that partial disclosure occurs when the topic of HIV is brought up but not fully explained to the child and fails to adequately express that a child is living with the virus. Britto *et al* (2016:15) found that some parents and caregivers experienced the partial-disclosure procedure as helpful because they believed it made it easier for them to have a more-in-depth discussion about the child's HIV status. Full disclosure is when the child is provided explicitly with the name of the illness they are suffering from. The path of physiology, mode of transmission, and the importance of adhering to treatment are explained in detail. Moreover, all questions asked are truthfully answered and support is provided (Dlamini & Matlakala 2020; Hayfron-Benjamin *et al* 2018; Britto *et al* 2016).

In light of the above, parents who have partially or fully disclosed to their children their HIV-positive status would be of great assistance in this study as they could volunteer data on how they navigated partial and full disclosure, as well as the challenges encountered in the process. The next section examines barriers to HIV-positive status disclosure to children.

2.8 BARRIERS TO HIV-POSITIVE STATUS DISCLOSURE TO CHILDREN

Since children living with HIV live into adulthood, parents face the challenging process of telling their children about their HIV-positive status (Dlamini & Matlakala 2020:14). Research studies have identified multiple reasons cited by parents and caregivers for refraining from disclosing their children's HIV-positive status to them (De Moura Bubadué & Cabral 2018; Klutsey *et al* 2021; Msoka, Mtesha, Masika, Maro, Swai, Emmanuel, Ngowi & Sumari-De Boer 2023). Four of the commonly given reasons for non-disclosure are stigma, discrimination, parents' feelings of guilt, and the child's cognitive development related to their age (Dlamini & Matlakala 2020; De Moura Bubadué & Cabral 2018; Klutsey *et al* 2021; Msoka *et al* 2023). In addition, parents fear that their children may be stigmatised, and there is also the fear that disclosure to the child will lead to the inadvertent disclosure of their own status, which might lead to stigmatisation and discrimination against the child and the whole family (Hayfron-Benjamin *et al* 2018:11).

In South Africa the leading reason parents and caregivers give for non-disclosure is that their children are too young and will experience depression upon hearing their diagnosis and may lose their zeal for life (UNAIDS 2014). To the contrary, as the literature has shown, children who know their HIV-positive status manage their condition well, which leads to increased life expectancy (UNAIDS 2014; Klutsey *et al* 2021; De Moura Bubadué & Cabral 2018; Msoka *et al* 2023). It is against this backdrop that this study sought to unearth why parents and caregivers in rural areas withhold children's HIV-positive status from them.

The mother-to-child mode of HIV transmission is the common route that infects 90% of children. This causes parents to feel guilty for "having infected an innocent child" and results in parents hiding their children's HIV-positive status from them (Hayfron-Benjamin *et al* 2018:310). Although parents in Appiah, Kroidl, Hoelscher, Ivanova and Dapaah (2019:26) study expressed the desire to tell their children about their HIV-positive status, they were hindered by feelings of shame, possible depression, perceived self-stigma, and the disclosure process itself. Identifying the reasons why parents and caregivers delay disclosure or do not disclose the HIV-positive status is very important for HIV-positive children as these barriers need to be addressed to support appropriate disclosure. The following section pays attention to the process of disclosing children's HIV-positive status to them.

2.9 PROCESS AND STAGES OF HIV-POSITIVE STATUS DISCLOSURE BY PARENTS

A qualitative study conducted by Sariah, Rugemalila, Somba, Minja, Makuchilo, Tarimo, Urassa and Siril (2016) in Dar es Salaam, Tanzania, on experiences with disclosing the HIV-positive status to the infected child found that the specific age at which a child who is HIV positive can be disclosed to is between four and nine years, but the child's cognitive developmental ability should be considered. Contrary to the WHO's (2011) indications, Joyce *et al* (2022) and Khangale, Raliphaswa and Tshililo (2022) state that the correct age for HIV disclosure to a child is between the age of six and 12. The process of disclosure by parents and caregivers to children infected with HIV was found to be a challenging one where parents cited difficulties during disclosure such as blame, the child's negative emotional reaction when disclosed to, and concerns about the child being too young and immature to understand the HIV condition (Sariah *et al* 2016; Khangale *et al* 2022). Van Dyk *et al* (2017:342) argue that a person who has received pre-and post-HIV test counselling is more likely to adhere to or comply with treatment and they respond much better to treatment than those who did not receive counselling.

Guidelines on HIV disclosure for children up to 12 years old by Glaser, Kaplan-Lewis, Ventuneac, Gates, Cruz, Aracena, Tider, Duah, Aberg and Urbina (2018:71) state that after the truth is out, more conversations will follow as the repercussions of having an HIV-positive family member become clear. According to the WHO (2021:43), parental disclosure must be a process, rather than a one-time event, that occurs over time, which takes into account the various stages of the child's life and ongoing communication with families. The WHO (2021) further indicates that the process may last for several months or years, depending on the cognitive development of the child. As a result, the importance of respect for family needs, beliefs, and socio-cultural, community, and societal norms must be taken into consideration (WHO 2021:73).

Disclosure should not be treated as an end point because it is a process that is repeated as new information is shared between the parent/caregiver and the child

(Yetti, Lindayani & Huang 2020:7). Yetti *et al* (2020), Agyonko-Poku, Bannor, Sorvor, and Ankobea-Konkroe (2023), and Chanie, Abebe, Muche and Worku (2022) argue that for disclosure to be successful, there are stages that must be followed. The stages of disclosure comprise preparation and a disclosure plan, preparing the parents, preparing the child, actual disclosure, and emotional support and follow-up.

Stage 1 focuses on the preparation and a disclosure plan. In order for the disclosure to be successful, during the preparation stage, barriers to disclosure must be minimised (Hayfron-Benjamin *et al* 2018:35). The aims of the preparation and planning stage are to ensure that the parents are equipped with the correct information, skills, language, and tools to assist both the parents and child during the actual disclosure (DoH 2016:44). The DoH's (2016) guidelines further state that parents need to fully understand the benefits of disclosure during the preparation stage. Disclosure is a series of answers to a long list of questions that can take place over a period of time. It is for this reason that during the planning stage, healthcare providers that are trained and knowledgeable about disclosure should help parents with information that will be beneficial when the actual disclosure takes place (Chanie *et al* 2022:469).

Stage 2 focuses more on preparing the parents. Parents and caregivers carry the primary responsibility for disclosure (Yetti *et al* 2020:45). Hayfron-Benjamin *et al* (2018:42) indicate that parents understand the importance of disclosure, yet disclosure by parents to their HIV-positive children is very low in South Africa. In addition, according to Hayfron-Benjamin *et al* (2018:42), parents and caregivers need counselling and support to ensure that they have dealt with their own unresolved emotional trauma before they can disclose to their children. The DoH (2016:39) emphasises that healthcare providers should assist parents to process their own HIV status, grief, anger, guilt, and shame. The guidelines further indicate that healthcare workers need to assess parents' current knowledge and beliefs on HIV. The advantages and disadvantages of HIV disclosure need to be outlined prior to disclosure by healthcare workers.

Stage 3 focuses on preparing the child. According to Opondo, Lindo, Morris and Chen's (2022:18) framework of experiences of HIV disclosure to children living with HIV in Uganda, children make dramatic changes over time, from birth to adulthood, and as they grow, they start to learn and understand life around them. This happens in stages of childhood and development that are associated with different ages. The framework states that when preparing the child for disclosure, parents and caregivers should bear in mind that children mature differently; the age of the child should therefore not be used as a scale to inform how disclosure should be tackled. Similarly, a study conducted by Finnegan *et al* (2019:77) regarding the prevalence and process of paediatric HIV disclosure found that when parents are preparing a child for disclosure, they need to concentrate on the child's developmental stages in terms of emotional and cognitive development to guide the process of disclosure. During the preparation stage, parents must decide when to disclose, who should disclose, and where disclosure should take place (Finnegan *et al* 2019:78).

Stage 4 is concerned with the actual disclosure to children. Finnegan *et al* (2019), Chanie *et al* (2022), and Klutsey *et al* (2021) argue that it is crucial to assess whether the child is ready to be disclosed to and/or the extent to which the disclosure is important. Furthermore, Finnegan *et al* (2019:81) argue that during disclosure, privacy and a friendly environment must be ensured. Children should be allowed to ask questions and answers should be as truthful as possible. The WHO (2011:19) also stresses that during the disclosure process, children should be encouraged to express their feelings and views and they should be provided with honest and developmentally appropriate responses. The key elements of the disclosure process are to recognise and value the emotions and past experiences of the child, no matter how small or big they may be (WHO 2011:25).

Lastly, Stage 5 focuses more on emotional and ongoing support. When disclosure is complete, children require ongoing emotional support in order for them to be able to handle more information about the sickness and treatment as they develop (DoH 2016:85). The DoH's (2016) guidelines emphasise that after disclosure, parents and healthcare workers, from whom the child collects their monthly refill, should enrol the child in a support group for children. In Mpumalanga it would preferably be the Kidz Alive I ACT support group. This creates a fun atmosphere where children learn more about their illness and medication in a non-threatening way and they get to meet other HIV-positive children. According to the Children's Act, every child is entitled to receive full information about their medical condition in order for them to make informed decisions.

HIV disclosure is an ongoing emotional process for most parents and caregivers because there are many daily challenges in the family that must be addressed in order for the disclosure to be successful (Finnegan *et al* 2019:88). Parents and caregivers have a primary and ethical responsibility to disclose the child's HIV status; however, lack of information or skills on how to approach disclosure prevents many parents from disclosure (Pantelic *et al* 2017:77). This study's aim was therefore to identify areas of support and improvement in assisting parents with disclosing their children's HIV-positive status to them.

The following discussion establishes the theoretical framework of the study and pays particular attention to Goffman's (1963) stigma theory and the socio-ecological theory.

2.10 THEORETICAL FRAMEWORK

According to Lempriere (2019:5), a study's theoretical framework is its supporting structure. The socio-ecological theory and Goffman's (1963) stigma theory served as the theoretical underpinnings of this study. These two theories were recognised as pivotal for this study, which sought to theorise and develop nuanced insights into the challenges encountered by parents and caregivers in navigating the disclosure of their children's HIV-positive status to them in rural settings. Disclosure has been recognised as a crucial component of HIV prevention and treatment due to its close connection to secondary prevention, healthcare access, treatment adherence, and family management for people living with HIV (Qiao, Li, Zhou, Shen, Tang & Stanton 2015:32).

The disclosure of children's HIV-positive status to them can benefit both the parents and the children in the long run; however, disclosing the children's HIV status to them is a significant challenge for many parents due to HIV-related stigma and other intrapersonal, interpersonal, socio-cultural, and community barriers (Qiao *et al* 2015:31). To identify constraints to decision making about HIV disclosure by parents at the intrapersonal, interpersonal, societal, and community levels, Qiao *et al* (2015:34) propose a socio-ecological approach. This study adopted the socio-ecological theory to understand why parents and caregivers struggle to tell their children that they are infected with HIV and to discover how they negotiate and manage HIV-related stigma in their communities.

2.10.1 HIV disclosure by parents to children based on the socio-ecological theory

2.10.1.1 Intrapersonal level

An individual's background, demographics, emotions, and psychosocial elements are considered to be at the intrapersonal level (Qiao *et al* 2015:19). On the intrapersonal level, a person's attitude is fuelled by their knowledge, beliefs, and past experiences (Qiao *et al* 2015:20). The individual's knowledge and abilities are the primary concern at the intrapersonal level because one's attitudes and decisions can be influenced by one's understanding of a particular illness (Centres for Disease Control and Prevention 2018; Qiao *et al* 2015).

The study conducted by Finnegan *et al* (2019:70), applying Bronfenbrenner's (1979) theory on the prevalence and process of paediatric HIV disclosure to children between the ages of nine and 15, showed that only 26% of children knew their HIV status. Even though many parents believe that children should know their HIV-positive status, due to the limited understanding of the right age of disclosure, who should disclose, and when and how to disclose the HIV-positive status to their infected children, parents and caregivers conceal their children's HIV-positive status (Finnegan *et al* 2019). In a similar study conducted by Hayfron-Benjamin *et al* (2018:310), 90% of the children who tested positive for HIV were infected at birth, which makes parents feel guilty for infecting an innocent child and leads them to hide the truth from their children. Specific strategies, such as training in life skills and education about an HIV-positive status and disclosure, are crucial at the intrapersonal level (Finnegan *et al* 2019:71).

It is evident from the above information that a lack of proper practical guidelines as to when, how, by whom, and what information must be conveyed during disclosure acts as a barrier for disclosure to children. This is in line with previous studies (Hayfron-Benjamin *et al* 2018; Finnegan *et al* 2019:71) that showed that at the intrapersonal level, even though parents and caregivers understand the importance of disclosure, they might choose to keep the children's status a secret due to a lack of knowledge. Finnegan *et al*'s (2019) study is relevant to this study as it emphasises that the lack of life skills and education about disclosure acts as a barrier to many parents and caregivers; relevant training on HIV disclosure and management can therefore be beneficial to parents.

2.10.1.2 Interpersonal level

The interpersonal level is where factors such as family structure, parenting styles, personal relationships, social networks, and support play a significant role (Qiao *et al* 2015:19). This level concentrates on a close relationship that may increase the amount of support or risk involved when parents disclose children's HIV status to them. Placek *et al* (2019:48) argue that a person's closest social circle, which includes peers, romantic partners, and family members, affects their behaviour and influences the decisions they make. However, social contacts can either enhance interpersonal development that encourages healthy conduct or function as a barrier (Placek *et al* 2019:48). In a family context, the individual will be able to open up about their HIV status only if the family provides the necessary social support and fights HIV-related stigma and discrimination collectively.

At this level, social support and a healthy relationship between the parents, caregivers, and HIV-positive children are crucial because parents can have conversations with their children about HIV, treatment, disclosure, and safe sex (Centres for Disease Control and Prevention 2018:25). Promoting healthy relationships, mentoring, and peer programmes such as the Kidz ALIVE I Act support group programme can be beneficial at this level.

From the above information it is evident that before parents and caregivers decide to disclose or not to disclose, they consider many factors, which include the child's age; the amount of support from the family, society, and healthcare providers; as well as the risk involved and the benefits of disclosure to the child. Lack of family and healthcare support remains a barrier to HIV disclosure and optimal HIV treatment behaviours and outcomes. This is consistent with the study conducted by Placek *et al* (2019), which indicated that in order for the parents and caregivers to handle the difficult and complex process of telling their children that they are HIV positive, they require support from their families, communities, and healthcare organisations. Holistic interventions increase HIV-status disclosure to children by their parents.

2.10.1.3 Societal level

A certain manner of living may be supported or outlawed on the social level depending on social circumstances (Qiao *et al* 2015:22). Social and cultural standards that promote a particular activity as acceptable are among these elements. The health, economic, educational, and social policies that support the preservation of social or economic disparities between groups in society are additional, significant social issues (Placek *et al* 2019:18). According to Goffman (1963:27), people act in a “front stage” manner when they are aware that others are watching. This awareness guides their behaviour and dictates what to say. These expectations lead people to adhere to established standards and social conventions regarding what they should do or how they should behave in various settings. Socio-cultural and societal values and beliefs are vital in forming and influencing beliefs and values that may have a direct impact on attitudes towards HIV care, treatment, and disclosure (Qiao *et al* 2015:25). Culture plays a significant role in determining the decision-making roles in families, as well as attitudes and beliefs about HIV disclosure. Society’s cultural perceptions of a child’s level of thinking must be examined in relation to stigmatisation after disclosure (Placek *et al* 2019:20).

It is evident from the above discussion that socio-cultural and societal norms are more likely to influence disclosure conversations. Society and personal experiences have the power to influence parents’ and caregivers’ attitudes to HIV disclosure with regard to when and how disclosure should be addressed. This is in line with the social learning theory that asserts that a person belongs to their immediate family, extended family, peer group, school, society, and nation (Placek *et al* 2019:21). People are immediately impacted by the attitudes, viewpoints, and actions of others; in addition to the environment they reside in. It is challenging to address HIV-transmission channels with children in many South African cultures when it comes to sexuality and parental sexual behaviour, which can negatively influence HIV disclosure.

2.10.1.4 Community level

The community level examines the environments in which individuals interact with one another, such as schools, neighbourhoods, organisations, and institutions, and attempts to pinpoint the features of these environments that influence health (Placek *et al* 2019:24). Established social standards, whether formal or informal, among people, groups, or organisations can restrict or promote healthy conduct (Qiao *et al* 2015:33). A person with HIV can be seen as inflicting shame on the community in areas where cultural systems place strong emphasis on collectivism (Placek *et al* 2019:28). However, the organisational level has the capacity to reach out and inform more individuals in many community sectors about HIV and the value of a support system for an HIV-positive person (Placek *et al* 2019:26). With the assistance of community HIV counsellors and local pastors, organisations such as schools and churches can teach learners and church members about the significance of HIV testing, treatment, disclosure, and the stigma associated with HIV. Community clinics can also organise health-related activities to educate and equip parents and caregivers with knowledge about the value of disclosure and its procedures (Qiao *et al* 2015:36).

In line with the socio-ecological theory, community stigma and discrimination against people who are living with HIV are reasons for non-disclosure. Most parents and caregivers may be willing to disclose the HIV-positive status to their children but due to the perceived threat of community discriminatory and stigmatising attitudes towards the parents, some parents may decide not to disclose and this behaviour increases new HIV transmissions within the community. Judging from the above discussion of the various levels of the socio-ecological theory that the implementation of disclosure interventions to teach people not to hold discriminatory attitudes towards people who are living with HIV and parents and caregivers who are raising HIV-positive children and perceived stigma in the communities is crucial (Placek *et al* 2019:27). In some instances, parents and caregivers who were open about their children's HIV-positive status received support in the community of Nkangala. However, disclosure does not always result in parents and caregivers receiving the support they are longing for; for some, it means rejection by the individuals they disclosed to.

2.10.2 Goffman's stigma theory and parents' disclosure of children's HIV-positive status

This section presents and discusses definitions of stigma, stigma theory and parental disclosure, factors associated with HIV stigma, manifestations of HIV stigma, perceived or felt stigma, and enacted stigma.

2.10.2.1 Definitions of stigma

Goffman (1963:3) defines stigma as an "attribute that is deeply discrediting that reduces the bearer from a whole and usual person to a tainted, discounted one". However, the attribute is not itself discrediting; rather, it is discrediting as a result of how people are classified in society and the normative expectations that are attached to a particular category of people. Due to the negative meaning and prejudices associated with some attributes, they are made to appear undesirable (Goffman 1963).

Goffman (1963) argues that not all bad attributes are an issue; only those that conflict with stereotypes that outline what particular types of people should be like or how they should behave. Those who break from the expected attributes or actions connected with their categories, or those who are stereotyped, are as a result marginalised, undermined, and rejected by society. Being diagnosed with HIV or being connected with someone who is HIV positive is often rejected by society because it goes against the stereotype of how people in a certain society should behave (Madiba & Diko 2021:18. Many people in South African societies think that HIV originates from sexual deviances and is equal to immorality (Madiba & Diko 2021:20. Especially HIV-positive women are regarded as prostitutes, which then discredits the infected person in the eyes of society (Madiba & Diko 2021:13).

Similarly, in the context of HIV, stigma is described as an unfavourable opinion of a person based on the most fundamental aspects of the human experience, such as gender, illness, lifestyle, and mortality (UNAIDS 2016:23). When compared to persons with other illnesses such as TB and cancer, HIV-positive patients, especially women, are frequently blamed for their illness and viewed as careless individuals (Mugo, Firdawsi, Wang, Njuguna, Wamalwa, Slyker, John-Steward, O'Malley & Wagner 2023:9). Fauk, Ward, Hawke and Mwanri (2021:3) explain that stigma refers to unfavourable attitudes and beliefs that cause individuals to reject, avoid, or fear others who are seen to be different. Similarly, Parker and Aggleton (2003:36) refer to stigma as a socially devalued attribute that results in social inequality through labelling, stereotyping, devaluation, status loss, and/or discrimination because of the social judgement made towards a person who holds the devalued attribute. It puts those with socially devalued traits in a position of relative inferiority to others without those traits

(Parker & Aggleton 2003:37). In light of the definitions provided above, stigma thus refers to the social oppression of a person or group of people based on a particular discredited attribute.

2.10.2.2 Stigma theory and parental disclosure

HIV stigma impacts all people who are living with HIV, yet there is limited information on how HIV stigma affects the estimated 2.1 million HIV-infected children, of whom 90% reside in sub-Saharan Africa (UNAIDS 2020:78). Stigma is defined by social exclusion, rejection, denial, disapproval, indifference, and underrating (Goffman 1963:4). Goffman (1963:3) argues that stigma can be thought of as a process. Stigmatisation is a method of devaluation. Whether or not this occurs later, the process starts when influential groups notice human differences. The majority of the time, stigma is attached by society to individuals who are deemed abnormal or different, particularly those who suffer from mental illness, physical disabilities, sexual diversity, or who act differently due of their unique characteristics (Goffman 1963:4). Goffman (1963:4) argues that power and dominance in society are closely related to stigma, which are crucial in the creation and perpetuation of power relations. In essence, societal disparity feeds and perpetuates stigma. Society has its roots in the rules and values that underpin much of daily life, as well as the basic foundation of society. When someone deviates from society’s accepted standards and rules, society’s initial reaction is to stigmatise them (Goffman 1963:44).

