(COMPLETED RESEARCH)

CAREGIVERS' PERCEPTIONS TOWARDS DISCLOSURE OF HUMAN IMMUNODEFICIENCY VIRUS POSITIVE STATUS TO CHILDREN LIVING WITH HIV AT MOHODI COMMUNITY IN THE LIMPOPO PROVINCE

by

MAKGAKGA BETTY NOKO

[redacted]

MINI-DISSERTATION

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DECLARATION

I, Makgakga Betty Noko hereby declare that the mini dissertation titled “caregivers’ perceptions towards disclosure of Human Immunodeficiency Virus positive status to children living with HIV at Mohodi Community in the Limpopo Province” is my original work. I further declare that the information derived from the literature has been duly acknowledged in the text and list of references provided.

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Makgakga Betty Noko Date

DEDICATION

I would like to dedicate this dissertation to my children who have been all behaved throughout my study times. To all my former classmates and tutor I will forever be indebted for your contribution.

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LIST OF ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
HIV:	Human Immunodeficiency Virus
C&A:	Child(ren) &/or Adolescent(s)
C&ALHA:	Child(ren) &/or Adolescent(s) Living with HIV/ AIDS
HCP:	Healthcare Providers
TREC:	Turfloop Research Ethics Committee
WHO:	World Health Organization

ABSTRACT

Background: the purpose of this study was to explore the caregiver's perceptions towards disclosure of human immunodeficiency virus positive status to children living with HIV at Mohodi community in the Limpopo province. Many children who are HIV positive grow up unaware of their HIV positive status, because caregivers are afraid or uncomfortable to inform their children about their positive HIV status. Evidence from some studies have identified non-disclosure of HIV positive status to children as one of the actors that lead to a delay in access to treatment. Therefore the study seek to explore caregivers' perceptions towards disclosure of HIV positive status to children living with HIV at Mohodi community in the Limpopo Province. The objectives of the current study were to discover the insights of caregivers towards disclosing the HIV positive status to their children living with HIV and to determine contributory factors to the delayed disclosure of HIV positive status to children living with HIV amongst caregivers at Mohodi community in the Limpopo Province.

Methods: The study used the qualitative research design. A qualitative exploratory descriptive design was used to reflect the naturistic perspective and to understand a phenomenon in a natural setting. Participants of the study were caregivers taking care of children who are living with HIV. The children who are unaware of their HIV status. Data was collected through in-depth interview with open ended questions, participants were interviewed one by one using an interview guide. The sample size was 10 participants which was determined by saturation of data. An audiotape was also used to record interviews with participants, and field notes were also taken during the interview. Data was analysed through Thematic Content Analysis.

Results: HIV disclosure to children is generally low, even among adolescents. Significant factors influencing disclosure include the child's age, the child's persistent questioning and caregivers’ perceptions of the child's ability to understand and cope up with HIV. The literature suggest that caregivers identify many barriers to disclosure within these settings, the most prominent being fear of stigma and of negative consequences for children's emotional and social well-being. In the midst of caregivers’ worries about disclosure and low prevalence of disclosure, there is only limited evidence to suggest how disclosure should be conducted. The study provide useful qualitative enquiry of how the caregivers at Mohodi village perceive the disclosure of HIV towards their children living with HIV.

Conclusions: The study revealed that the reasons for non-disclosure from caregivers is that they believe that the child is either not old enough or not ready to comprehend the meaning of their HIV positive status. Some are of the view that the children are not sufficiently mature to cope with their HIV positive status. Some believe that, their children would not keep their diagnosis private and therefore concerned that their children would be exposed to stigmatisation and discrimination in their communities and families. These concerns suggest that improved psychosocial support services could aid in the disclosure process, Social workers and health care professionals to work hand in hand to