HIV stigma is a set of unfavourable attitudes and preconceptions about people with the virus (Fauk *et al* 2021:3). Due to the fact that unprotected sexual contact is a prevalent way for HIV to be transmitted, the stigma surrounding HIV is linked to sexual stigma. Consequently, the stigma associated with HIV is a result of fear, labelling, denial, misinformation, lack of knowledge, and social judgement (Fauk *et al* 2021:4). The stigma attached to HIV and AIDS prevents people from receiving the treatment, care, and support they need to stay healthy (Hayfron-Benjamin *et al* 2018:4). It continues to be the biggest obstacle to many HIV-positive people seeking care and disclosing their status, especially women and the parents of HIV-positive children.

A qualitative study conducted by Celeste-Villalvir *et al* (2023:18) on exploring gender differences in HIV-related stigma and social support in a low-resource setting in the

Dominican Republic, found that while both men and women experience stigma , including verbal abuse, however the stigma associated with HIV was more subtle for men, while women described outright rejection and instances of physical violence. Furthermore, the study found that men sometimes blamed women for their HIV positive, this act fills them with feelings of shame and guilty, stress, mental illness and suicidal, and this act may cause more intensified isolation (Celeste-Villalvir et al 2023:19). Moreover, women bear the responsibility of caring for individuals who are ill due to HIV-positive status and raising orphaned children left behind by parents who have succumbed to HIV-related illnesses. Similar to a qualitative study conducted by Sokhela, Orton, Nokes and Samuels (2023 :8) on exploring intersectionality and HIV stigma in persons receiving HIV care in nurse-led public clinics in Durban, South Africa, found that men might adopt risky sexual behaviour to meet gendered expectations around masculinity, sexual powers and sexual performances for an example having multiple sex partners, and consuming alcohol prior to sex.

South Africa has achieved great progress in attempting to meet the 90-90-90 goal set by UNAIDS. UNAIDS (2016:44) set a goal for the global fight against HIV called the 90-90-90 strategy, which states that by 2020, 90% of people with HIV will be aware of their status, 90% of those who have been diagnosed will be receiving ART, and 90% of those who are already receiving treatment will have undetectable viral loads. At the time of writing this thesis, 87% of people receiving treatment had a reduced viral load, more than 90% of people infected with HIV have been diagnosed, and 68% of them were on treatment (UNAIDS 2019:119). In order to accomplish the 90-90-90 goal, it is imperative to be aware of and comprehend the problems with HIV testing and treatment facilities (UNAIDS 2016:52). Children who contracted HIV from their mothers and are now living into adolescence and adulthood are becoming more common due to improvements in HIV treatment and care (Vaz *et al* 2010). Regardless of all the progress documented, stigma continues to negatively affect programmes and HIV disclosure by making it very difficult for parents and caregivers to disclose their children’s HIV-positive status to them (UNAIDS 2020:75). A study conducted by Vreeman *et al* (2017:23) in Kenya about stigma among the youth emphasised that children and youths encounter HIV stigma in the form of rumours, bullying, or taunting because of their HIV-positive status or the status of a family member. This can cause difficulties with school performance or gaining access to peer support networks.

Vreeman *et al* (2017:23) state that stigma and discrimination have a significant impact on parents', caregivers', and children's decision making, as well as disclosing an HIV-positive status. These factors are important in determining the process and procedure of disclosure.

Hayfron-Benjamin *et al* (2018:11) argue that stigma and discrimination still pose a big threat to timely disclosure, and if they are not adequately addressed, South Africa will be confronted with a majority of young adults who do not receive timely disclosure from their parents because of concern about rejection and discrimination. One of the main justifications given by parents for not telling their children they have HIV is to protect them from the stigma associated with the disease (Hayfron-Benjamin *et al* 2018:11). Although some parents of children who are living with HIV understand the value of disclosure, they may choose to give their children incorrect information or withhold it from them in an effort to live a normal or acceptable life (Hayfron-Benjamin *et al* 2018:12). This could result in the children not adhering to treatment and increasing the risk of new transmissions among young people (Hayfron-Benjamin *et al* 2018:12). Goffman (1963:5) argues that in most cases people select one of three defensive strategies, namely falsification, concealment, or discretion, because doing so offers the incentive of being accepted by society. When someone intentionally provides false facts to construct a fictitious, unstigmatised identity, it is called fabrication (Croteau, Anderson & VanderWal 2008:534). Concealment involves intentionally preventing other people from knowing personal information that can potentially disclose the stigmatised HIV status. Lastly, using discretion entails staying away from HIV conversations that can result in any type of private HIV disclosure by an HIV-positive person (Croteau *et al* 2008:534).

In this study, stigma affected the participants' willingness to disclose their children's HIV-positive status to them, which is congruent with previous studies that asserted that even though parents and caregivers value and understand the importance of disclosure, because of the stigma related to HIV, they may choose to tell the children wrong information or withhold it from the children to protect them. It is evident that Goffman's stigma theory is relevant in the context of this study since some of the parents and caregivers feared that disclosure would expose their children to stigma. A lack of disclosure increases the likelihood that children will refuse to take their medication, encourages hostility and resentment against parents and caregivers, increases the risk of secondary HIV transmission, and has a negative impact on the children's health.

2.10.2.3 Factors associated with HIV stigma

Numerous factors, including ignorance of the illness, false beliefs about how the virus spreads, lack of access to treatment, careless media coverage of the illness, discrimination and worries about a range of socially sensitive topics, including sexuality, the loss of a family member, and drugs and alcohol abuse, all contribute to the stigma associated with HIV (Hayfron-Benjamin *et al* 2018:18). HIV stigma is connected to moral and social judgement for contracting the disease and infecting unborn children (UNAIDS 2018:20). Despite the fact that HIV disclosure is essential for HIV-positive people to receive the appropriate support, ignorance of the issue and social stigma hinder them from coming forward (UNAIDS 2018:21).

Given that stigma is a social construct, people with HIV are more likely to notice a change in their partners', families', and friends' attitudes after disclosing their status (Nyasulu, Tshuma, Sigwadhi, Nyasulu, Ogunrombi & Chimoyi 2021:151). Due to their fear of being rejected, people who are living with HIV are less likely to disclose their status and then do not receive the support they need from their family or friends, which has an impact on HIV-prevention efforts (Nyasulu *et al* 2021:152). These factors exacerbate the disease's personal suffering for everyone impacted by it, including those who have already been diagnosed and those who are left to care for parents, caregivers, family members, and spouses.

2.10.2.4 Manifestations of HIV stigma

Although HIV-related stigma has decreased in South Africa since the 1980s, when HIV first appeared in the country, the stigma persists in some places, particularly in rural areas (Dlamini & Matlakala 2020:11). According to Nabunya, Byansi, Bahar, McKay, Ssewamala and Damulira's (2020:17) study on HIV disclosure and HIV-related stigma among adolescents living with HIV in south-western rural Uganda, 35% of the respondents said they would not buy anything from a street vendor who was either living with HIV or taking care of someone who had HIV. The study also found that those who are HIV positive face stigma and discrimination in medical settings, where they are denied medical care and have their statuses revealed without their permission (Byansi 2020). HIV stigma, which indirectly encourages a culture of silence among parents, nurtures fear and denial, prevents parents and caregivers from getting their children tested for HIV, and prevents them from disclosing the children’s HIV-positive status to them (Byansi 2020:11). HIV-related stigma is unquestionably one of the biggest barriers to slowing the spread of HIV and managing HIV among children (Nabunya *et al* 2020:24).

People from all walks of life continue to be affected by stigma. Recently, the COVID-19 pandemic brought back the stigma and discrimination associated with contagious illnesses; this time affecting not only the dead but also the survivors (Dar, Khurshid, Wani, Khanam, Shah, Shahnawaz & Mustafa 2020:2). In some of the tragic deaths of family members, the survivors experienced anxiety, sadness, and bereavement. Society’s concern that survivors of COVID-19 and HIV are still contagious is a major factor in both COVID-19 and HIV stigma (Dar *et al* 2020:11). Stigma is a product of fear, ignorance, and lack of knowledge. Nabunya *et al* (2020:18) suggest that stigma can appear in two different ways, which is internal due to perceived or felt stigma, and external due to enacted stigma and in the below subsections I unpack these two concepts.

2.10.2.5 Perceived or felt stigma

Fear of being discriminated against, which results from societal perceptions, is known as perceived stigma (Nabunya *et al* 2020:24). Stigma is mostly a social challenge whereby society assigns a person a negative standing. However, a person may self-stigmatise their illness, form bad opinions of themselves, and experience shame and embarrassment as a result of having HIV (Tesfaw, Kibru & Ayano 2020:60). These emotions, in turn, increase the likelihood of not disclosing information and predict psychological discomfort, including depression and post-traumatic stress disorder; feelings of loneliness, humiliation, and social isolation; and poor treatment compliance and HIV-related management (UNAIDS 2018:16). The term “perceived stigma” describes the anxiety, either real or imagined, regarding society’s attitudes or reactions towards a certain unwanted characteristic or illness, such as HIV. According to Tesfaw *et al* (2020:67), HIV-related stigma is linked to a variety of detrimental emotional and psychological effects, such as decreased self-efficacy, low self-esteem, and depressive symptoms. People who are stigmatised are hesitant to ask their families or the larger community for social support (Nabunya *et al* 2020:24).

2.10.2.6 Enacted stigma

Enacted stigma is when prejudice or discrimination is present in another person's actions or attitude. These could be specifically intended for an HIV-positive person (Kimera *et al*. 2020:2).Enacted stigma creates social barriers for people who are HIV positive especially women, including access to healthcare, which leads to non-disclosure strategies as a form of stigma management. This has a negative effect on their daily lives because they frequently hear disparaging comments from society about people who are infected with HIV (Kimera *et al* 2020:3). Parents and caregivers who are raising children with HIV experience a major impact on their psychological wellbeing as a result of the attached stigma (Tesfaw *et al* 2020:70). When people of a particular religion, race, or sexual identity are blatantly discriminated against, Goffman (1963:4) characterises enacted stigma as what we would currently refer to as discrimination.

2.11 CONCLUSION

This chapter discussed previous literature on HIV disclosure by parents, which suggests that disclosure of an HIV-positive status to children is vital because it is the first step towards treatment adherence and HIV management. Disclosure serves as a starting point in meeting the educational needs of children who are living with HIV, mostly in their daily lives, and influences the decisions and choices they make in their social lives. However, based on local and international literature, it is evident that the prevalence of disclosure of HIV status by parents to their children is still low in many countries, including South Africa, due to reasons such as fear of stigma and discrimination, and parents being blamed for their children's HIV-positive status by their children and others, as well as a lack of information in knowing who should disclose, how, and when.

As the literature demonstrates, stigma affects HIV-prevention efforts by preventing people who are living with HIV from seeking healthcare services and social support from their families and friends because of fear of rejection. Despite international and national legal frameworks and policies that protect the rights of children, the majority of these are silent with regard to the treatment of minors specifically for HIV disclosure. In order to achieve the 90-90-90 goal, parents and caregivers must be encouraged, protected, and supported by legal frameworks and policies, healthcare providers, and communities when it comes to the disclosure of children’s HIV-positive status.

The next chapter discusses the research design and methods employed by this study.

CHAPTER 3:
RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

This chapter discusses the research design and methods employed to achieve the goals of this study. The objectives of this research were driven by the desire to understand parents' and caregivers' experiences in terms of navigating the issue of HIV-positive status disclosure to their children. This necessitated choosing a research method that would help to achieve this goal. The qualitative research design that was chosen for this study allowed the researcher to interact with the participants and learn their perspectives as per the aims of this study. A hermeneutical phenomenology research approach was adopted for this study to describe, explore, and interpret the social and psychological impact of HIV-positive status disclosure by parents and caregivers to their children.

This chapter introduces the research design by beginning with an explanation of the hermeneutical phenomenology approach used and its impact on methodological decisions. It then delves into the study's research approach and methods, including aspects such as research population, sampling, instrument development, and the detailed processes of data collection, management, and analysis. Additionally, the chapter outlines the measures taken to ensure the study's trustworthiness and to address the ethical considerations surrounding the study. The concluding section reflects on the researcher's positionality in the research process.

3.2 HERMENEUTICAL PHENOMENOLOGICAL APPROACH

According to Mohajan (2018:309), in hermeneutical phenomenology, researchers aim to capture the perceptions, lived experiences, and views of research participants. When a topic is controversial and a thorough comprehension of human lived experiences is necessary to solve the research problem, the hermeneutical phenomenological approach is most suitable (Mohajan 2018:309). The information that was gathered from the participants about their experiences with HIV disclosure will contribute to a greater understanding of their challenges and generate possible strategies that can assist in supporting parents and caregivers when it comes to the subject of HIV-status disclosure to children. This study adopted a hermeneutical phenomenology approach that required the exploration of human lived experiences (Neubauer, Witkop & Varpio 2019:93). The hermeneutical phenomenology approach was used for this study to describe, explore, and interpret the social and psychological implications of children's HIV-positive status disclosure to from the perspectives of their parents and caregivers. It is vital for researchers to recognise and take into account the understanding that people develop in the daily lives since knowledge is deeply rooted in daily experience (Neubauer *et al* 2019:94). The use of the hermeneutical method enabled the research participants to share their own narratives based on their personal experiences of HIV-status disclosure.

3.3 QUALITATIVE RESEARCH DESIGN FOR HIV-POSITIVE STATUS DISCLOSURE BY PARENTS AND CAREGIVERS

According to Jalil (2013:5), research design comprises the overall strategy that researchers select in order to logically and clearly combine the many study components to guarantee that the research challenge is successfully handled. People's lived experiences can be explored, and an attempt can be made to comprehend them through the use of a qualitative research design (Terre Blanche, Kelly & Durrheim 2006). According to Grove *et al* (2013:196) the goal of qualitative research is to examine the subjective experiences of individual. Qualitative research makes it possible for researchers to gather comprehensive information that can give them a profound insight of social interactions and human behaviour (Grove *et al* 2013:197) The qualitative research design was relevant to this study since the goal of this study was to produce a comprehensive collection of data about parents' and caregivers' real-world experiences of raising HIV-positive children and disclosing their children's HIV-positive status to them.

3.4 SAMPLING METHOD AND THE SELECTION OF PARTICIPANTS

Grove, Burns and Gray (2013:109) define a sample as a group of individuals who are selected for a specific study. The participants for this study were chosen using the purposive sampling technique. Purposive sampling is a non-probability sampling method where the researcher chooses participants based on their perceived informational value (Polit & Beck 2017:189). Rai and Thapa-Kathmandu (2015:9) argue that in adopting purposive sampling, researchers rely on their own judgement and handpick participants from a target demographic for inclusion in their studies based on predetermined inclusion criteria. Purpose sampling provides the advantage of enabling the researcher to choose the sample based on how well possible respondents perceive and understand the phenomenon under study (Rai & Thapa-Kathmandu 2015:8).

The research criteria were guided by the objectives of the study. In this study, parents and caregivers of children who are HIV positive and who receive treatment on a monthly basis were selected. Four males and eight females, of whom six were the biological parents of HIV-positive children and six were caregivers, participated in 12 face-to-face semi-structured interviews. The participants were recruited by the nurse in charge of the unit when they came for their monthly clinic visits. The researcher consulted the nurse in charge to identify potential participants because of the strong relationship she has with her patients, as well as due to the provisions of the Protection of Personal Information Act No 4 of 2013 and the sensitivity of the study. The information sheet and interview guide were provided to the nurse in charge to share with potential participants and give them an overview of what participation in the study would entail.

The following selection criteria were employed to recruit participants; the participants had to:

- be parents or caregivers of HIV-positive children between the ages of seven and 14;
- attend the wellness clinic on a monthly basis for medication refills, including viral load and psychosocial follow-up;
- be male or female parents or caregivers who attend the wellness clinic; and
- be based in the Nkangala District in Mpumalanga in the rural and semi-rural areas.

Ultimately, the sample consisted of 12 participants. Table 3.1 provides an overview of the participants.

Table 3.1: Profile of the participants

Participant	Age	Gender	Gender of child	Age of child	Relationship	Status disclosed
Participant 1	48	Female	Girl	12	Caregiver/aunt	Yes

Participant 2	63	Female	Boy	7	Caregiver/grandmother	No
Participant 3	33	Female	Boy	9	Mother	Yes
Participant 4	40	Male	Boy	13	Father	No
Participant 5	22	Female	Girl	9	Caregiver/aunt	Yes
Participant 6	62	Female	Boy	13	Caregiver/grandmother	No
Participant 7	38	Male	Girl	8	Father	Yes
Participant 8	43	Male	Girl	10	Father	Yes
Participant 9	40	Male	Boy	11	Father	No
Participant 10	41	Female	Girl	11	Mother	No
Participant 11	37	Female	Girl	13	Caregiver/aunt	Yes
Participant 12	53	Female	Girl	7	Caregiver/aunt	Yes

3.5 DATA-COLLECTION METHODS

According to Mohajan (2018:39), data collection in qualitative phenomenological studies often includes direct observation and in-depth interviews. In this study, in-depth face-to-face interviews with parents and caregivers were conducted to gather data. In-depth face-to-face interviews were deemed a relevant data-collection method for the purposes of this study because this method makes provision for probing and obtaining data from interviews (Mohajan 2018:39). The in-depth face-to-face interview method enabled the participants to provide deep and detailed discussions of their experiences, which allowed the researcher to explore their experiences in depth and, where necessary, to respectfully probe for more information and clarity. The interviews enabled the researcher to achieve her goal of acquiring a thorough understanding of the participants' perspectives on how parents negotiate HIV disclosure to their children.

Du Plooy-Cilliers, Davis and Bezuidenhout (2014:171) state that an additional advantage of in-depth interviews is that they grant the researcher a chance to observe the participants' body language as they answer the questions, which serves as an extra source of data that can be used when analysing and interpreting data. By using the face-to-face interviewing technique, the researcher was able to capitalise on social indications such as shifts in voice tone and body language. These worked to the researcher's advantage as it afforded the opportunity to obtain more contextual data that were used to follow up on the participants' answers.

In line with the in-depth face-to-face interviews method, open-ended questions were used in order to explore the challenges that parents and caregivers face and the social and psychological impact that these challenges have on their daily lives with their children.

In developing the interview guide (see Annexure H) for this study, Section A of the questionnaire asked demographic questions, which included gender, race, age, educational level, and occupation. Since the researcher applied a narrative approach to collect data, questions about the impact of non-disclosure and experiences of parents raising and living with children diagnosed with HIV were asked with the aim to establish how the participants understood the impact of their children's HIV status on them and how important they thought disclosure to the children was. Most of the questions were aimed at establishing how the parents and caregivers understood the importance of disclosure and what challenges they faced with regard to the issue of disclosure.

The questions were formulated in English; however, some participants opted to use their native language when they could not express themselves well in English. The Nguni languages that the participants used were isiNdebele and isiZulu. To enhance the quality of the research, these interviews were translated by a professional translator who is fluent in both languages. The interviews were conducted between April and June 2023. All the interviews were conducted in a small boardroom at a hospital located in the Mpumalanga province. The longest interview was 70 minutes and the shortest one was 29 minutes.

The purpose and the objectives of the study were explained to the participants before each interview began. Permission to use an audio recorder was obtained from the participants prior to and on the day of the interview. The participants were also provided with written consent forms (see Annexure E) to indicate their willingness to participate in the study. The researcher prepared the consent forms prior to the study and the content was read together with the participants before the interviews. The participants were reminded that they could withdraw from the study at any given time without being penalised since their participation was voluntary. Notes were taken during all the interviews.

As per the nature of in-depth face-to-face interviews, the researcher encountered some minor challenges during the interviews. Due to the fact that some parents had left their young children at home, they asked to not turn their cell phones on silent, while others said they were expecting calls from their workplaces; incoming calls thus impacted the recordings and interrupted the interviews. However, the interruptions did not affect the quality of the interviews, as the researcher paused the recordings and checked if the participants were ready to continue after their calls. Due to the fact that all the participants knew that I am a social worker by profession, they sometimes wanted to divert the interview and use it as a consultation to talk about their personal problems and expected advice. To avoid diverting from the interviews, I advised the participants that they could make appointments to see me in my capacity as a social worker, since I was interviewing them as a researcher. I reminded them that I was not interviewing them in my professional capacity as a social worker and that I could only advise on their personal issues outside the context of the interviews through a planned appointment.

3.6 METHOD OF DATA ANALYSIS

The study utilised the thematic data-analysis method for the purpose of analysing the collected data. According to Renz, Carington, Badger and Terry (2018:117), thematic analysis is a method of analysing qualitative data that is typically used with a collection of texts, such as the transcripts of interviews. Renz *et al* (2018) and Clarke, Hayfield and Terry (2019:203) state that thematic analysis helps to identify, evaluate, and capture patterns in data. To establish significant patterns, thematic analysis was conducted through (Braun & Clarke 2023) six stages of thematic analysis. These stages involve (1) becoming familiar with the data, (2) creating preliminary codes, (3)looking for themes, (4) reviewing the themes, (5) defining the themes, and (6) creating the final report (Braun & Clarke 2023:5). After the transcription process, I read through the transcribed interviews to familiarise myself with the data and to identify themes and patterns in the responses in an effort to help answer the research questions.

Schurink, Fouché and De Vos (2011:412) argue that the open coding process involves separating data into distinct components, carefully examining and comparing them for similarities and differences, and posing questions about the phenomenon as it is reflected in the data. In light of this, the I used open coding to find themes that appeared in the participants’ narratives. I then carefully listened to the recordings and read over the transcripts after conducting all the planned interviews to ensure that all the required information had been collected.

Organising the data into significant smaller pieces generated themes by searching for models that were of interest to the study. Sub-themes emerged from the main themes, and the final report was produced. Alphanumeric codes were used to identify the participants while maintaining their anonymity.

For each key comment from the transcripts, I created broader statements (see Table 3.2). For all relevant utterances, I produced defined meanings, which were subsequently grouped into themed clusters.

Table 3.2: Example of a key statement

Key statement	Constructed meaning	Theme	Sub-theme
"My child is still young, I cannot tell her. I don't think telling her that she has HIV is important for now. When she is a bit older, my main concern is to see her taking the treatment correctly."	Parents have difficulty in disclosing their children's HIV status due to the age factor.	Is it important to disclose?	When to tell: Identifying the right time to disclose

The final themes that capture the meaningful voices that reflect the daily experiences of parents are: is it important to disclose, reasons for non-disclosure, and disclosure motivation and procedure.

Table 3.3: Summary of the themes and sub-themes

Theme	Sub-theme
1. Is it important to disclose?	• When to disclose: Identifying the right time to disclose • Consequences of biological parents' and caregivers' HIV-status disclosure
2. Reasons for non-disclosure	• Treatment adherence and deception as a coping strategy before disclosure • Fear of the unknown
3. Disclosure motivation and procedure	• Perceived advantages and disadvantages of disclosure to children • Reactions to disclosure

3.7 ADDRESSING ETHICAL CONCERNS

Polit and Beck (2014:146) define ethics as moral principles that guide human behaviour in the research context and that protect the rights of participants. The focus of this study is on human beings and how they navigate the terrain of HIV-status disclosure. It was crucial to consider research ethics to ensure the protection of the participants' rights, privacy, and dignity throughout the data collection process. Bless, Higson-Smith and Sithole (2013:89) state that ethics are crucial in social research to prevent researchers from abusing their social influence and jeopardising the participants' human rights. HIV-status disclosure requires people to talk about the private, sensitive aspects of their lives, and their personal information should be protected. For this reason, it was important to ensure that the dignity and privacy of the research participants were protected throughout the study. Considering the sensitive nature of this study's topic, the following measures were taken to comply with research ethical considerations:

- The University of South Africa's College of Human Sciences Research Ethics Committee granted ethical clearance for the study after the requirements for ethical considerations were fulfilled.
- Permission to conduct this research at the hospital in question was requested and permission was granted by the DoH in the Mpumalanga province (see Annexures B and C).
- The basic considerations when embarking on social research, namely informed consent, autonomy, beneficence, non-beneficence, privacy, and confidentiality, were observed throughout the study.

3.7.1 Informed consent and voluntary participation

Informed consent refers to permission granted in full knowledge and understanding of the possible risks involved by the participants in a research project (Babbie & Mouton 2009:20). The sample of this study comprised parents and caregivers of children between the ages of seven and 14 who are living with HIV and are on ART. An information sheet containing details of the research was shared with the participants prior to their participation in the research (see Annexure E). All the participants were informed of the objectives of the study, and the importance of participating in the study was outlined. The participants were informed that participation was voluntary and that they could withdraw from the study at any time with no consequences. Upon understanding the nature of the study and what participation would entail, the participants were requested to sign informed consent forms (see Annexure E). Information concerning the storage and dissemination of the findings were also discussed (see Annexure E).

3.7.2 Confidentiality, privacy, and anonymity

Confidentiality refers to protecting all participants by not sharing their personal information publicly without their knowledge (Polit & Beck 2014:377). According to Bengu (2018:23), confidentiality is a crucial aspect of research; there is thus a need to anonymise collected data. Upholding high levels of confidentiality was imperative for this study, since compromising the participants' personal information would put them at risk of being stigmatised. In order to maintain confidentiality and privacy, all interviews were conducted in a small boardroom with one participant at a time. The participants' personal information, audio recordings, and the notes that were used to collect the data were accessible to the researcher and the supervisor only. Numbers were allocated to each participant to protect their identities. Furthermore, all files related to the study were kept securely in a Google Drive password-protected folder, and they will be deleted once the study is finalised and the dissertation has been examined and approved.

3.7.3 Beneficence and non-maleficence

Schurink *et al* (2011:115) assert that it is a duty of researchers to safeguard the participants from any physical and psychological risks that may result from the research activity. Since the study was considered high risk and it was anticipated that some questions could trigger emotional or psychological distress among the participants, the researcher arranged for a psychologist working in the hospital unit to be on standby to provide psychological services in case they were needed. Fortunately, the participants did not at any stage require psychological intervention. The researcher asked carefully considered questions, without compromising the objectives of the study.

3.8 STRATEGIES EMPLOYED TO ENSURE THE TRUSTWORTHINESS OF THE STUDY

Babbie and Mouton (2011:405) define trustworthiness as the level of assurance a qualitative researcher has in the information they collected. In this study, reliability, credibility, dependability, and confirmability were ensured in order to establish trustworthiness.

3.8.1 Reliability

Golafshani (2003:67) states that the purpose is to analyse the participants’ comments and to provide context for them; whereas reliability is a notion that is used to assess responsibility in a qualitative study. According to Creswell and Poth (2013:212), reliability in qualitative research refers to the consistency of replies to various coders of datasets. Field notes, audio recordings, and the transcription of digital information can all improve reliability.

In this study, I ensured reliability by documenting all data gathered during the interviews, debriefing the participants, and revisiting previous research outcomes on HIV disclosure by parents to their children. Since limited data are available on the topic of this study in South Africa, I examined international literature from countries such as Thailand, the USA, Canada, Kenya, Ethiopia, Zimbabwe, and eSwatini. I used the same notebook to take notes during all the interviews. The notes were an important resource in ensuring the reliability of the research findings.

3.8.2 Credibility

Credibility refers to an accurate account of research (Babbie & Mouton 2011:406). I selected participants for the study using purposive sampling in an effort to gather rich data on the impact of HIV disclosure to children by their parents. During the initial session of recruitment with the participants, I briefly explained the purpose of the study, which was beneficial in establishing and building rapport.

3.8.3 Dependability

Dependability is the consistency of data over time and under varying circumstances (Polit & Beck 2014:166). Dependability in this study was achieved by using an audio recorder and writing notes during the interviews. The participants narrated their experiences and the data were recorded with their consent.

3.8.4 Confirmability

I read the transcripts several times to ensure that the data were recorded accurately. Brink, Van der Walt and Van Rensburg (2012:116) describe confirmability as an assurance that the results, conclusions, and suggestions are supported by facts and strengthen the internal consistency between the evidence and the researcher's interpretation. My supervisor reviewed the field notes and recordings that were used throughout the study. The transcripts were reviewed by the supervisor to confirm the validity of the research.

3.9 REFLECTIONS OF THE RESEARCHER

The study of lived experiences that are typically difficult to describe is the main emphasis of hermeneutic phenomenology, which honours each person's account of their own experiences (Mohajan 2018:114). Hermeneutic phenomenology enables the researcher to explore and interpret the emotional journey and the resources of support available for the participants. Since this study adopted the hermeneutic phenomenology approach, it was important throughout the study to respect the participants' opinions and social, political, and cultural beliefs without imposing the researcher's own beliefs on them and to allow them to narrate their experiences without feeling judged. In order to reduce bias and produce valid research, researchers must locate themselves in the process since the researcher's position has an influence on the participants' narratives. According to Ali (2015:98), reflexivity is when a researcher comprehends both the "self" and the "other" as means of producing knowledge. Reflexivity is necessary for researchers to avoid imposing their own biases on the research participants' narratives (Ali 2015:98). According to Neubauer *et al* (2019), in conjunction with Ali (2015), the purpose of reflexivity is neutralising the influence of subjectivity by acknowledging it, explaining it, or capitalising on it. Neutralising, also known as bracketing, is a process through which researchers attempt to set aside any aspects of themselves (Neubauer *et al* 2019:68). I currently works as a social worker in a wellness clinic, in the ARV unit, which enables me to advocate for children and fight against the stigma associated with HIV, as well as parental and caregiver non-disclosure of HIV to children. I entered into the research process with my own ideas and assumptions about HIV disclosure from parents to their children based on significant reading of the literature and work experience, which she had to reflect on during the research process. However, I have no experience of parenting an HIV-positive child and cannot claim to know the participants' position. Participant 11 mentioned that she feel sorry for her niece because immediately when she start dating she need to disclosure her HIV positive status to her partner which is not easy because women who are HIV positive are perceived as 'whore', as a woman I felt her pain and frustration and wanted to offer words of encouragement and support, however I had to remind myself that my advice might influence the interview and lead to responses that reflect my views, instead of what the participant wanted to express. As such, when examining the participants' stories, I had to adopt a reflexive process to set aside any aspects of knowledge of pre-existing theories and personal or professional views and take their perspective into account and be aware that I was not in their position. In order to minimise potential bias, I adopted and engaged in reflexivity during data collection and analysis processes and reflected on their positionality through the entire research processes.

3.10 CONCLUSION

The hermeneutical phenomenological approach and a qualitative research design were considered relevant to explore the experiences and attitudes of parents who are living with and raising children who are HIV positive, on ART, and not aware about their HIV status were. Subsequently, the chapter discussed the data-collection tools and processes used in the study. I used in-depth face-to-face interviews for the purposes of data collection. The data-collection process that were followed helped the researcher to gain a deeper and nuance understanding of how raising children who are HIV positive changed their parents and caregivers' lives. The thematic analysis method was outlined and the themes that emerged were described. I was able to establish trustworthiness in the study by following ethical processes and requirements. The chapter concluded with the reflexive processes that I engaged in throughout the study.

The next chapter discusses parents and caregivers' experiences of navigating HIV-related stigma in their communities.

CHAPTER 4:
WHAT IF THEY TELL OTHERS? PARENTS AND CAREGIVERS NAVIGATING HIV-RELATED STIGMA IN RURAL TOWNSHIP COMMUNITIES

4.1 INTRODUCTION

As an introduction to the findings of this study, this chapter pays attention to parents' experiences of negotiating HIV-related stigma in rural township communities. Numerous studies have demonstrated the link between HIV-related stigma and discrimination and isolation associated with an individual's HIV-positive status (Kalembo *et al* 2018; Pantelic, Casale, Cluver, Toska & Moshabela 2020; Doat, Navab & Sadat Hoseini 2021). Stigma and discrimination are linked to negative impacts on various aspects of the lives of people who are living with HIV, including poor ART adherence; psychological issues such as anxiety; as well as overall negative health outcomes (Li *et al* 2018; UNAIDS 2021). Stigmatisation is seen as a priority for both primary and secondary prevention of HIV and AIDS because it remains a significant obstacle to accessing HIV testing, disclosure, and care and treatment services (UNAIDS 2021:3). In South Africa, children who are living with HIV increased from 130 000 in 2002 to 270 000 in 2021. This represents an average annual rate of 4.12%, yet little is known about their families' experiences (UNAIDS 2021:2).

In Chapter 5 it was established that parents fear disclosing children's HIV-positive status due to the anticipation of exclusion, stigma, and discrimination from community members. The parents and caregivers expressed fear that should the children know about their HIV-positive status, they would possibly disclose it to other people in their communities, which would lead to them being stigmatised. This chapter focuses on how the parents and caregivers of children living with HIV navigate the stigma associated with the disease in their rural and township communities. This chapter unpacks the impact of stigma on parental disclosure of HIV, as well as the steps that parents and caregivers take and practise as stigma management strategies, which include passing, normalcy, and secrecy. The perception of stigma in the community and HIV-related stigma and discrimination in the rural areas and townships according to the participants' perspective are also considered.

4.2 THE IMPACT OF STIGMA ON PARENTAL DISCLOSURE OF HIV

Mugo *et al* (2023:11) state that the stigmatised aspect of HIV may hinder open family communication, affect other health outcomes, and have an impact on whether or not a parent discloses the child’s HIV status to them. This study found that one of the reasons parents gave for non-disclosure was their desire to shield their children and their families from psychological suffering and social humiliation. In line with the findings of a qualitative study conducted by Bingaman, Hamilton, Olivera, Crowell and Fair (2022:16) in the USA, this study found that the hardest part about having an HIV-positive child in the rural areas and townships was stigma. HIV stigma was reported as a challenge with long-lasting psychological and social implications for the parents and caregivers in this study.

HIV and AIDS impose a significant psychological burden on parents and caregivers who often suffer from fear, judgement, rejection, and anxiety as they adjust to the impact of the HIV diagnosis and face the challenges of raising a child with a chronic illness (Neppl, Jeon, Schofield & Donnellan 2015:8). The participants explained:

> *“My fear was what if he fails to accept the fact that he is sick with the virus and I was also scared that he will be in denial and not wanting to accept his HIV status, blame me for putting his life at risk, or go as far as attempting to end his life but fortunately he understood”* (P3, female, 33 years old, mother to a nine-year-old boy).
>
> *“If other people, especially relatives and neighbours, find out that my grandson is sick, definitely they will isolate and reject him. People are very judgemental and narrow -minded, therefore it is better to be safe than sorry. I will tell him when the time is right or [when he is] old enough to defend himself”* (P2, female, 63 years old, caregiver to her seven-year-old grandson).
>
> *“Our neighbours gossip too much. Should they know that my son is HIV positive, they will gossip about us to other people. My son is still too young to keep secrets, I am scared he might disclose his HIV status to his friends while playing”* (P9, male, 40 years old, father to an 11-year-old boy).

People living with HIV face many negative impacts when it comes to disclosing their status, especially for parents and caregivers who are raising children who are HIV positive. These negative impacts may exist due to the lack of family, societal, and professional support. The findings of this study reflected some negative impacts faced by the participants, such as judgement and rejection. The studies conducted by Klutsey *et al* (2021) and Msoka *et al* (2023) found that people are scared to disclose their HIV-positive status due to perceived adverse effects associated with such disclosure. According to Tesfay, Javanparast, Mwanri and Ziersch's (2020:9) research on barriers to the utilisation of a nutritional programme in HIV care services in the Tigray region in Ethiopia, people's judgemental attitudes are a reflection of stigma.

The participants in this study feared judgemental attitudes, which prevented some parents and caregivers from telling their children that they were HIV positive even though some had not personally encountered any judgement regarding their status. The participants believed that disclosure would have negative effects and, as a result, they might think that others' responses or behaviour to their disclosure are judgemental. This study also discovered that gossip was linked to stigma and judgemental attitudes. Some participants expressed concern that their children might become the subject of gossip if others found out they were HIV positive.

Fear of rejection is one of the leading challenges to HIV management and disclosure in HIV research (Maman, Van Rooyen & Groves 2014; Bingaman *et al* 2022; Msoka *et al* 2023). Parents are faced with a dilemma wherein they fear losing the people who are closest to their children once they have disclosed their HIV-positive status. This is supported by a study conducted by Maman *et al* (2014:33), which found that partners in sexual relationships were reluctant to disclose their HIV status for fear of losing their relationships. The parents and caregivers in this study were hesitant to tell their children that they were HIV positive due to their fear of being rejected. Fear of stigma influences family conversations and HIV disclosure. Parents and caregivers who care for children have an underlying concern that having a child with HIV will bring them sorrow. The worry that comes with having a highly stigmatised illness is the source of distress, not the illness itself; it is the dread of rejection and isolation. Stigma was mentioned as a barrier to disclosure since parents and caregivers were unable to tell their children that they were HIV positive at birth and to discuss the implications for their development and treatment in the home and social contexts. Rejection is a problem that is intimately related to stigma (Msoka *et al* 2023:28).

It is evident from the participants' narratives that there is a need for better understanding by society and healthcare professionals of the mental and emotional effects of raising children who are HIV positive, especially when it comes to emotional support, assessment, and treatment for both parents and children. The lack of understanding and the misconceptions people have about the virus cause them to reject people who are living with HIV and AIDS. There is often fear of disclosure among parents to their children due to stigma and discrimination related to HIV in their communities.

4.3 STIGMA MANAGEMENT STRATEGIES

This section pays attention to the positive and negative self-coping mechanisms parents adopt in order to cope with stigma. The development of strategies to manage stigma, along with parents' approaches to disclosing the HIV-positive status to their children and discussing it within their families, is shaped by the opinions and experiences of parents and caregivers regarding HIV-related stigma in their environment, as well as the prevailing attitudes of those around them. This shapes when and how disclosure is addressed in their families.

At a family-focused level, parents and caregivers in this study lessened stigma towards their children by adopting the idea of normalcy, by discussing HIV in the home setting, involving children in HIV-related television shows, as well as using passing as a coping strategy.

4.3.1 Normalcy as a stigma management strategy at home

"Normal" in the context of this study means "unaffected by any particular infection or experimental treatment" (Bhardwaj & Hole 2020:1). In this study, parents and caregivers addressed the concept of being normal within the framework of the belief that normal children do not have to worry about their HIV status.

The concept of normalcy, in this context as expressed by the participants, stems from the knowledge that healthy children lead normal lives and do not have to worry about their health.

Some participants expressed how hard they were trying to guarantee that their children have a normal life, regardless of the virus. P2 explained:

> *"My grandson does not know anything for now. He is still young, I don't want to stress him. I want him to live a normal life like any other children of his age without worrying about sickness and medication. Every time when he asks why I am giving him medication, I tell him that he's got asthma; however, I encourage him to read books about HIV"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).

P2 had not disclosed her grandson's status to him because she wanted him to live a normal life. The idea of being normal is living a life without HIV. She further stated that parents who are raising "normal" children do not have to stress about the child being sick or having a chronic illness. She further said that she kept his HIV status a secret from him mostly because she wanted to raise a "normal" child like other parents. P3 and P11 discussed how they wondered what it felt like to have a "normal" child who did not have to deal with the stress of having HIV. According to P11, raising a child who is HIV positive means they have to constantly wonder about the normalcy of their children's childhood with the virus. The participants noted:

> *"I wonder how my niece's life would have turned out if she had not tested positive for HIV. She might have a lot of friends and neither of us would be as stressed out. She sometimes shuts herself in the room and does not talk to anyone. I worry that even when she starts dating, having HIV would make her life difficult because she will have to disclose to her partner. But this is her life; all she needs to do is be resilient. Living with HIV is not easy. I always start conversations about HIV and other sexually transmitted infections when I see her depressed. We frequently listen to podcasts about HIV and have lengthy talks about HIV"* (P11, female, 37 years old, caregiver to her 13-year-old niece).

> *"It is difficult to think about life in any other manner. I am unable to picture his life without HIV since I am not familiar with what that existence would look like.*

> *Even though sometimes I ask myself how would his life be like but I don't want to worry about how his life may have turned out if he had not been infected with HIV. Being HIV positive is his normal; the only thing he needs to do is to take his medication correctly. Disclosing to him was the best decision ever; however, I have to constantly remind him to keep his status a secret. Together we read children's books and watch cartoons about HIV"* (P3, female, 33 years old, mother to a nine-year-old boy).

P11 wondered what it would be like to have a "normal" niece. According to her, living with HIV means not being able to have a normal life and normal relationships. She mentioned that her niece will have challenges with being HIV positive when she starts dating because she will be expected to disclose her status to her partner. She stressed about how difficult it is to live with HIV because it means that one must always worry about their unusual illness and rejection. For her a "normal" life is one without HIV, which is a stereotype because, P3 said her son's HIV-positive status was his normal and that she could not imagine any other life without HIV because a life with HIV is what her son has always known. However, she also emphasised the importance of ART adherence in order for her son to live a completely normal life. Thus, for P3 normalcy is not tied to a life without HIV, as she believes that everyone's normal depends on how they view their lives. The above narratives by P11 and P3 concur with Celeste-Villalvir *et al* (2023:18) findings, which stress that while both men and women experience stigma, including verbal abuse, however men's experience of HIV stigma were subtler , while women described outright rejection and instances of physical violence.

The majority of parents and caregivers helped to normalise HIV by fostering a family dynamic and atmosphere in which their children felt comfortable talking about their status. P11 normalised HIV by encouraging her niece to discuss HIV topics and listen to podcasts on HIV with her and her cousins. Another participant noted that after disclosing her own HIV status to her niece, it made her niece feel less isolated. Even though some families encouraged discussions of HIV in their homes, the parents still emphasised keeping their children's HIV-positive status a secret to extended family members and society (Bingaman *et al* 2022:17).

4.3.2 Secrecy or non-disclosure

In secrecy or non-disclosure as a stigma management strategy, the parents tried to strike a balance between the need to protect their children from stigma and discrimination and the desire to advocate for their children by acknowledging both the negative and positive effects of disclosure and non-disclosure. Due to stigma, age, and the level of maturity, the majority of the participants struggled with the issue of whether to disclose to their children and others. Most parents and caregivers stated that their original desire was to be completely transparent about their children's status, but they later changed their minds. Most parents were worried that their children would tell others about their HIV-positive status, especially when the parents were not around to control the situation.

> *"My daughter knows nothing about her HIV status. I was planning to disclose to her last year but due to the community's stigma I am scared. What if she tells others about her disease? Keeping secrets is not my style but on this issue, I have no choice to wait until maybe she is 15 or 16 years"* (P10, female, 41 years old, mother to an 11-year-old girl).
>
> *"I have not yet told my son that he is sick. I am waiting for the right time. I will tell him when I see that he's old enough to defend himself against stigma. For now, we are still keeping his HIV status a secret. I am happy because he still adheres to his ART without questioning us; however, it is not easy to live with a secret. It is draining emotionally, it's like you are carrying a heavy load on your shoulders. Look, if we have visitors at home, we are forced to wait for them to go before we can give our son his daily dose"* (P9, male, 40 years old, father to an 11-year-old boy).

It is evident from the above narratives that secrecy or non-disclosure may have a negative effect on an individual's emotional and psychological health, as alluded by P9. In this study, as a result of secrecy, the researcher noted a disturbance to treatment adherence as the parents changed the time of their children's daily dose of ARVs in order to avoid it being noticed by visitors. The participants created their own ways of navigating HIV-related stigma, which were frequently connected with how much information a family felt comfortable to share with others. P9 shared that once his son is old enough to defend himself against HIV discrimination, he will tell him about his status. The parents described the non-disclosure act as “not a secret but confidential”. P10 explained:

> *“So, if you ate pap and spinach at your house, do you go around telling everyone that you ate pap and spinach? No, that’s not how we behave. It is not wrong to eat pap and spinach but is not for everyone to know, what matters is that you are full”* (P10, female, 41 years, mother to an 11-year-old girl).

The majority of the participants said that their approach to disclosure was influenced by both anticipated and actual stigma. Some parents in this study stated that disclosing their children’s HIV-positive status would weaken the link between the family members:

> *“Look, my daughter is not the only child at home. I have other children and they don’t share the same father, so should they know that their younger sister is HIV positive they might treat her different, especially when I am not around”* (P10, female, 41 years old, mother to an 11-year-old girl).

The experiences highlighted by P10 demonstrate the role that parents and caregivers play in protecting their children from HIV-related stigma. Parents and caregivers change their behaviour when it comes to disclosure in response to actual or anticipated undesirable reactions, and keep secrets or hide information as a stigma management approach. Even though P10’s daughter was aware of her HIV status, the family had to come up with ways to keep the child’s HIV-positive status from society by constantly reminding her that HIV is a secret that she must not discuss with anyone.

4.3.3 Goffman’s (1963) passing as an HIV-related stigma management strategy

Goffman (1963) developed the term “passing” to characterise the process of concealing one’s stigmatised identity and adopting an unstigmatised identity in order to fit in. Stigma and discrimination against people who are living with HIV can even go to the extreme of violent attacks or deep hatred. For example, Miss Gugu Dlamini was stoned to death on 16 December 1998 after her public HIV disclosure. Dlamini believed that in order to overcome HIV-related stigma and educate people across all social spheres, it was crucial to talk openly about the disease (McNeil 2019:2).

Similarly, the qualitative study conducted by Sharma, Bidari, Bidari, Neupane and Sapkota (2023:91) in Kenya on the real-world impact of integrating HIV-assisted partner services found that the community stopped from buying from some businesses after the owners had disclosed their HIV-positive status.

It is evident from the above information that people who are living with HIV still face challenges of isolation, fear, and rejection; therefore, in order to minimise the stigma associated with being HIV positive, individuals will adopt "passing" as a stigma management strategy. By "passing", Goffman (1963) implies that the stigmatised person chooses a non-stigmatised way of life to escape the negative effects of the stigma. Regarding HIV, passing is purposefully hiding one's HIV-positive status (the discredited attribute) and leading an HIV-negative lifestyle (the credited attribute) to deflect unfavourable attention from the individual and the community.

While passing has helped some parents and caregivers with managing HIV non-disclosure, it has rendered HIV management invisible. In this study, some participants wished to disclose to their children, but they were reluctant to do so because they feared rejection and as a result they hide the HIV status from their children in order to live an open life, where they can live freely without any fear of being discriminated against. To avoid discrimination, parents and caregivers engage in passing as an HIV-stigma management strategy.

> *"Hmmm, you see, he is still a child and if you are not careful, he might even stop taking the medication. I have to be careful; I cannot talk anyhow, just like now I am talking to you, with him it is different. You cannot mention big and scary words to the child. He knows that he needs to take his treatment daily but I told him that his mother died because of a weak heart; therefore, in order to protect him from suffering from a weak heart, he needs to take medication daily"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).

> *"When he turns 16 years and ready to go to the mountain school, I will tell him the truth, but for now I told him that the medication is preventing him to have cancer and diabetes since there's a history of diabetes in our family. The society we live in is cruel; it is not safe for me to tell him now. Unfortunately I am forced to live a double life"* (P6, female, 62 years old, caregiver to her 13-year-old grandson).

Based on the above narratives, the participants adopted passing as a coping mechanism due to their perceived lack of familial and societal support and fear of rejection. Researchers argue that people who are living with HIV frequently assume a false negative status in order to escape the potential consequences of disclosing their actual HIV status (Croteau *et al* 2008; Bingaman *et al* 2022). It is evident that the participants in this study engaged in a critical observation of the environment that they found themselves in. P2 and P6 observed that the environment was not safe for their children to know their HIV-positive status, which made them aware that they had to adopt ways of avoiding exposure of their children's HIV-positive status and possible rejection by and isolation from other people. The participants lived double lives where they knew their childrens' HIV positive statuses but provided false information to the children because they deemed their societies unsafe. This study found that passing made it easy for the participants to avoid many questions from their children; however, it forced them to deny their values and live a dishonest life, which can have negative emotional implications for them. This is in line with Bingaman *et al*'s (2022:77) study, which argues that passing carries the danger of psychological and emotional strain because it requires careful attention to detail while creating acceptable behaviour.

The next section examines perceptions of HIV stigma in communities.

4.4 PERCEPTIONS OF HIV STIGMA IN RURAL TOWNSHIP COMMUNITIES

When informed of their HIV status, many children are sworn to secrecy by their parents and caregivers. Out of fear that children will tell others in the community, their HIV-positive status is hardly shared in communities. Certain people prefer to keep their status a secret or to disclose it only to their immediate family members, while others choose to come forward publicly. Several African beliefs hold that "it takes a village to raise a child" and this is the approach that most parents and caregivers in this study were afraid to follow. Kalembo *et al* (2018:36) argue that there is value in different people knowing about the child's HIV status, which includes social structures and support groups within the community that the child might be part of. The community's support is highlighted as a vital precondition for creating healthy social structures that aid, support, and increase the possibilities of excellent health and wellbeing for individuals living with HIV (Campbell & Cornish 2010; Bingaman *et al* 2022). One of the benefits of disclosure is that children who know their status can receive various forms of support from the community.

However, this is not often the case, because there is still a great deal of shame in being HIV positive for both children and adults, especially women (Doat *et al* 2019 and Celeste-Villalvir 2022). This is the source of perceived stigma in communities. This study also revealed that most participants still chose to conceal their children's status because of the stigma attached to HIV. This study further discovered that there is frequently a subtle hostile attitude toward those living with HIV, despite the various educational campaigns and outreach initiatives that have been launched to raise awareness of the virus in the participants' communities.

In many communities, as is the case in Nkangala, individuals refrain from openly discussing discrimination based on many identities, such as someone's HIV status. Discrimination against individuals may have legal consequences. Nevertheless, laws that protect HIV-positive individuals, particularly those that prohibit discrimination, do not end the stigma and discrimination surrounding those who are living with the virus on a social level. The social norms that stigmatise being HIV positive are what prevent or hinder persons from disclosing their status to their families or the community. Concerning people's social networks, the fear of the community learning their children's HIV status was a major concern to many participants because it might cause ties and connections to break down. The following was shared by P4:

> *"My son loves soccer. I guess my wife is scared that should we disclose to him his HIV status, he will disclose to others and, as a result, if he can be injured during their soccer matches, no one will want to assist him. His friends will distance themselves from him and all the connections he has for his soccer career will be destroyed. Stigma is still alive in our communities"* (P4, male, 40 years old, father to a 13-year-old boy).

Participation in the community is emphasised as a crucial prerequisite for developing health-enabling social contexts that help and support people and maximise their chances for health and wellbeing (Campbell & Cornish 2010; Bingaman *et al* 2022). However, community involvement frequently results in stigma for HIV-positive adults and children. With the aid of community mobilisation, various social groups can come together to discuss current problems and look for workable solutions. Despite the fact that this mobilisation is crucial for encouraging healthy habits and lowering HIV transmission, people with HIV and AIDS are still subjected to stigma (Coetzee, Hildebrand, Boulle, Maartens, Louis, Labatala, Reuter, Ntwana & Goemaere 2004; Msoka *et al* 2023).

The literature identifies several aspects of HIV-related stigma, including anticipated stigma (fear and anticipation of experiencing HIV-related stigma), perceptions of stigma in the community (known as normative or felt stigma), enacted stigma (actual acts of discrimination and abuse), and internalised stigma (often referred to as self-stigma, which occurs when people who are living with HIV internalise negative attitudes that they perceive to exist in the community) (Turan *et al* 2019:23). The progress that has been made to address the social surroundings of HIV in communities continues to be hampered by these various forms of stigma. While there have been some advancements in HIV disclosure among sexual partners and ART adherence, stigma still hinders full advancement (Rintamaki, Kosenko, Hogan, Scott, Dobmeier, Tingue & Peek 2019; Turan *et al* 2019).

4.4.1 HIV stigma and discrimination in the townships

Anticipated stigma and perceived stigma remain high in most South African townships (Meyer-Rath, Jamieson & Pillay 2023:17). Most parents and caregivers in this study concurred that the primary barriers to disclosing their children’s HIV status to them were stigma and discrimination. They expressed serious concerns about how the community stigmatised and isolated those who were HIV positive and they thought that stigma was still prevalent in their community. They instead opted not to reveal their children’s HIV-positive status. The following was shared by the participants:

> *“My grandson is a lead drum player in our Ndebele cultural group. I am afraid that should he become aware of his status accidentally, he might disclose to his close friend and his friend will tell others and as a result they will isolate him and all his hopes and dreams about being the best drum player will be destroyed. Stigma is still alive in our communities”* (P6, female, 62 years old, caregiver to a 13-year-old boy).

> *“I cannot tell my grandson that he has HIV. The child will not be able to keep the status a secret. He might even tell others while playing and the news will*

> *spread like wildfire and, in the end, they will discriminate against him. In fact, neighbours can end up talking about us behind our back saying in that homestead, all the people staying there are* Amagama amathathu *[in the context of this study, it means the 'family that has HIV']. They call HIV* Amagama amathathu *in siSwati"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).
>
> *"My boy doesn't know. His mother believes that the child will accidentally mention to his school mates and the relatives, then eventually they will know that we are also taking ARVs and as a result they will stigmatise us and start labelling us as the family* Lephakayo.[2] *If you are collecting your ARV monthly refill, they say* Uyaphaka *in isiNdebele"* (P9, male, 40 years old, father to an 11-year-old boy).

From the above it is evident that stigma is a social issue that has a negative impact on the parents and caregivers who are living with and raising children who are HIV positive. The participants raised the issue of power and control that townships have over the lives of individuals and families who are HIV positive or raising children who are HIV positive and they also mentioned bullying and name-calling that no individual wishes to experience. Due to the lack of acceptance of people living with HIV in the townships and the fear of discrimination, as is the case with the above participants, some parents and caregivers felt obligated to hide their children's HIV status.

Based on the participants' narratives, their community was not deemed a safe place for them to be open about their children's HIV status, since there was a general lack of understanding among people who are not HIV positive. The participants found it difficult to tell their children because they saw instances of HIV-positive people being labelled and receiving poor treatment, which made them fearful and discouraged them from disclosing to their children. HIV-positive individuals generally face prejudice, which is a sign of the ongoing stigmatisation and intolerance in the South African society. Some members of society do not see HIV testing, treatment, and disclosure as something to celebrate, support, and encourage; they see it as a way to

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[2] *Lephakayo* is a colloquial Ndebele term that is used by community members to refer to families that collect ARVs. The term is derogatory in that it is used to shame families of people who are HIV positive.

demonstrate difference by demeaning those who are living with the virus. Even though P12's niece was aware of her HIV status, the family had to come up with ways to keep the child's HIV-positive status from society by constantly reminding her that HIV is a secret that she must not discuss with anyone.

> *"My sister's child is aware that she is HIV positive but since she is still young, and you know young children talk a lot, we have to remind her that under no circumstances can she discuss her condition with her friends. We are scared they will discriminate [against her] and isolate her. Name-calling and bullying are rough in our township, even though some people acknowledge that stigma is inhumane and it should stop"* (P12, female, 53 years old, caregiver to her seven-year-old niece).

Some participants acknowledged that society's negative perceptions of people who are living with HIV are slowly changing. However, P10 argued that there will always be what she referred to as "rotten potatoes" who will always treat those who are HIV positive negatively and instigate hatred towards those who speak openly about their HIV-positive status in society. P10 indicated that as much as she wanted to discuss their HIV status with her child, external forces prevented her from doing so as she did not have control as to what would happen after society becomes aware of her HIV status.

The inability to control information raises other, additional problems. P10 further stated:

> *"I will never have complete control over how this might all turn out. I want to disclose and I strongly believe that people who are HIV positive should be free to discuss their sicknesses openly, like those who are suffering from cancer or diabetes, but we are limited and it becomes stressful"* P10, female, 41 years old, mother to an 11-year-old girl).

Participant 11 shared her actual experience of stigma and discrimination, particularly from the neighbours, who referred to their house as the "house of *Amagama amathathu* [the house of HIV]". She claimed that such remarks have a long-term effect on her mental health.

These limitations that P10 referred to are perpetuated by the hostility of her community. She therefore felt helpless when it comes to living a life with secrets and fighting the negative perceptions of people who are living with HIV in the community. There was no doubt in the discussions with the participants that stigma, discrimination and the fear of being bullied and rejected were the main reasons that prevented the parents and caregivers from disclosing their children's HIV-positive status to them. According to the participants, discrimination occurs when community members use insulting phrases and hold negative opinions about those who are HIV positive. The participants argued that because it attacked a significant aspect of their health and had an impact on some of their emotional and psychological wellbeing, it constituted discrimination.

The study's overall results on stigma and discrimination in the townships are consistent with research conducted by Vreeman *et al* (2017:23), which demonstrated that stigma and discrimination play a crucial role in determining the process and procedure of disclosure, as well as parents', caregivers', and children's decision making and perceived effects of disclosing their HIV-positive status.

4.4.2 Stigma and discrimination by association

HIV-related stigma has been found to be a barrier to care enrolment and heightens the risk of non-retention and the non-disclosure of one's status (Li *et al* 2018; Nabunya *et al* 2023). Additionally, studies have shown the detrimental effects of HIV-related stigma on the mental and physical health of those who are living with the virus, including depression and post-traumatic stress disorder, social isolation and loneliness, and an overall decline in quality of life (Dos Santos et al. 2014; Li *et al* 2018; Adam et al. 2021).

Even if some family members of children living with HIV may not be HIV positive themselves, they nonetheless suffer from stigma by association, which is characterised as prejudice and discrimination against those who are connected to those who are stigmatised. Since they are associated with an HIV-positive family member, family members are frequently stigmatised and condemned in similar ways. These forms of stigma can take the form of harassment, rejection, isolation, name-calling, gossip, and loss of social support (Adam *et al* 2021:7). For example, P1 and

P2 were both HIV negative and both loved the HIV-positive children under their care, but due to stigma and discrimination by association, they were forced to observe that their environment was not fit for people who are HIV positive or raising children who are HIV positive. This made them realise that they needed to adopt new ways to protect the children under their care and themselves from possible bullying, rejection, and stigma by association.

> *"My sister's child is aware that she is HIV positive; her mother told her before she passed on. I love her; she's a good child and she speaks freely about her positive status to me even though she knows I'm HIV negative, but it is my responsibility to remind her to stay far from boys and to tell her to keep her HIV status a secret because I am a cheerleader in my church and I am scared that should church members find out that my niece is HIV positive, they might treat me bad or even demote me"* (P1, female, 48 years old, caregiver to her 12-year-old niece).

> *"My daughter's son does not know that he is sick. I will tell him when the time is right. I am aware that he might be angry about the news and that I kept this information from him for such a long time, but I also have to protect myself. I don't want people, especially the grannies I am playing* stokvel *with, to know that the grandson is HIV positive because they will isolate and reject me"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).

From the above quotations it is evident that with individual, family, and community experiences of blaming and isolating caregivers or parents who are raising HIV-positive children, P1 and P2 had to develop mechanisms to cope with and survive the harsh and painful realities that people who are HIV positive endure on a daily basis. P1 and P2 indicated that such feelings or experiences negatively affect the wellbeing of the children in their care.

The above narratives concur with the study conducted by Nabunya *et al* (2023:4) on stigma by association and the parental stress and mental health of caregivers of adolescents living with HIV, which found that family members are often condemned and stigmatised in a similar way by virtue of their association with an HIV-infected child, and they are often held accountable for the child's HIV- positive status. In addition to harbouring guilt and self-blame, caregivers fear being blamed and disliked by society. Furthermore, these emotions impair family functioning and caregiving responsibilities. The findings in this section indicate that stigma by association is associated with feelings of guilt, fear of rejection and isolation, and parental stress. This is an indication that care and support programmes should integrate strategies for managing stigma specifically designed for children living with HIV and their parents or caregivers.

4.5 CONCLUSION

This chapter demonstrated that managing HIV-related stigma can be a challenge for parents and caregivers of HIV positive children who live in rural townships. The chapter illustrated that the ongoing stigmatisation of and discrimination against people who are HIV positive in rural and township communities inhibit the disclosure of children's HIV-positive status to them. The HIV-related stigma prevalent in the participants' communities forced them to adopt stigma management strategies to protect their children from harm. In line with Goffman (1963), HIV-related stigma is highly discrediting and reduces the chances of children's HIV-positive status disclosure by their parents and caregivers, who seek to reduce the impact of stigma on their children's lives.

The following chapter provides an in-depth discussion of the parents' and caregivers' experiences of managing the socio-psychological aspects children's HIV positive status disclosure to them.

CHAPTER 5:

THE PSYCHO-SOCIAL ASPECT OF CHILDREN'S HIV-POSITIVE STATUS DISCLOSURE: NARRATIVES OF PARENTS AND CAREGIVERS

5.1 INTRODUCTION

Should a child be informed of their HIV-positive status? When is the child old enough to know their HIV status? Most parents and caregivers in this study believed that in order for HIV-positive children to make sense of anything in their life, particularly when it comes to their health, they should be informed of their status. However, their opinions differed when it came to the subject of age. While it is already well known that disclosing an adult's HIV status can be controversial, disclosing a child's status is even more complicated. HIV-positive status disclosure to children is becoming more and more significant because of South Africa's high HIV prevalence, as well as the expansion of HIV treatment programmes throughout the country. The existing provisions of the Children's Act and Child Care Act, as discussed in Chapter 2, also fail to adequately consider the potential ethical conflicts that may arise between the obligation to reveal the truth or the beneficence of knowing versus non-maleficence, or between the autonomy of the consent giver and the autonomy of the child.

In order to increase the quality of long-term care, more focus should be placed on the issues of HIV testing and disclosure to infected children. According to some participants, the disclosure of a child's status is multi-layered because it is shared with the child, their parents, other siblings, and family members; in addition to it being anticipated that the child might share their status with friends, extended family, and the community. The primary emphasis of this study is the narratives of parents and caregivers who are parenting children between the ages of seven and 14. It was essential to analyse these narratives using the context of the carers' daily lives.

This chapter begins by exploring parents' and caregivers' experiences of the disclosure of their children's HIV-positive status amidst stigma in their rural communities. The chapter further discusses the parents' and caregivers' views on the importance of HIV disclosure and how it affects treatment adherence. The chapter also covers when parents decide to disclose their children's HIV status and examines the consequences for biological parents and caregivers. It addresses reasons for non-disclosure, treatment adherence, and the use of deception as a coping strategy before disclosure. The final section focuses on disclosure motivation and procedure, as well as the advantages and disadvantages of disclosing to children. The data, drawn from participant interviews and literature, are analysed based on the emergent themes and sub-themes.

5.2 THEME 1: IS IT IMPORTANT TO DISCLOSE?

In previous studies, parents often used a child's age to indicate when they thought the child would be emotionally developed enough to understand how HIV is transmitted and how the disease progresses without experiencing emotional discomfort (Kiwanuka, Mulogo & Haberer 2014; Mengesha, Dessie & Roba 2018; Mugo *et al* 2023). Parents and caregivers in previous studies expressed great reluctance to disclose when their children were young or emotionally immature due to their fear that the children would not be able to understand how HIV is transmitted (Mengesha *et al* 2018:34). However, all the parents and caregivers who participated in this study expressed their strong belief that a child has the right to know whether or not they are HIV positive. This belief might originate from the ethical concerns of parents and caregivers about what is morally proper, or it may derive from a more practical need to ensure that their children are aware of their HIV-positive status when the time to take charge of their own health comes. The parents and caregivers were aware that informing children of their HIV status would increase drug compliance. Most participants felt that children should be made aware of their HIV status at an early age, although some have not yet done so:

> *"My understanding towards HIV disclosure to children is that it is very important to disclose to them especially when they are young rather than disclosing the information when they are old[er], because when they are still young it will be easy for them to adjust to living with the virus"* (P5, female, 22 years old, caregiver to her nine-year-old niece).

> *"I think it is important to tell children about their statuses; however, I believe that parents should wait a bit longer, maybe until the child is emotionally mature enough to comprehend the HIV virus [and] its consequences, and it will improve*

> *understanding about the daily medication"* (P9, male, 41 years old, father to an 11-year-old child).

Although most participants believed that it was important to disclose a child's HIV-positive status to them, it is evident from P9's narrative that parents may be more likely to disclose to older children than younger ones because parents and caregivers believe that older children have the ability to understand their illness. An understanding of the illness will improve the children's adherence to their ART and it might encourage them to learn more about the disease and its management. P8 said:

> *"It is important for the children to know about their HIV statuses since it is something they are going to live with for the rest of their lives. So, they need to know from the earliest age possible what they are dealing with because the earlier you know something, the earlier she starts taking responsibility about her health, the better it is to adapt and even take care of her five-year-old cousin, who is also HIV positive"* (P8, male, 43 years old, father to a 10-year-old girl).

It is evident from P8's narrative that some parents believe that in order for children to adhere to ART, they need to know the truth about their HIV status. Some parents talked about the advantages of telling their children that they are HIV positive. Parental impressions of the benefits of disclosure have improved, shown by caregivers and parents describing how children are becoming older, more emotionally mature, and capable of taking on additional responsibilities in the family. The parents also said that if a child is old or mature enough, they can even help and support their parents who are HIV positive:

> *"Disclosing a child's status is not easy, especially if you lack the necessary tools of disclosure, but I feel it is important for us as caregivers to discuss with our children about HIV and their statuses when they are still young, because it will help to reduce the spread of HIV. And it will help them to make informed decisions about their sexual lifestyle when they are older. Using protection to protect themselves and their sexual partners will be key"* (P12, female, 53 years old, caregiver to her seven-year-old niece).

P12 concurred with P8 about the importance of disclosing children’s HIV-positive status; however, she acknowledged the challenges that come with disclosure, especially if the parent or caregiver lacks the necessary tools of disclosure. The parents and caregivers explained that disclosing the child’s HIV-positive status can help to educate them to avoid HIV infection of others by pointing out that the child’s future sexual activity could be a motivator. Parents and caregivers expressed their willingness to tell the children that they are HIV positive in the future, but they also asked for tools from healthcare professionals to help them with the disclosure process. The fact that parents and caregivers in this study requested disclosure tools indicates that they were unable or lacked the confidence to explain their children’s HIV status in a way that they thought the children could comprehend. They believed that the tools would offer safety nets to address their worries about the disclosure-related stress and anxiety that the children might experience. The above narratives by the participants concur with Klutsey *et al*’s (2021:2) findings, which stress that disclosure is an important issue in HIV management, as it increases adherence to treatment, improves the accessibility to support services, and opens lines of HIV discussions within families.

The results in this section reveal that the participants knew and understood the importance of HIV disclosure to children; however, they require help from healthcare professionals. While the parents and caregivers did not agree on a specific age at which to initiate the conversation about HIV with children, Punpanich *et al* (2014:22), suggest that parents and caregivers should consider it when the child is cognitively capable of understanding such a sensitive subject, which is generally around the age of 10 years old.

5.2.1 Sub-theme 1.1: When to disclose: Identifying the time for disclosure

The most difficult task for parents and caregivers is telling their children that they are HIV positive. It is a complicated and challenging process. The findings in this study indicate that the main problem for most parents is that as these children grow into teenagers and adults, they may start engaging in risky behaviours related to HIV if they remain in the dark about their HIV status. The requirement to determine the appropriate time for concrete disclosure is growing as a result. The children’s needs and behaviour force families to decide when to disclose. This study’s findings did not pinpoint an exact age. The parents and caregivers who withheld the children’s HIV-positive status pointed to the child’s maturity and cognitive development as a barrier. Since children need to be old enough to understand how HIV is transmitted, how it affects their health, and how it affects the entire family, the parents felt compelled to wait to disclose until later. The following narratives are illustrative of the parents’ and caregivers’ views on the right time to let children know that they are HIV positive:

> *“My daughter is still young. I feel like it’s unfair for me to tell her at this age that she is sick. I prefer to wait until she is a bit matured, in high school or until she starts dating. At least by then it will be easy for me to discuss issues that involve sex with her”* (P11, female, 37 years old, caregiver to a 13-year-old girl).
>
> *“My son does not know that he is HIV positive because his mother feels that he is still too immature to be informed about his HIV status. As a father it pains me every time my son asks why he has to take medication every day while his older sister does not. I want him to know but I guess my wife is right [that] we should wait a little bit”* (P4, male, 40 years old, father to a 13-year-old boy).
>
> *“Look, my grandchild, is only seven years old, he is very, very young to understand what is HIV. It will be cruel of me to tell him that he is sick. I do not want to scare him; he must enjoy his childhood like any other children, without having to worry about adult issues. To be HIV positive is not child’s play; it is draining to me as an adult, so what’s more about a child. I know it is important for him to know but when he is older, maybe at the age of 17, when he is ready for the mountain school and chasing girls, not now”* (P2, female, 63 years old, caregiver to a seven-year-old boy).

It is clear from the narratives above that parents and caregivers are reluctant to talk to their children about their HIV-positive status. The conversation appears to have been put on hold by parents until they become worried about their child possibly engaging in sexual activities. Parents understand that their children will soon start a sexual life, which will rationalise the need for disclosure. The parents and caregiver’s concerns concur with the Statistics South Africa (2020), which stress that in 2020 alone, approximately 688 girls between the age of nine and 10 gave birth. The statistics demonstrate the need for children to be aware of their HIV status from a young age since they may engage in sexual intercourse, either voluntarily or involuntarily.

Disclosure, according to some parents and caregivers, is a means of preventing HIV transmission to others. One participant expressed that HIV possesses the ability to take lives, and that those who have the virus possess that ability. The participants believed that it was their duty to tell their children about their HIV-positive status when they were older in order to prevent others from becoming infected with the virus. This ideological formation contributes to participants' anxiety about dating and HIV-positive interactions. When to tell the child is a debate without a straightforward answer. Most participants could not agree on a specific age; however, Punpanich *et al* (2014) and Kiwanuka *et al* (2014) advise parents and caregivers to disclose when their child is cognitively capable of understanding such a delicate topic, which is usually around the age of 10. Some parents in this study were raising children who were already older than 10 years, yet they had not disclosed the children's HIV-positive status to them, which is concerning since children in their teenage years may engage in sexual activities without their parents knowing and run the risk of infecting others.

The findings in this section reveal the complexity of determining the right age to disclose children's HIV-positive status to them. Most of the parents and caregivers in this study were taking care of children over the age of 10 years and some of these children were not aware of their HIV-positive status, as the parents do not consider them mature enough to understand their status. There was concern among the parents and caregivers that disclosure would harm the children psychologically. A lack of disclosure will result in children not adhering to their treatment, which will increase the risk of new transmissions among young people. In the study conducted by Klutsey *et al* (2021:13) on to disclose or not to disclose, caregivers suggested that the correct age to disclose to children should be 18 years and older; however, the stages of disclosure can start from the age of 10 and older, when children can start to understand what HIV is and what its effects are. The WHO (2011) recommends that school-age children must be informed of their HIV-positive status and diagnosis; delaying disclosure until the child is older therefore goes against this recommendation. Nonetheless, the WHO (2011) and other authors remain silent regarding the fears and challenges parents face in disclosing the HIV status to their children and how to help them get over those fears. This study's findings demonstrate that disclosure to a child is not an easy process and that parents struggle to disclose because they fear harming their children psychologically and exposing them to information that could be too much for them to handle. The next subsection discusses how the disclosure of a child's HIV-positive status affects the parents and caregivers.

5.2.2 Sub-theme 1.2: Consequences of biological parents' and caregivers' HIV status disclosure

The literature discussed in Chapter 2 views HIV-status disclosure as a process and advises that biological parents and caregivers should be the ones who disclose the information, with arrangements made to accommodate the cognitive development of the child (Mengesha *et al* 2018; Li *et al* 2018; WHO 2018; Shallo & Tassew 2020). For parents and caregivers, disclosing HIV acquired during pregnancy is undoubtedly a difficult and complicated procedure. Four participants in this study indicated that they used the term "partial disclosure" to make the children aware of the fact that they have a health condition that requires them to take medication on a daily basis even if they are not visibly sick, without mentioning the word "HIV". When the caregivers were asked why they found it difficult to disclose the child's HIV-positive status, they explained that their reluctance was based on their anxiety about the unknown potential psychological outcomes. They feared that it would take away their children's happiness and opportunity to live a normal life. They lacked disclosure skills and wanted to avoid talking about the HIV status of the biological parents.

> *"My niece is aware that she is sick. We told her when she was eight years old, immediately after the passing of her mother. It was not an easy thing to do because we felt as if we were badmouthing her mother who was no more but we had no choice. I wish her mother told her before she passed on but now she has accepted her status and is taking her medication correctly"* (P1, female, 48 years old, caregiver to her 12-year-old niece).

> *"My grandson is young, he is only seven years old, he will not understand if I can just say you are HIV positive and how it is spread. But it is important to start educating him about handling of blood when someone gets injured at the soccer field. I did not go to school, I don't know much about this sickness, that is why I think it will be better to start with the little I know, then with the help of nurses and doctors I can be able to tell him everything. However, I still feel that his*

> *mother was the one who was supposed to tell him"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).

The majority of caregivers believed that the biological parents should be the ones to inform their children of their HIV-positive status, despite concerns that they may not be able to do so effectively. They believed that the parents have an obligation to disclose HIV information to their children. Numerous biological parents in this study stated that the children's HIV diagnosis took a toll on them. They expressed regret for infecting their children and worried that the information would damage the bond between them, with disastrous results. They also cited their grief, sorrow, and fear of confrontation, as well as their anxiety of disclosing their own status to others. As a result, they found it difficult to inform their children of their HIV-positive status. Most families try to hide the fact that there is an HIV-positive member in the family. P3 brought up the point that keeping things secret shapes how the illness is managed on a daily basis, especially actions such as ensuring that certain family members and other people do not have access to items like ARV bottles and medical records in order to conceal the disease. P3 was reluctant to tell her child about his HIV status in fear that the child would disclose his status to other people and make others aware of HIV in their family. She also mentioned the feeling of guilt for making her son sick. She highlighted the following:

> *"Telling my child that he is sick, it was 100% difficult, extremely difficult, because in telling him that he is HIV positive, I was telling him that I am also HIV positive, you know. Another thing I felt like he is sick because of me. And now I have to tell this child that I am responsible for what he has to live with his whole life"* (P3, female, 33 years old, mother to a nine-year-old boy).

Similarly, P10 explained that informing her daughter of her HIV status would cause the child to resent her. She said that the reason she could not tell the child about her HIV status was that she did not want her to become worried about her health and give up on her future dreams. She emphasised the idea that children should be free to live normal lives, have normal dreams, and be blissfully unaware of their HIV status:

> *"I have not yet told my daughter that she is sick. I'm scared that should I disclose her status to her, she will hate me for not protecting myself and her. She will be worried and end up forgetting about her dreams. You know children of today,*

> *after disclosing, what if she demands to know how she was infected? Should I start discussing my bedroom life with an 11-year-old? No. By not telling her about her HIV status, I avoid so many confrontations"* (P10, female, 41 years old, mother to an 11-year-old girl).

Given that a biological parent is more directly accountable and responsible for the possible reactions of their children, it is clear from the biological parents' narratives that it is more difficult for them to inform their children that they are HIV positive than for caregivers since they are also HIV positive. The main concern that puts these parents in this predicament is the fear of conflict with the child. Parents assume that their children will inevitably ask them a variety of questions about how they got sick. They think that if the children found out about their HIV diagnosis, they would think that their parents are to blame for their suffering, which could lead to feelings of animosity and anger and cause arguments between the parents and their children.

This section highlights the relevance of self-preservation in this process by noting that children under the care of caregivers are more likely than those under the care of biological parents to be informed of their HIV-positive status. Since most caregivers volunteer to look after children living with HIV, they would be grateful for any help in ensuring these children receive high-quality care. Caregivers therefore think that telling the children that they have HIV makes it easier for them to get the right care and treatment. The following was stated by the participants:

> *"My niece is aware that she is HIV positive. It was this other time, they were both sick with cold and flu with my younger sister. We gave them the medication for flu. After three days they were healed and my sister stopped taking medication altogether, while my niece had to continue with her ART treatment; that's when she started to ask questions and then my mom decided to tell her the truth"* (P5, female, 22 years old, caregiver to her nine-year-old niece).

> *"At first it was difficult to tell her the truth because I did not want to discuss my late sister's sexual lifestyle, but eventually I managed to gather strength and disclose to her when she was nine years old"* (P11, female, 37 years old, caregiver to her 13-year-old niece).

> *"Children of today are very smart. I knew that if I hide the truth from her, she will find out by herself and she will lose trust in me. I decided to tell her about her HIV status; however, I have a responsibility of reminding her now and then to keep her HIV status a secret, even from other relatives"* (P12, female, 53 years old, caregiver to her seven-year-old niece).

Concerns like shying away from conflict with the child and indirectly disclosing the parents' HIV status were less relevant to them. The main worries expressed by the caregivers included robbing the child of happiness, knowledge of disclosing the HIV diagnosis to the child, and potential stigma and discrimination the child may face if others outside of their trusted circle found out.

> *"My concern was that if I tell her that she is sick with the HIV virus she will be scared and think that she is going to die just like her mother. Fortunately, she understood, even though we have to remind her to keep the HIV-positive status a secret"* (P12, female, 53 years old, caregiver to her seven-year-old niece).

> *"I disclosed to her when she was nine years; however, since then she knows that she needs to keep her positive status a secret. I am scared that should her HIV status be known to others, she might be subjected to stigma and discrimination and all of us might be discriminated against"* (P11, female, 37 years old, caregiver to her 13-year-old niece).

The findings of the study show that since the caregivers' HIV status was not connected to the child, they believed that disclosing the child's HIV-positive status would not compromise their dignity, which made the disclosure process more manageable compared to a biological parent, who might be concerned about their own status being made known in the community. The findings of this section are consistent with those of studies conducted by Hayati, Muchtar, Maulina, Syamsuddin, Elwirehardja & Pardamean (2023:7), Hayfron-Benjamin *et al* (2018), and Mugo *et al* (2023), whose studies found that the prevalence of biological parental disclosure was as low as 11% to 50%, compared to other disclosures, including caregivers and to sexual partners, which were between 30% to 90%. Hayati *et al*'s (2023) and Hayfron-Benjamin *et al*'s (2018) studies examined the difficulties faced by family caregivers and discovered that 90% of children who were HIV positive were infected during pregnancy, birth, or breastfeeding and this is what made the parents feel guilty for having infected an innocent child and resulting in parents keeping the information a secret from their children.

5.3 THEME 2: REASONS FOR NON-DISCLOSURE

Some parents and caregivers indicated that their children’s HIV status was a secret to them. The parents and caregivers who have not told their children about their HIV-positive status provided many reasons for why they had not yet done so and further explained their concerns about disclosure. The reasons included the children being too young and immature to absorb the news, while others worried about adverse reactions and poor academic performance. Some parents worried that their children would tell others about their HIV-positive status if they were told and they wished to shield themselves and other family members from possible stigmatisation. The expression “keep secret” was commonly used in relation to the HIV-positive status and the desire to keep the child’s condition a secret from others. The following was stated by the participants:

> *“My child is still young and innocent, a baby of 11 years, what are you going to say to her… I think she is still too young to understand. I cannot tell her because she is too young to keep secrets. I don’t trust her, she can disclose to her friends and as a result they will isolate her. No, no, no, I cannot. I’m going to wait a bit longer, until she is a bit older to manage HIV-related stigma”* (P10, female, 41 years old, mother to an 11-year-old girl).
>
> *“My grandson does not know anything for now. He is still young, I don’t want to stress him. I want him to live a normal life like any other children of his age without worrying about sickness and medication. Every time when he asks why I am giving him medication, I tell him that he’s got asthma; however, I encourage him to read books about HIV”* (P2, female, 63 years old, caregiver to a seven-year-old boy).

Some of the caregivers did not want to inform the children that they were HIV positive in case the child unintentionally disclosed their status to others, in an effort to protect the child and other family members from additional stress and anxiety. This was especially the case if the family had already experienced a HIV-related death of other family members. P6 stated that the mother of the child under her care was very sick before she passed on due to HIV treatment defaulting. Unfortunately, she never disclosed her HIV-positive status to anyone, not even to the biological father (P6's son) of the child in her care. She described the situation as a very complicated one and said her son had since married and the wife was pregnant with twins; it was therefore her duty to protect her son and her daughter-in-law by keeping the grandson's HIV-positive status a secret. Another significant obstacle to telling children and adolescents their HIV status was the concern that doing so would make the children anxious and afraid that they might become ill or die like their biological parents did (Madiba & Mokwena 2012; Dlamini & Matlakala 2020). This anxiety was something some caregivers in this study were very concerned about.

> *"My grandson is not aware that he is taking HIV medication. All these years I have managed to keep the secret away from him. His mother was very sick before she passed on and the boy was there to witness everything, therefore I cannot tell him. I don't want to worry him; he is still young. My plan was to tell him when he is 16 years old, when he is ready for initiation school but it might be too late by then because I can see he is starting to disturb girls when they are passing by the house"* (P6, female, 62 years old, caregiver to a 13-year-old grandson).

HIV-positive parents refrained from disclosing to children who had contracted the virus during pregnancy because they felt terrible and did not want to be held responsible for the virus' spread to their children or to others. Even though some of the parents were aware of their children's HIV-positive status when the children were much younger, making the revelation required them to confront their own intense shame and guilt. The parents stated that they were not yet ready for the disclosure process because they did not have the emotional capacity to deal with the shame of being HIV positive, especially the biological parents. In addition, the parents were afraid that their children would reject them or make fun of them, which had been noted in previous literature as a typical response from teenagers when they learn that they are HIV positive (Pilowsky, Yirmiya, Arbelle & Mozes 2000; Patel, Ratner, Gore-Felton, Kadzirange, Woelk & Katzenstein 2012; Klutsey *et al* 2021).

> *"My son does not know about his HIV-positive status. His mother believes that after hearing the news the boy will be stressed, perform poorly at school, start*

> *disrespecting us, or even develop anger and deliberately infect other children of his age"* (P4, male, 40 years old, father to a 13-year-old boy).

As noted above, some parents and caregivers believed that their children were too young and immature to be informed of their HIV-positive status. The parents feared that their children might have a negative emotional response, similar to what P4 indicated, and believed that their children were not cognitively developed enough to understand what it means to be HIV positive. Most parents and caregivers suppressed disclosure to the children for a variety of reasons, including fear that the child would reveal the diagnosis to others and the possibility of stigma and discrimination. The findings in this section are in line with those of a study conducted by Dlamini and Matlakala (2020:14) on HIV-positive status disclosure to children by their parents, which revealed that the leading reason for parental non-disclosure was that the child was still young and might, upon learning their HIV status, accidentally disclose it to others and suffer stigma and discrimination. The parents also feared that the child would become depressed and perform poorly at school. Because of fear related to disclosure, the parents and caregivers resorted to concealment as a way of protecting their children.

5.3.1 Sub-theme 2.1: Treatment adherence and deception as a coping strategy before disclosure

The parents and caregivers believed that even if they could not tell their children that they were HIV positive, there is a unique way of communicating with children to make them understand why they have to take their medication on a daily basis, as well as the importance of adherence. All the parents believed that if they disclosed the HIV-positive status to their children, it would encourage them to take greater personal responsibility for their own care. The parents' comments highlighted their belief in ART and acknowledged that the child's survival and quality of life depended on regular adherence. However, some parents feared that if their children's HIV status was revealed, they might experience depression, guilt, hopelessness, social disengagement, self-harm, or even suicidal thoughts. The parents were regularly given the chance to start the disclosure process as the children routinely wondered why they had to take daily medication and some even asked outright if they were HIV positive. However, the parents and caregivers frequently fabricated stories to tell their HIV-positive children to prevent disclosure due to the aforementioned psychological implications.

The following was said by the participants:

> *"Every time when my daughter asks why she has medication on a daily basis and every time I tell her that it is because she is asthmatic; therefore, in order for her to be well and strong just like other children, she needs to take medication well"* (P10, female, 41 years old, mother to an 11-year-old girl).

> *"My daughter is under the impression that she has a weak heart; that is why she is on chronic medication. That is what her mother told her"* (P7, male, 38 years old, father to an eight-year-old girl).

As a coping strategy for their low self-efficacy in handling disclosure and fear of unfavourable consequences, parents and caregivers turn to deception. The participants often mentioned fear of encountering unfavourable views and worried that the children might not be able to conceal the illness as a factor of their deception. Regretfully, some of the incorrect information shared by the parents and caregivers might make disclosure more challenging in the future. Parents must understand that time will not always be on their side; as children grow up, they become more knowledgeable about their own health issues, which naturally leads to questions or searching, whose answers will reveal their HIV-positive status. From this disempowered position, parents resort to other strategies to avoid disclosure.

P6 stated that she started staying with her grandson after the passing of his mother, when the child was seven years old. It was easy for her because the boy could not read or write, but as the time progressed, she noticed that the boy had a tendency of searching things on Google. As a way to conceal information from him, she came up with the strategy of destroying the original container of the child's ARVs and using different packaging with no information on it. P2 said she used a black container for the morning medication, which the boy takes at 6 am (black represents morning), and a red container for the evening medication, which the boy takes at 6 pm in the evening (red represents night).

> *"Every time when it is a collection day, I make sure that I come with two containers. As soon as I collect the medication from the pharmacy, I put them*

> *in different containers, the one that I use for morning medication is black and the one for evening is red"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).
>
> *"I told him that his mother died because of cancer; therefore he is required to take medication on a daily basis so that he cannot suffer from cancer as well because in our family we have a history of cancer. To cover myself, I make sure that as soon as I collect the medication, I destroy the original boxes and use a container with no information on the outside"* (P6, female, 62 years old, caregiver to her 13-year-old grandson).

The above findings are congruent with the study conducted by Khangale, Raliphaswa and Tsililo (2022:6), which found that although many perinatally infected children are not informed of their HIV-positive status until they are adolescents, some parents use fear tactics, concealment, or misinformation to force treatment adherence. Nevertheless, adherence to medication was high in this section's findings.

5.3.2 Sub-theme 2.1: Fear of the unknown: "Children of today are weak; when they feel pain, they commit suicide"

Some parents and caregivers were concerned that if they told their children about their HIV-positive status, they would not be able to handle it well. They expressed concern that disclosing to the children might lead to them developing anxiety, depression, or even suicidal thoughts. Caring for children who are HIV positive comes with emotional, psychological, and physical obstacles that require support from the healthcare team, family, and society. Challenges that were stated by the parents and caregivers that hindered disclosure of the children's HIV-positive status to them included a lack of support from the healthcare team, especially social workers, on pre- and post-disclosure, extra care when the child has minor illnesses, public stigma from their society, and financial burden.

The participants were asked what challenges they feared to encounter when it comes to HIV disclosure. P2 responded that parents needed to be careful in handling disclosure as some children might resort to killing themselves if the disclosure process was not done correctly. P2 further stated that most parents and caregivers lacked the necessary skills and information to approach disclosure; they were thus forced by circumstances to disclose to their children without being helped by professionals who are knowledgeable, such as nurses. Similar to P2 mentioning children overdosing on pills and killing themselves after learning their HIV-positive status, P3 explained that children sometimes failed to come to terms with their HIV-positive status and as a result they end up blaming or hating their parents:

> *"My fear was what if he fails to accept the fact that he is sick with the virus and I was also scared that after disclosure he will be in denial and not wanting to accept his HIV status, then later hate me for putting his life at risk by infecting him, but I'm happy now he knows his HIV-positive status"* (P3, female, 33 years old, mother to a nine-year-old boy).

Like P2, P11 responded to the question by explaining that disclosure was important but that it needed to be done correctly to avoid children committing suicide.

> *"My concern is disclosure needs to be done properly because if we are not careful as parents on understanding which information you can tell the child, when, and how, the child might be resentful and [it might] affect their progress at school due to stress and depression or they may even commit suicide"* (P11, female, 37 years, caregiver to her 13-year-old niece).

While all the participants shared the same fears, they all agreed that it was important to disclose the children's HIV-positive status to them. However, P2 had not disclosed yet because of the psychosocial factors related to the disclosure of an HIV-positive status. Although P3 and P11 had disclosed to the children, they were aware of instances that other parents encountered after disclosure; they therefore kept stating that if disclosure is not done correctly, the child might experience psychosocial issues such as anxiety, stress, and depression.

The discussion in this section indicates that the parents and caregivers were concerned about disclosure being conducted in a manner that would protect the children from psychosocial harm. The study conducted by Li et al. (2019:9) on changes in behavioural outcomes among children affected by HIV stated that some children experienced psychological impacts, and that boys had significantly more negative behaviour than girls because of their stronger associations with risk factors and delinquency. Most participants stated that the reason for not disclosing was concern about potential emotional and psychological harm to the child and, as a result, several parents and caregivers waited until the child began asking questions before disclosing.

5.4 THEME 3: DISCLOSURE MOTIVATION AND PROCEDURE

When the parents and caregivers did disclose, it was usually because of circumstances. The parents and caregivers decided to reveal the child's HIV-positive status under pressure; not because it was planned or desired. The results in this section show that while most parents and caregivers had no intention of disclosing their children's HIV-positive status any time soon due to a number of reasons, the children's curiosity regarding their frequent medication and unintentional disclosure drove some of the participants to disclose. Some parents and caregivers reported that the children's endless inquiries about why they were taking medication daily, when they would be able to quit using medication, and whether they would ever be healed of the disease were what ultimately led to the disclosure. The parents reported that as children get older, the answers they receive leave them feeling less satisfied. P12's niece was the only person in the house taking medication (ARVs); she was therefore always curious as to why her cousins did not take daily medication.

> *"I have two other children of my own, so I'm staying with three children of almost the same age. One time they were all sick, having cold and flu, and I took them to the doctor and he gave them medication. After a week they were all healed; unfortunately, the one had to continue taking her ARVs, and after two weeks of compliance she asked why the other two are no longer drinking the chest medication. Remember, initially I told her that she is taking medication for the chest. She started crying and indicating that her chest is not painful anymore. That is when I decided to come clean and tell her"* (P12, female, 53 years old, caregiver to her seven-year-old niece).

> *"The time my sister started to get sick, she was staying with her child. At some stage she was very weak to a point that she could not collect the monthly refill for her and her daughter so the child was forced to collect. I think she was 10 years. You know, 10-year-old children can read. At the hospital they gave her two files and sent her to the pharmacy, where they gave her ARVs for both. The child became so curious and started googling the medication. Since her mother*

> *was sick, she decided to call me and informed me about her news. I then advised my sister to disclose to her, starting with the partial disclosure. Fortunately she did so before God remembered her, so for me what was left was to do the full disclosure"* (P1, female, 48 years old, caregiver to her 12-year-old niece).

Disclosure is also a response to questions from other members of the household in homes where taking pills is not a discreet or guarded practice. P8 stated that his daughter and her siblings questioned why their sister used medication every day. He then decided to disclose her HIV-positive status to his daughter first and then later made the other siblings aware of their sister's HIV status. This curious behaviour puts parents and caregivers in a difficult position and they find themselves disclosing in fear that the children will stop taking the ARVs and get sick:

> *"She was overly curious about why she is taking the medication every day, exactly like her granny who has high blood pressure. She then questioned as to whether she must continue taking the medication until she reaches her grandmother's age. It really pained me, so I decided to tell her the truth even though her mother was against the idea. I gave her general HIV information before full disclosure"* (P8, male, 43 years old, father to a 10-year-old girl).

P8 was under pressure to disclose due to the child's excessive curiosity, which left him with no other option. Most parents and caregivers agreed that they disclosed the HIV-positive status to their children simply because they were refusing to adhere to their ART. In reality, any human being would want to know why they have to use medication if they are not overtly sick. The same applies to HIV-positive children who are on treatment but do not know why. The children in question demanded explanations regarding their daily intake of medication, and upon noticing that their parents and caregivers were reluctant to tell them what exactly their sickness was, stopped the ART completely. P11 alluded that her top priority was to see her niece adhering to the treatment and having to witness her stop taking her ARVs pained her and she thus decided to disclose to her:

> *"The truth always has a way of coming out. I took her in when she was seven years but then I felt that she was still young and I did not want to stress her with adult information. When she was nine years, she got tired of taking the*

> *medication. I tried to bribe her with sweets and money for a few months but after that my plan could not work anymore. I saw that she was no longer swallowing the medication; instead she would hide it under the tongue, go to her room, and throw it under the bed. I was so stressed. I informed the counsellors and they advised that she deserved to know the truth, so they assisted me to disclose"* (P11, female, 37 years old, caregiver to her 13-year-old niece).

Two of the six participants who had not yet disclosed to the children indicated that they did not know how to do so without hurting the children's feelings. Disclosing an HIV-positive status to children is a most challenging task for many parents and caregivers because of limited skills, feeling like one is "badmouthing" the deceased parent, and cultural values. P6, who is a caregiver, said she felt like it was not her place to talk about her grandson's mother, who passed on due to HIV. She said that by telling the boy that he is HIV positive, she would be indirectly disclosing his late mother's status. In line with Airhihenbuwa and Webster (2004) and Doyal (2009), another contributing factor to the unease among parents and caregivers when talking about HIV is the recognition that the illness is primarily spread through sexual contact.

Discussions about sexual and reproductive health and rights with children are still taboo in many African societies, particularly in South Africa where these topics are normally covered in health facilities and schools and not in the home (Cooper, Morroni, Orner, Moodley, Harries, Cullingworth & Hoffman 2004; Andrews, Skinner & Zuma 2006; Campbell & Cornish 2010). P6 stated that according to isiNdebele cultural practices, issues around sex are not discussed in the family, especially with young children. She believed that, as a result, she was unable to talk about the alleged sexual behaviour of the boy's late mother. Similarly, P10 expressed challenges in discussing HIV with her 11-year-old daughter. This difficulty arose from her contracting the virus through sexual intercourse, which caused her to feel uneasy about addressing adult topics with a child. Additionally, she grappled with a sense of being uncultured, along with feelings of irresponsibility and recklessness for not using protection during the encounter. P6 said:

> *"My child, I did not go to school. When growing up, we were taught not to discuss adult issues with children, but times have changed. Now people tell*

> *children everything; even when parents get divorced, the children will know. I am still old school. I want to tell the boy about his sickness but it is difficult. It was going to be easy if I could be given pictures or a voice recorder of a professional telling children about their disease, so that when I get home, I can just give him my phone and tell him to listen to the nurse"* (P6, female, 62 years, caregiver to her 13-year-old grandson).
>
> *"The boy does not know what kind of medication he is taking. I wanted to delay the disclosure until he is a bit older but hey, this boy has started to check girls, he is becoming naughty. Hmmm, I am scared he will start to sleep around without using the protection and get sick again. Children of today engage in adult stuff as young as 10 years. So I asked the social worker to help me to tell him about his sickness, so we are coming back to the hospital after two weeks"* (P2, female, 63 years old, caregiver to her seven-year-old grandson).
>
> *"I know it is important for her to know her HIV status and it is better for her to get the truth from me, from us as her parents, rather than a stranger, but where do I begin? I feel like I would cry so much, especially if she would cry. Eish, this thing is heavy on me, because by telling her that she is HIV positive, indirectly I will be disclosing my own HIV-positive status. So I asked the nurses to tell her but I will be there when they tell her"* (P10, female, 41 years old, mother to an 11-year-old girl).

The findings presented so far in this section align with the findings of the study conducted by Chanie *et al* (2022:465), which revealed that despite parents recognising the significance of HIV disclosure, they tend to postpone it due to uncertainty about how to convey the information in a less stressful manner. The participants in this study reported a lack of the necessary knowledge and skills for effective disclosure. The majority of the parents and caregivers believed that healthcare providers should take the lead in initiating the disclosure process and offering assistance where needed. The parents expressed eagerness to support the children by responding to any concerns the children might have later on about the virus, but only after social workers and nurses had informed them of their HIV-positive status. There were instances during the interviews where the parents and caregivers asked the researcher to talk to their children about HIV. This highlighted the parents' urgent need for support and intervention from their families and healthcare authorities to assist them to cope.

Since HIV is sexually transmitted, parents and caregivers find it difficult to bring up the topic due to the enduring culture of secrecy surrounding sex-related matters in their rural communities. The lack of communication concerning disclosure has led parents to ask nurses and social workers to start the disclosure process and, to some extent, to be accessible to answer any sex-related questions the children may have as they learn about their HIV-positive status. Some parents and caregivers delay the disclosure of their HIV status to the children as a way of protecting the family's dignity and customs but some alluded that there are more advantages to disclosure than disadvantages.

5.4.1 Sub-theme 3.1: Perceived advantages and disadvantages of disclosure to children

A few parents and caregivers alluded that in deciding whether or not to disclose, there is a considerable amount of evidence that demonstrates the barriers that individuals experience, which are often emotional challenges. A qualitative study conducted by Shallo and Tassew (2020:508) in Ethiopia on HIV-positive status disclosure and its associated factors among children on ART in West Shoa Zone found that the majority of children only learned their HIV-positive status during monthly ART refill visits when they were asked to mention the names of the medication they were taking. Based on this, it is evident that parents and caregivers should be encouraged and supported to disclose the HIV-positive status to their children early so that they are prepared for the outcome. One participant stated that her non-disclosure decision was fuelled by the stigma related to HIV. She believed that disclosing the HIV-positive status might subject her child to being alienated by peers and extended family members. By definition, HIV-related stigma highlights disapproval and can be detrimental to one's self-esteem, as well as to social and family support.

> *"My child is still young and innocent, a baby of 11 years, what are you going to say to her… I think she is still too young to understand. I cannot tell her because she is too young to keep secrets. I don't trust her, she can disclose to her friends and as a result they will isolate her. No, no, no, I cannot. I'm going to wait a bit*

> *longer, until she is a bit older to manage HIV-related stigma"* (P10, female, 41 years old, mother to an 11-year-old girl).

Of the seven participants who had already disclosed the HIV status to their children, two participants highlighted some instances where they felt that the children became depressed. P11 reported that her niece became resentful and this resentment affected the relationship with her cousins. Evidence from the literature shows that when adolescents and young children learn they are HIV positive, they often experience some form of emotional grief or even illness (Cluver, Orkin, Gardner & Boyes 2012; Cluver, Orkin, Boyes, Gardner & Nikelo 2012; Chaudhury, Kirk, Ingabire, Mukunzi, Nyiradagijimana, Godfrey, Brennan & Betancourt 2016). P5 narrated:

> *"My fear was what if she's going to fail at school because she was not doing well. Teachers were also worried about her sudden change of behaviour at school. She wasn't naughty but she was displaying passive-aggressive behaviour. Even at home she would just sit alone and when you call her, she would keep quiet and pretend as if she doesn't hear you. She became better after my mom took her to see the psychologist; now she's back to her normal self"* (P5, female, 22 years old, caregiver to her nine-year-old niece).

Despite the challenges, the parents and caregivers mentioned many benefits to status disclosure such as a sense of relief, less anxiety, family bonds, and a feeling of empowerment. Gilbert, Selikow and Walker (2010), Gachanja and Burkholder (2016), Namukwaya *et al* (2017), Li *et al* (2018), and Shallo and Tassew (2020) reveal that young children and adolescents who are aware of their HIV-positive status have better mental health and psychological assistance. They are also better equipped to deal with stigma since they understand why they would face discrimination from community members. Knowing their HIV status helped them to accept this truth a little more easily. Similar to previous studies (Gilbert, Selikow and Walker (2010), Gachanja and Burkholder (2016), and Namukwaya *et al* (2017), the parents and caregivers in this study reported that their children's ART adherence habits improved once they moved past the emotional stage of disclosure. The children responded significantly better to their treatment, according to the parents and caregivers, when the entire disclosure process was completed, which was reinforced by ongoing family discussions:

> *"My niece is aware that she is sick. We told her when she was eight years, immediately after the passing of her mother. She has accepted her status and is taking her medication correctly. She sometimes collects her monthly refill by herself now that she is 12 years, especially if I have to travel out of town because of work. Informing her about her positive status was the best decision ever"* (P1, female, 48 years old, caregiver to her 12-year-old niece).
>
> *"My daughter knows that she is HIV positive because she accidentally heard us discussing her treatment. Now that she is aware of her HIV-positive status, she is proactive about her medication. Every time when we travel to [location removed for anonymity] to visit her granny, she always says, 'Pops, please do not forget our little secret'"* (P7, male, 38 years old, father to an eight-year-old girl).

One participant stated that being aware of their status helped the children make an educated choice about whom to disclose to. Some parents were proud to announce that, after disclosure, the children ensured that their parents learned more about HIV and AIDS through social media and educational resources. Some parents and caregivers used the disclosure space to outline the difference between HIV and AIDS, as well as the value of adherence, especially for those who went to school.

It is evident from the above that lack of disclosure creates tension between parents and children as there is no open discussion about the child's HIV-positive status. Children who are living with HIV may become curious about their disease as a result of this culture of secrecy. These findings are in line with Amankwah-Poku, Klutsey and Asante's (2021:18) research, which found that when children are informed of their HIV-positive status, they are more likely to take ownership of their health and wellbeing. This reduces the load on parents and caregivers to ensure that their children take their medications as prescribed and visit the hospital frequently for check-ups.

5.4.2 Sub-theme 3.2: Reactions to disclosure

The parents and caregivers were also asked about the children's reaction after the disclosure of their HIV-positive status. P1 reported that immediately after the emotional stage, which lasted a few days, her niece provided emotional support to her biological mother (who has since passed) and she often stated her unconditional love for her and gave her many hugs. After the passing of her mother, every time the child in question saw her aunt sick or quiet, she would give the very same love and support to the aunt.

P11 described the aftermath of disclosure as family closeness. She stated that at first it was difficult for them to tell the child about her HIV-positive status, but after the child became aware of her HIV status, she started to be more involved in household responsibilities and communicating with her more frequently about matters of life. Being on hypertension treatment herself (P11), her niece is now the one who reminds her to take her medication on time. She went as far as learning more about HIV and AIDS and hypertension and the importance of taking their medication correctly. P11 stated:

> *"My main focus was to see her taking her medication correctly, but after disclosure she became my pillar"* (P11, female, 37 years old, caregiver to her 13-year-old niece).

However, P7 stated that his child experienced severe emotional distress in reaction to the HIV disclosure. He stated that his daughter showed feelings of deep sadness, which lasted for about two weeks before the child was back to her normal behaviour.

> *"She was extremely silent for the first two weeks following disclosure. By nature, my child is talkative and energetic. I felt bad about informing her about her HIV-positive status and emphasising that she needs to take her medication daily because there is no cure for HIV. When I questioned what was wrong, she assured me that everything was fine. I was worried about her. Fortunately, after reassuring her that nothing has changed about her and she won't die because of HIV, she eventually returned to her usual self and I am happy because now both of us can freely discuss ARVs and the importance of adherence"* (P7, male, 38 years old, father to an eight-year-old girl).

Based on P7's narrative, the child developed negative emotional reactions, including withdrawal and sadness. These reactions imply that after the child learned about her HIV-positive status, she started to comprehend the consequences of having to live with HIV for the rest of her life. With reassurance and support from her father, the child eventually overcame the negative feelings and emotions.

It is evident from the above discussion that even though the disclosure of a child's HIV-positive status is difficult for most parents and caregivers, there are many benefits that the parents enjoy after disclosure. Some parents and caregivers agreed that their main focus was to see their children taking their medication correctly; however, after noticing that they were no longer taking their ARVs accordingly, the children were informed as a way to prevent them from defaulting on their ART. Almost all the parents and caregivers stated that, after disclosure, the children started to take their medication seriously and played a leading role in managing their own health. These findings are in line with Amankwah-Poku *et al*'s (2021:18) research, which found that when children are informed of their HIV-positive status, they are more likely to take ownership of their health and wellbeing.

5.5 DISCUSSION OF THE FINDINGS

The findings discussed in this chapter, showed that the parents and caregivers were aware of the significance of telling the children about their HIV-positive status. They recognised the advantages of managing HIV care and treatment adherence. Most participants in this study indicated that children should be made aware of their HIV status as early as possible. Bakai et al. (2023:3) research on disclosure of HIV status and adherence to ART among children and adolescents showed that children who are knowledgeable about their HIV status are twice as likely to demonstrate high treatment adherence, and that disclosure also lowers the likelihood of reinfection and high-risk behaviour.

Regardless of the benefits and importance of disclosure mentioned by the participants, it was intriguing to note that some parents and caregivers had not told their children about their HIV status, and even though some indicated a desire to tell them, they were planning to delay the disclosure. In this study, the parents' desire to delay the disclosure was frequently accompanied by concerns about the children's age and emotional immaturity. Klutsey *et al* (2021:10) found that parents preferred to disclose to older children because they believed that younger children had not yet reached the developmental stage where they could understand and effectively deal with the disease. Similarly, in this study, all the parents and caregivers understood and knew the importance of HIV-status disclosure, yet some indicated that disclosure should happen when the child is old enough to comprehend what HIV and its effects are;

however, they did not agree on an appropriate age. The lack of disclosure or delaying disclosure will result in children engaging in unprotected sex with their peers without their parents' knowledge.

The study revealed that HIV disclosure to children in the Nkangala region is still a challenge. From the interviews that were conducted on HIV disclosure, almost half of the children were not aware of their HIV-positive status. The parents and caregivers gave justifications for withholding information about their children's HIV status from them that were consistent with the literature, such as the children's age, level of maturity, stigma and discrimination, and fear of the unknown, which included anxiety and negative reactions upon learning about their status (Dlamini & Matlakala 2020; Klutsey *et al* 2021; Bakai *et al* 2023). The parents expressed concerns that due to the children's young age, they might reveal they HIV-positive status to others without understanding the implications.

The majority of the participants expressed fear of the rejection by friends and society. According to some parents and caregivers, there is labelling and name-calling in Nkangala's rural communities because people believe that contracting HIV is a punishment for having many sexual partners. To prevent such labelling and social rejection, some parents chose to keep their children's status a secret. It is clear that greater societal stigmatising factors have a major impact on parents' and caregivers' decisions about whether to tell their children that they have HIV or not. Out of the 12 participants, 7 experienced enacted stigma while 5 experienced perceived stigma.

Curiosity and inquisitiveness, as well as poor adherence to ART, were the main reasons that led to the disclosure of the children's HIV-positive status to them in this study. Their children's concerns about their medication use while being in seemingly good health forced the parents to reveal the children's HIV-positive status to them. This probably arises from the fact that, as they grow older and develop cognitively, they start to challenge the status quo to comprehend the motives behind particular actions and behaviours, which in turn increases their curiosity and inquisitiveness. This suggests that although parents may not disclose their children's HIV status when they are young, as they grow older, parents should prepare to do so as children will start asking questions and seeking more information on why they are using chronic medication.

Another finding from the study was that some participants expressed not knowing much about how to tell their children their HIV-positive status without hurting or confusing them. The parents and caregivers emphasised the need for guidance from medical specialists so that they can tell their children about their HIV status. One participant said that she was able to tell her niece by following the process of disclosure, after she got tips from a counsellor about HIV disclosure to children, which is indicative of the important role that healthcare practitioners should play in supporting the parents and caregivers of children who are HIV positive.

5.6 CONCLUSION

Data regarding the psycho-social factors of disclosing HIV-positive status to children between the ages of seven and 14 by their parents and caregivers were presented and discussed in this chapter. The participants' demographic data were presented in the first section. Findings from relevant literature were incorporated to support the themes that were identified during the data analysis process. This chapter established that parents and caregivers who are raising HIV-positive children require help from healthcare specialists so that they can tell their children the truth about their HIV status. Some parents were forced to disclose it because their children were questioning the daily medication intake despite being in excellent physical health. When some children learned they had HIV, they displayed negative emotional reactions, including sadness and withdrawal. They were able to adjust and stopped displaying negative emotional reactions over time with ongoing support from their parents and caregivers. Children benefited greatly from counselling, even if it was not provided by professionals. This suggests that for children living with HIV, psychological intervention or counselling services provided by social workers or ARV counsellors is just as important as medical care. The parents have also emphasised and stated that HIV-related stigma and discrimination had a negative impact on their decision making regarding disclosing their children's HIV-positive status to them.

The following chapter summarises the research findings and offer recommendations for future researchers, healthcare practitioners, and policymakers on the assistance that parents and caregivers require when it comes to disclosing children's HIV-positive status to them.

CHAPTER 6:
SUMMARY OF FINDINGS, RECOMMENDATIONS, AND CONCLUDING REMARKS

6.1 INTRODUCTION

This study found that disclosure of children's HIV-positive status to them by their parents and caregivers is still a problem in South Africa. The literature indicates that legislation and policies that support and promote HIV disclosure to children are insufficient in successfully eradicating stigma and discrimination related to HIV and AIDS (Pantelic *et al* 2017; Finnegan *et al* 2019; Klutsey *et al* 2021). The stigma against HIV and AIDS prevents people from receiving the treatment, care, and support they need to stay healthy (Hayfron-Benjamin *et al* 2018:4). It continues to be the biggest obstacle to many HIV-positive people seeking care and disclosing their status, especially the parents and caregivers of HIV-positive children. How parents and caregivers handle HIV-related stigma was discussed in Chapter 4. In this study, the focus was on the challenges faced by parents and caregivers regarding the disclosure of their children's HIV-positive status to the children. The coping strategies adopted by parents and caregivers to deal with stigma related to HIV were also acknowledged. It was crucial to take into consideration the participants' understanding of the importance of HIV-positive status disclosure based on their experiences, which was achieved by investigating their day-to-day lived experiences.

This chapter contains the researcher's conclusions, recommendations, and guidelines for both healthcare authorities and potential future research projects. The next section discusses the study's research questions and how they were answered.

6.2 MANAGING CHILDREN'S HIV-POSITIVE STATUS DISCLOSURE: A SUMMARY OF THE FINDINGS

As mentioned in Chapter 1, the main research question of this study was: How do parents and caregivers navigate the social and psychological factors that influence the disclosure of the children HIV positive statuses?

Three secondary research questions were also stated, namely:

- What are the challenges faced by parents and caregivers in the disclosure of the HIV-positive status to their infected children in the Nkangala District in Mpumalanga?
- What are the social and psychosocial impacts of HIV-positive status disclosure on parents and caregivers and their children in the Nkangala District in Mpumalanga?
- What kind of assistance do parents and caregivers need in order for them to be fully equipped to disclose the status of their HIV-positive children to them in the Nkangala District in Mpumalanga?

The secondary questions were used to help answer the main research question. The following discussions indicate the answers to the secondary research questions, which will lead to an answer to the main research question.

6.2.1 What are the challenges faced by parents and caregivers in the disclosure of an HIV-positive status to their infected children in the Nkangala District in Mpumalanga? (Theme 1: Is it important to disclose?)

The need to tell infected children about their HIV-positive status was understood by the parents and caregivers in this study. The participants noted that disclosure is crucial in circumstances where parents are not present to monitor children's medication intake because it helps them understand why they are taking ARVs and assists in guaranteeing adherence. Furthermore, two participants felt that the importance of disclosure had improved their children's medication adherence in comparison to before the disclosure. They believed that by being open, their children were better able to understand why they were taking medication, which increased their adherence to it.

The appropriate age to disclose to children was a major concern that was revealed under this theme. The parents and caregivers who had not disclosed the children's HIV-positive status to them pointed out that the children were too young and immature to be made aware of their HIV status. Concerns were raised regarding children's cognitive development and their ability to understand information about HIV, particularly what it is, how it spreads, and its implications and effects on the family.

As a result, some participants decided that they should keep their children's status a secret until they are old enough to grasp it.

Even though the parents did not agree on a specific age when a child can be disclosed to, some participants suggested that the ideal time to completely reveal a child's HIV-positive status should be in late adolescence, around 18 years and older, because by that time the child would have grown intellectually and would be able to understand what HIV and its consequences are.

This is in contrast with the WHO's (2011) guidelines on HIV disclosure counselling for children. The WHO (2011) advises that children should be informed of their HIV status between the ages of six and 12 years and that full disclosure of HIV and AIDS should be made in a compassionate and supportive way between the ages of eight and 10 years. The UN Convention, which South Africa became a signatory to, states that children above the age of 12 and those deemed to be "sufficiently mature" can consent to HIV testing, treatment plans, and full disclosure (UN 2021:5).

Regarding disclosure, the majority of the caregivers felt that the biological parents should be the ones to convey the information to the children, especially since vertical transmission is the primary source of the majority of paediatric HIV infections. However, most parents described these moments in life as challenging and stressful. The parents understood that it was their responsibility to disclose to their children but some lacked the relevant knowledge about the process of disclosure, while others felt that disclosing their children's HIV-positive status to them would indirectly reveal their own HIV status. The parents and caregivers who disclosed reported that after they informed their children of their HIV-positive status, they no longer had any worries after the disclosure.

6.2.2 What are the social and psychosocial impacts of HIV-positive status disclosure on parents and caregivers and their children in the Nkangala District in Mpumalanga? (Theme 2: Reasons for non-disclosure)

The study revealed that the child's age and maturity level, concerns about the child's reaction to disclosure, especially suicide, and worries that the youngster might reveal their status to other children while playing were some defining contributors to non-disclosure. Some parents and caregivers feared that if they told their children they had

HIV, they might not be able to digest the news and that things would only become worse. They expressed concern that this information might make their children anxious and unwell. The parents and caregivers spoke about how the advice from the counsellors in the clinics motivated them to tell their HIV-positive children about their status. However, they lacked knowledge about when, how, and what information to disclose, as well as how to respond if the child is unable to manage the disclosure. The parents and caregivers expressed that they needed tools and support from healthcare teams to help them tell their children about their HIV status.

Another reason for non-disclosure, according to the parents and caregivers, was concern over the children's lack of secrecy regarding their HIV status, as well as concerns and fear regarding stigma and discrimination. The parents mentioned that their young children might accidentally expose their status to others through discussions because of their innocence and young age. Stigma and discrimination were often mentioned by the parents and caregivers as the primary reasons not to disclose their children's HIV-positive status to them. The way that society labels and excludes those who are HIV positive was of great concern to them and they felt that HIV-related stigma in the community was still at a high level.

The parents and caregivers' opinions were in congruent with Vreeman *et al*'s (2017:23) findings, which demonstrated that stigma and discrimination play a crucial role in determining the process and procedure of disclosure, as well as in parents', caregivers', and children's decision making and the effects of disclosing an HIV-positive status. Hayfron-Benjamin *et al*'s (2018:11) study also showed that although parents understood the importance of HIV disclosure, they chose to keep the information to themselves due to stigma related to HIV. This was interpreted as evidence that some parents and caregivers had disclosed information to their children partially or not at all.

6.2.3 What kind of assistance do parents and caregivers need in order for them to be fully equipped to disclose the status of their HIV-positive children to them in the Nkangala District in Mpumalanga? (Theme 3: Disclosure motivation and procedure)

In this study, the parents and caregivers had different justifications for disclosure and non-disclosure. Some factors, such as honouring children's right to know, the child's curiosity, or poor adherence to medication, forced those who had disclosed to do so. This was evident from the explanations they gave, such as their desire for the child to comprehend why they had to take the medication, their need for support from the child's immediate family, and their concern about the medication being questioned by the children. It appears that telling the children about their HIV status had a positive impact on how well the children used their medication. By explaining the children's HIV-positive status, the parents and caregivers helped the children to understand why they needed to take medication daily, the importance of taking charge of their own health, and the need for adherence to the medication.

A parent's ability to receive help in caring for their HIV-positive children can be strengthened by disclosing their HIV status to others, especially close family members or relatives. Instead of fully disclosing the child's illness, those who had practised partial disclosure mostly mentioned the medication the child needed to take. In general, people find it unpleasant to take medication if they are not physically ill or in pain. This may be the cause of the children's doubts about taking ARVs every day.

The parents and caregivers felt that because they knew their children better than anybody else, it was their duty to inform them that they had HIV. Some parents sought advice from healthcare teams on how to appropriately disclose the information to their children without harming them, despite the fact that most of them lacked the necessary expertise regarding the disclosure process. When asked to describe the details of their disclosure, some participants listed the following as the main points: the mention of germs to the child without mentioning HIV, the necessity of strict adherence to ART, and the mandate that their children keep their HIV status a secret due to the stigma associated with the condition.

It is evident from the above discussion that it is imperative that the healthcare sector in Mpumalanga must create a disclosure framework that considers contextual elements that either facilitate or hinder disclosure, such as age and maturity, in order to promote disclosure by parents of children living with HIV. The healthcare team, parents, and caregivers will receive clear instructions from this framework on when and how to tell children that they are HIV positive. It must outline the role that every interested party will play in the disclosure procedure. Furthermore, since stigma can have an impact on all aspects of a child's life, including disclosure, adherence, psychological wellbeing, and the burden of care, the South African National AIDS Council and the Mpumalanga Communicable Disease Control Programme should develop policies to lessen stigmatisation of children with HIV and their families. In addition, policymakers must develop and put into action measures to enhance the care given to parents and children living with HIV, particularly in the area of mental and psychological support for both groups. Accordingly, the study found that social workers, psychologists, and counsellors are essential in educating parents and children who have been diagnosed with HIV. As such, their roles should be reinforced in addressing some of the emotional challenges that may manifest as a result of disclosure. In order to address the issues facing parents and caregivers of children who are living with HIV, an integrated professional approach from healthcare teams is required.

6.3 CONTRIBUTION OF THE STUDY TO EXISTING KNOWLEDGE

Existing literature mostly focuses on the appropriate disclosure age based on the WHO's (2011) and DoH's (2016) guidelines, as well as the stigma surrounding adults who are living with HIV. This study's findings contribute to the literature by providing a nuanced understanding of parents' and caregivers' perspective of children's HIV-positive status disclosure in the rural township context as these are the spaces that have previously been neglected by researchers. It was important to pay attention to these spaces in order to gain a holistic understanding of the process of disclosure and how parents and caregivers navigate HIV-related stigma in their communities. Even though Goffman's (1963) theory was not originally based on HIV-related stigma, this study proved that the theory is relevant in understanding HIV-related stigma and that it advances our understanding of the theory by considering the stigmatisation of HIV-positive children in rural township spaces. While other researchers have used the theory, they used it to analyse the impact of HIV-related stigma on HIV-positive adults, without paying attention to the parents and caregivers of HIV-positive children and their experiences of stigma. Particularly, this study advances knowledge of how HIV-related stigma affects the parenting of HIV-positive children.

This study contributes to South African HIV health literature by offering a nuanced understanding of the needs of parents and caregivers regarding HIV-status disclosure to children, as well as their fears and barriers to disclosure. While there are guidelines in place on when to disclose the HIV status of children to them, there is a need for the healthcare sector to develop a practical disclosure framework that takes into account contextual factors that enhance disclosure, such as the correct information (practical tips) that needs to be conveyed during disclosure and emotional and psychological support for parents and caregivers before and after disclosure by a healthcare team. Furthermore, this study revealed that stigma serves as a significant obstacle to effectively managing HIV-status disclosure. It is therefore crucial to develop policies that are aimed at reducing stigma against children, parents, and caregivers. This approach will enhance the care and management required for children living with HIV and their families.

The study also contributes to the broader wellbeing of society by considering the experiences of a marginalised group, namely the parents and caregivers of children who are HIV positive. It can teach people and society how to engage and support parents and caregivers who are raising children who are HIV positive. From the narratives of the parents and caregivers it was gathered that it is not an easy journey and in conducting this research, the hope is to get people to understand so that they will be more sensitive to the needs of such children and the needs of their parents and caregivers.

6.4 RECOMMENDATIONS FOR FUTURE RESEARCH

Future research can expand on this study by considering healthcare providers' perspectives, as it appears that some parents sought their help, which aided them in disclosure to their children. While this study found that some children knew their HIV-positive status, the scope of the study did not allow for an exploration of the children's perspectives in terms of how they manage the disclosure of their HIV-positive status to other people, including friends and community members. As such, it is important for future research to focus on the perspectives of children who are aware of their HIV-positive status and how this awareness affects their daily lives and wellbeing. This study focused on black parents and caregivers in rural township communities; it is thus recommended that similar studies be conducted on parents and caregivers of other racial and ethnic groups to establish if their racial or ethnic background, including cultural traditions and religion, impact the experience of disclosing children's HIV-positive statuses to them. Additionally, future research can benefit from exploring how parents of different genders navigate disclosure since this study demonstrated that male and female parents did not agree on the age and processes that should be followed when disclosing a child's HIV-positive status to them. Intersectional understandings of children's HIV-status disclosure experiences are important since various intersecting identities, such as race, gender, religion, and cultural background, inform how disclosure in multiple spaces is navigated and negotiated.

6.5 RECOMMENDATIONS FOR HEALTHCARE PROVIDERS AND POLICYMAKERS

Firstly, healthcare providers should encourage, educate, and prepare parents and caregivers emotionally and psychologically for HIV disclosure to their children. As demonstrated by the findings of this study, parents and caregivers go through various challenges when it comes to making their children aware that they are HIV positive. Depending on how stigmatised HIV is in a particular location, there are various effects on the life of parents and caregivers. It is important to investigate and comprehend what parental and caregiver preparedness for the disclosure process entails. Understanding readiness is crucial since it influences when parents and caregivers tell their children that they are HIV positive. Assessing "readiness" can only be achieved through creating a supportive and friendly environment, such as support groups where caregivers and biological parents who are also HIV positive can deal with their own challenges before the actual disclosure to their children. There is also a need to design tools such as pamphlets and voice notes that can easily be shared via WhatsApp with crucial step-by-step practical tips on how to disclose HIV status to children and to seek the support of social workers and HIV counsellors to encourage and educate the public about the importance of HIV-status disclosure. These measures will ensure that parents and caregivers are aware of the significance of HIV-status disclosure to children.

Secondly, healthcare providers should ensure that parents and caregivers are able to deal with the obstacles and challenges that come with HIV disclosure. Various guidelines exist on when children and adolescents should be informed of their HIV status. Parents and caregivers must be encouraged to start the dialogue with their children as early as age six, and by the time they are 12, full disclosure should have been made (Kalembo *et al* 2018:34). There are no established tools available for parents and caregivers to comprehend and evaluate the idea of full disclosure. There is a need to develop an age-appropriate guideline booklet that clearly indicates the type of information to be shared during disclosure. Parents and caregivers need to be given an opportunity to express their worries, anxiety, and frustrations about telling their children that they have HIV. Furthermore, the support from community leaders, pastors, traditional healers, and community chiefs on dealing with stigma and discrimination experienced by people who are living with HIV and raising children who are HIV positive is mandatory. This measure will ensure a smooth process of HIV disclosure for parents and caregivers.

Thirdly, healthcare providers should establish a process of disclosure and ensure that parents and caregivers who are responsible for children follow the steps for HIV-status disclosure. Parents and caregivers must navigate the complicated and diverse psychosocial impacts of the disclosure process and procedures. It is important to determine what kind of assistance parents and caregivers will need before, during, and after disclosure and to customise that support for each individual family. Making arrangements for debriefing therapy for parents and caregivers before, during, and after they reveal their children’s HIV status to them will also be beneficiary. Creating a straightforward and easy uniform disclosure procedure for ART facilities will also be relevant. This intervention will ensure that the process of disclosure to children is understood and bearable for parents and caregivers who struggle with disclosure.

Finally, there is a lack of research on social and cultural contextual components. For this reason, it is necessary to modify the DoH’s (2016) and the WHO’s (2011) guidelines in order to take into consideration significant local, cultural, and social values that are linked to the sharing and handling of sensitive information pertaining to children’s lives. There is also a need to put in place quarterly initiatives that will monitor post-disclosure follow-up counselling to ensure that parents and children are coping. The past experience of parents and caregivers and assisting them to overcome those experiences need to be taken into consideration. Modelling positive behaviour for parents and children during and after disclosure and guiding the parents and caregivers on how to disclose without confusing the child are mandatory. These measures will help in ensuring that healthcare workers understand and execute their roles effectively.

6.6 LIMITATIONS OF THE STUDY

As opposed to a quantitative study, this study was solely qualitative. Twelve participants were assessed and the narratives in this study were limited to parents and caregivers and did not contain the perspectives of the children themselves. Furthermore, the study was conducted in one of the hospitals of Mpumalanga’s three districts; the findings therefore cannot be extrapolated to all districts, hospitals, or the country. Qualitative research provides researchers and participants with a great deal of freedom, but the presence of the researcher could also potentially influence the behaviour of the participants and therefore the study findings. Lastly, for the convenience of both the interviewer and participants, the interviews were held in the forensic boardroom at Middelburg Hospital. The researcher was perceived as a social worker, which may have led to overreporting of adherence in order to please the researcher.

6.7 CONCLUDING REMARKS

The main purpose of this study was to explore the psycho-social factors of disclosing an HIV-positive status to children between the ages of seven and 14 by their parents and caregivers. The results of this study call for the development of evidence-based, achievable recommendations to help parents and caregivers tell their HIV-positive children about their HIV status. The recommendations were outlined using the gaps identified with regard to HIV disclosure to children and the challenges and experiences of parents and caregivers regarding the disclosure of children’s HIV status. The study’s findings highlighted an urgent need for the standardisation of recommendations to aid parents and caregivers with HIV disclosure to their children. It was discovered that parents were unaware of the right age and type of information to express during disclosure. Policy guidelines and practical aids such as voice notes that can easily be shared through WhatsApp and social media platforms are required to assist parents and caregivers with HIV disclosure to their children. There is also an urgent need for clear directives on how to deal with stigma related to HIV in society.

The recommendations are intended to assist healthcare teams in facilitating and supporting parents' and caregivers' disclosure of their children's HIV-positive status to them. Following the completion of this study, these recommendations will be presented to the Mpumalanga DoH, Middelburg Hospital's management (the actual study location), and clinics where ARVs are distributed. The findings will also be disseminated by publishing the research findings or making presentations at relevant events such as workshops, support groups, and/or conferences.

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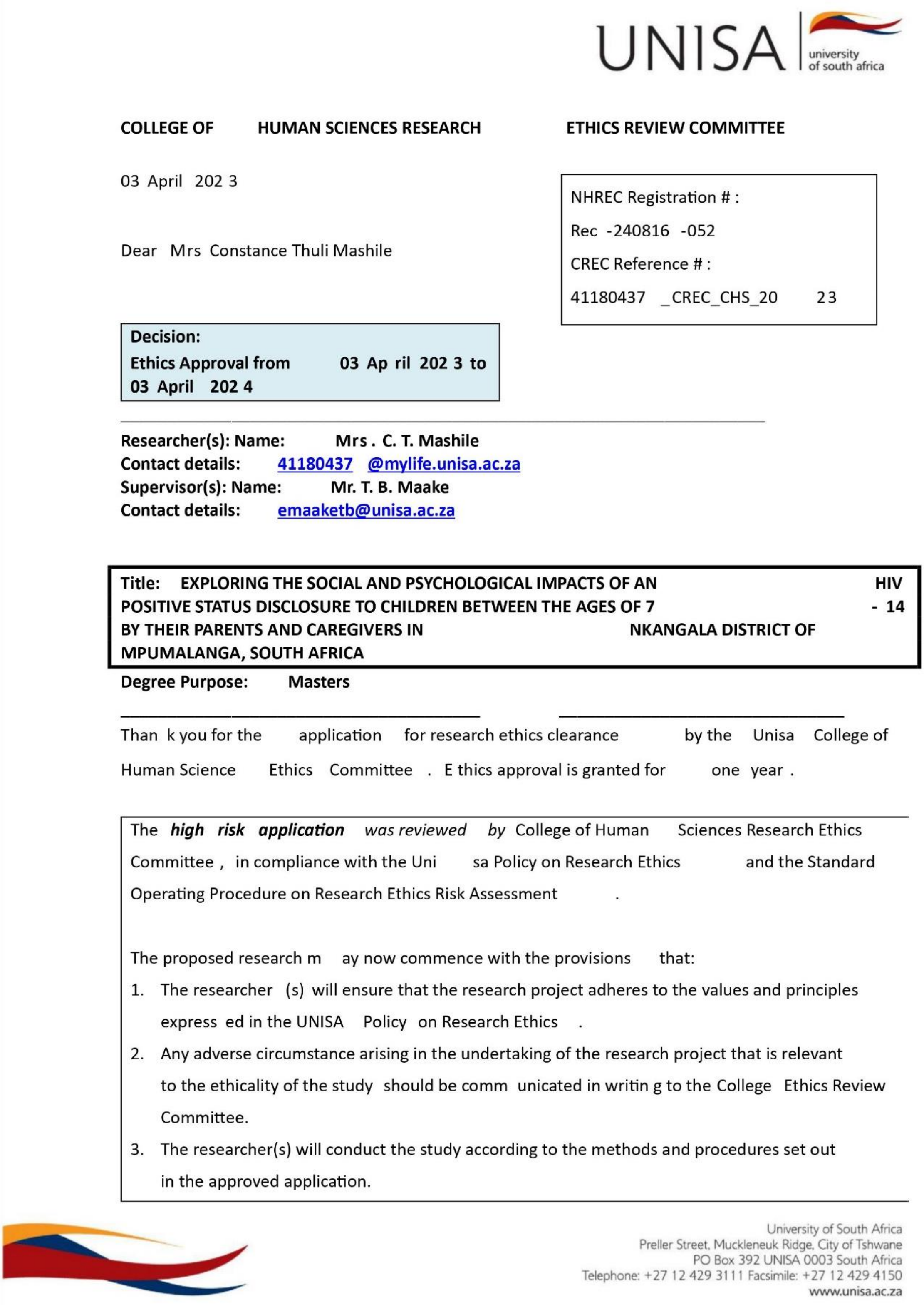
ANNEXURES

ANNEXURE A: ETHICAL APPROVAL FROM THE UNIVERSITY OF SOUTH AFRICA



COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

03 April 2023

NHREC Registration # :
Rec-240816-052
CREC Reference # :
41180437_CREC_CHS_2023

Dear Mrs Constance Thuli Mashile

Decision:
Ethics Approval from 03 April 2023 to 03 April 2024

Researcher(s): Name: **Mrs. C. T. Mashile**
Contact details: 41180437@mylife.unisa.ac.za
Supervisor(s): Name: **Mr. T. B. Maake**
Contact details: emaaketb@unisa.ac.za

Title: EXPLORING THE SOCIAL AND PSYCHOLOGICAL IMPACTS OF AN HIV POSITIVE STATUS DISCLOSURE TO CHILDREN BETWEEN THE AGES OF 7 - 14 BY THEIR PARENTS AND CAREGIVERS IN NKANGALA DISTRICT OF MPUMALANGA, SOUTH AFRICA

Degree Purpose: **Masters**

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for one year.

The ***high risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.

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PO Box 392 UNISA 0003 South Africa
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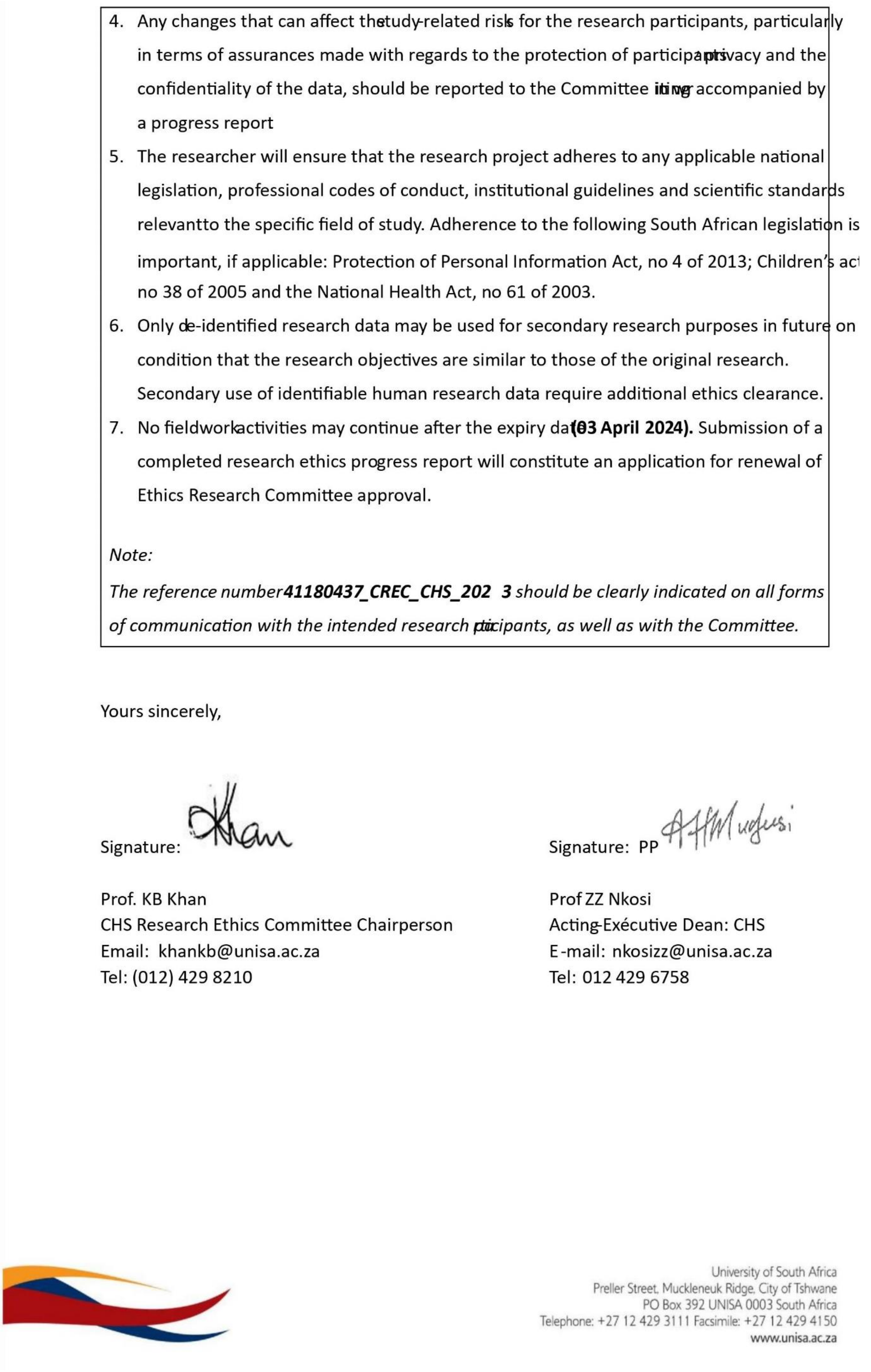
www.unisa.ac.za



4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing accompanied by a progress report
5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(03 April 2024).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

The reference number ***41180437_CREC_CHS_2023*** *should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature: Khan

Prof. KB Khan
CHS Research Ethics Committee Chairperson
Email: khankb@unisa.ac.za
Tel: (012) 429 8210

Signature: PP

Prof ZZ Nkosi
Acting-Executive Dean: CHS
E-mail: nkosizz@unisa.ac.za
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ANNEXURE B: REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN THE MPUMALANGA DEPARTMENT OF HEALTH

Request permission to conduct research Mpumalanga Department of Health (MDOH)

The Research Manager
Department of Health
Nelspruit
1200
Date: 02 March 2023

Dear Sir /Madam

Re: Requesting authorization to carry out research: Student number: 41180437

I Ms. Connie Mashile persal number 82203326, requesting approval to carry out a research study at the Wellness Clinic at Middelburg Hospital. I am currently working for the Department of Health -Mpumalanga stationed at Middelburg hospital Social Work Department as a Social Work Supervisor. I'm studying towards a Master's degree in Social behavioral studies in HIV and Aids with UNISA under the supervision of Mr. Tshepo Maake.

My study is entitled "Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa"

I will be interviewing 12 parents and caregivers of children who are on ARV treatment at Middelburg Wellness clinic. I am enclosing my copy of the research proposal. I will appreciate your timeous responses as your permission is one of the requirements for ethical approval of my proposal.

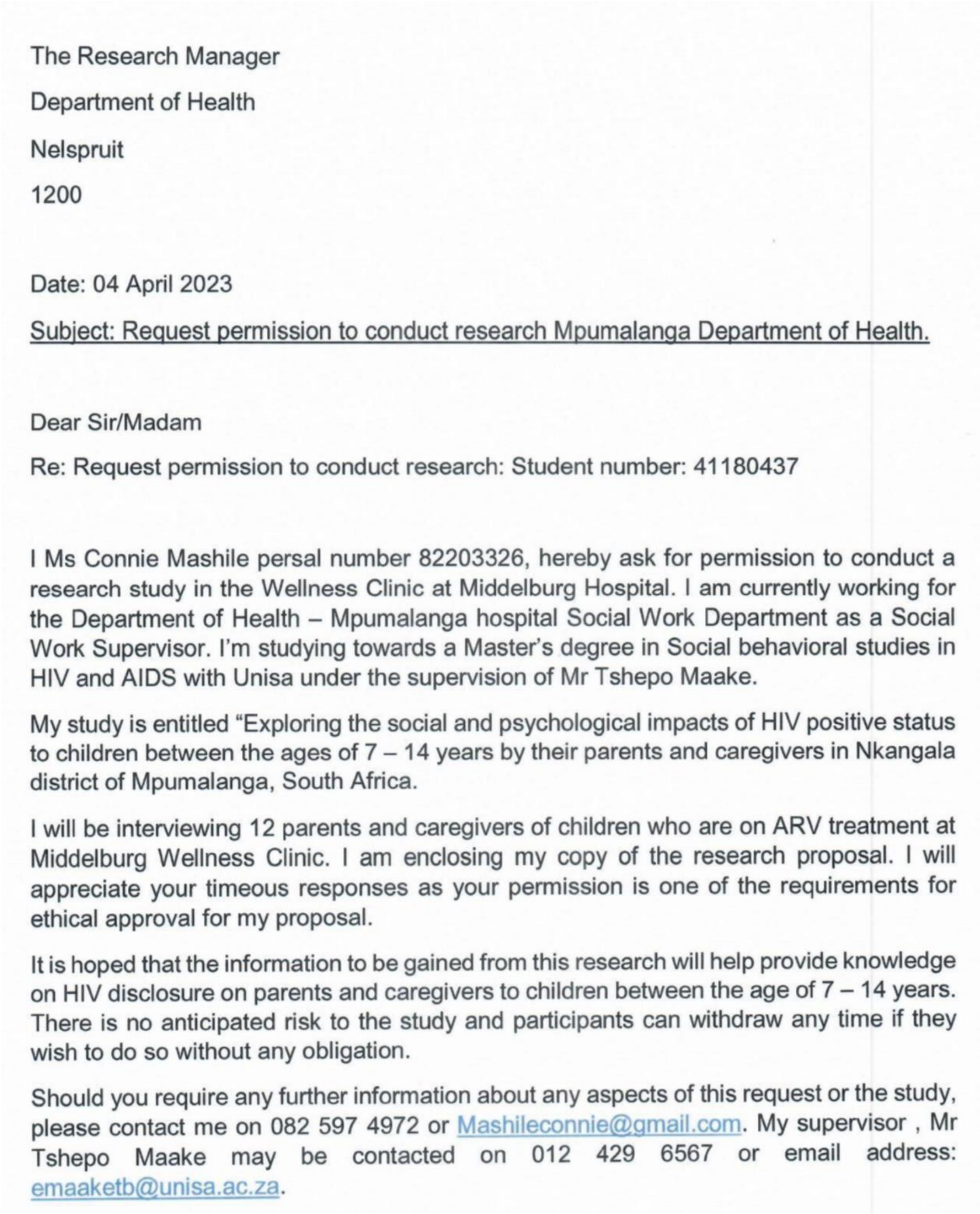
I anticipate that the information to be gained from this research will aid in supplying knowledge on HIV disclosure on parents and caregivers to children between the age of 7-14. There is no anticipated risk to the study and participants are under no obligation to continue participation and may withdraw at any moment.

Should you require any further information about any aspects of this request or the study, please contact me on 0825974972 or Mashileconnie84@gmail.com. My supervisor, Mr. Tshepo Maake may be contacted on 012 429 6567 or email address: emaaketb@unisa.ac.za.

Kind Regards,

Ms. Connie Mashile

ANNEXURE C: PERMISSION LETTER FROM THE DEPARTMENT OF HEALTH



The Research Manager
Department of Health
Nelspruit
1200

Date: 04 April 2023

<u>Subject: Request permission to conduct research Mpumalanga Department of Health.</u>

Dear Sir/Madam

Re: Request permission to conduct research: Student number: 41180437

I Ms Connie Mashile persal number 82203326, hereby ask for permission to conduct a research study in the Wellness Clinic at Middelburg Hospital. I am currently working for the Department of Health – Mpumalanga hospital Social Work Department as a Social Work Supervisor. I'm studying towards a Master's degree in Social behavioral studies in HIV and AIDS with Unisa under the supervision of Mr Tshepo Maake.

My study is entitled "Exploring the social and psychological impacts of HIV positive status to children between the ages of 7 – 14 years by their parents and caregivers in Nkangala district of Mpumalanga, South Africa.

I will be interviewing 12 parents and caregivers of children who are on ARV treatment at Middelburg Wellness Clinic. I am enclosing my copy of the research proposal. I will appreciate your timeous responses as your permission is one of the requirements for ethical approval for my proposal.

It is hoped that the information to be gained from this research will help provide knowledge on HIV disclosure on parents and caregivers to children between the age of 7 – 14 years. There is no anticipated risk to the study and participants can withdraw any time if they wish to do so without any obligation.

Should you require any further information about any aspects of this request or the study, please contact me on 082 597 4972 or Mashileconnie@gmail.com. My supervisor , Mr Tshepo Maake may be contacted on 012 429 6567 or email address: emaaketb@unisa.ac.za.

Kind Regards.

Ms Connie Mashile

CMashile
04/04/2023

[✓ RECOMMENDED]/NOT RECOMMENDED:

DR ML NTULI

SENIOR CLINICAL MANAGER MIDDELBURG HOSPITAL

05/04/203

APPROVER:

MR ME MODISE

CEO MIDDELBURG HOSPITAL

06/04/2023

ANNEXURE D: NURSE'S INFORMATION LETTER

"Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa"

Dear Sister in charge

For my master's dissertation, I would like you to identify participants on my behalf. Participants should be the parents and caregivers of children on ART who are HIV positive and between the ages of seven and 14 years old. It is important that people voluntarily participate, as coercion of any kind is unacceptable. I have provided you a leaflet that you may display to the participants first. The following could then be stated in further detail:

> *A master's student interested in exploring the psycho-social factors of an HIV-positive status disclosure has asked me to recruit some participants on her behalf. The study is interested in the impacts you have in disclosing the child's HIV status. Your participation in this study is voluntary and you are free to withdraw from the study at any time should you feel uncomfortable. If you have any questions or enquiries about the study, you can contact the researcher on the number that appears on the pamphlet I have provided you with.*

Due to the sensitivity of this study, it is crucial to protect the confidentiality of the participants. I would therefore like you to sign the confidentiality form and return it to me.

I, ____________________________________ (full names), hereby solemnly swear that I will not share the names of any interested parties with any third parties.

_____________________________________ ______________

Signature Date

ANNEXURE E: INFORMED CONSENT FORM FOR PARTICIPATION

"Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa"

I, ____ (full names of the participant), hereby consent to take part in the research. I am aware that the interview will last between 60 and 90 minutes. I am aware that I will not receive compensation for taking part in the study, and as participation is completely up to me, I am free to stop at any moment with no repercussions. I am aware that any information gathered will be encrypted and kept in a secure location that only the researcher has access to.

Signature of participant ________________________________ Date _______________

ANNEXURE F: INFORMED CONSENT FOR RECORDING OF INTERVIEW

“Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa”

I, ____ (full names of the participant), voluntarily consent to take part in the study. I am aware that the interview will be recorded on audio tape, and I have no issues with this.

Signature of participant ______________________________ Date ________________

ANNEXURE G: PARTICIPANT INFORMATION SHEET

Dear Participant

My name is Ms Connie Mashile, a master's student at the University of South Africa (UNISA), student number 41180437, in the Department of Sociology. As part of my master's degree requirements, I am currently doing a study on HIV disclosure by parents and caregivers to children between the ages of seven and 14 in the Nkangala District in Mpumalanga, South Africa. The study seeks to explore the disclosure of an HIV-positive status to children by their parents.

You will need to make yourself available for the study at least once or twice, depending on your schedule. The interview will be audio recorded, and I will be taking notes as we speak. The interview will last between 60 and 90 minutes. The Forensic Department of the hospital will host the interviews. The collected data will be maintained in a password-protected Google Drive folder, and only myself and my supervisor, Mr Maake, will have access to it.

Your name and personal information will be protected during the confidential interviews through the use of codes. You will not receive any rewards from me because the study is optional. You will not suffer any consequences if you leave the study at any point. The data gathered will be utilised for the master's dissertation and for upcoming publications.

Please feel free to contact me on my cellphone number, 083 317 7867, or via email at mashileconnie84@gmail.com if you have any further questions or concerns about the study, either during or after it has been completed.

Thank you for your participation.

Kind regards

Ms Connie Mashile

ANNEXURE H: INTERVIEW GUIDE FOR PARTICIPANTS

"Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa"

Participant number:

Instructions:

Interviews will only commence after the participant read the informed consent and information sheet and the participant indicating that they understood and consented to be interviewed.

Section A: Demographic information

1. How do you define your gender?
2. What is your age?
3. What is your marital status?
4. Where do you stay?
5. What is your educational level?
6. What is your home language?
7. What is your employment status?

Section B: Describe the impact of non-disclosure and disclosure to children who are infected with HIV

1. What is your understanding of HIV-positive status disclosure to children?
2. How old is your child?
3. How long has your child been living with HIV?
4. When did you find out that your child is HIV positive and what was your reaction?
5. Does your child know about their HIV-positive status?
6. How did you tell them that they are HIV positive?
7. If you have not told them, how do you think they would react if you told them?

8. What kind of assistance do parents need when disclosing the HIV-positive status to their children?

Section C: What are the underlying factors for parents not to disclose the HIV status to their HIV-positive children between the ages of seven and 14?

1. Do you believe that it is necessary for HIV-positive people to disclose their status? Why or why not?
2. Tell me about your experience of raising and living with a child diagnosed with HIV.
3. Why have you not disclosed your child’s HIV-positive status to them?
4. What are your concerns about disclosing your child’s HIV-positive status to them?

Section D: Ideally, how should disclosure be conducted?

1. According to you, when is the best time to tell children about their HIV status?
2. What information do you think children would prefer to hear when a parent/guardian is revealing their HIV-positive status?
3. Do you think telling your child about their HIV status can affect their performance at school and how they interact with other children in a negative way?

Section E: What kind of assistance do parents need in order for them to be fully equipped to disclose the status of their HIV-positive children to such children?

1. Are you fully aware of the challenges that you might come across when disclosing to your child that they are HIV positive?
2. What kind of support do you believe can help you when disclosing your child’s HIV-positive status to them?
3. How important is support from family members and friends in disclosing your child’s HIV-positive status to them?
4. How important is support from social workers and counsellors in disclosing your child’s HIV-positive status to them?

Section F: Do you think is important for parents/caregivers to disclose their HIV status to children between the ages of seven and 14? Why or why not?

1. Why do you think children should know about their HIV-positive status?
2. How do you feel about telling the HIV status to your infected children?
3. What can you say to a parent(s) with an HIV-positive child about disclosure?

Section G: Are there any questions you would like to ask?

THANK YOU.

ANNEXURE I: CONFIDENTIALITY AGREEMENT FORM

This agreement is between:

Lead researcher: Mrs Constance T. Mashile (student no. 41180437)

and

Translator: Ms Nhlonipho T. Malaza

RESEARCH TITLE: Exploring the psycho-social factors of an HIV-positive status disclosure to children between the ages of 7-14 by their parents and caregivers in Nkangala District of Mpumalanga, South Africa

Summary of job description: Translation of spoken language and audio-recorded research interviews

I agree to:

- keep all the information shared with me confidential. I will not share or discuss the research information with anyone other than the researcher or the researcher's supervisor;
- keep all research information secure while it is in my possession;
- return all research information to the researcher when I have completed the task or upon request, whichever is earlier;
- destroy all research information regarding this research project that is not returnable to the researcher after consulting with the researcher; and
- comply with the instructions of the researcher about requirements to physically or electronically secure records that include password protection, a file, or use of secure electronic transfer of recordings through file sharing.

Nhlonipho		12/01/2023
(Name)	(Signature)	(Date)

I agree to:

- provide detailed directions and instructions regarding my expectations for maintaining the confidentiality of research information so that the translator can comply with the above terms; and
- provide oversight and support to the translator in ensuring that confidentiality is maintained in accordance with UNISA’s policy on research ethics.

Researcher: Mrs C.T. Mashile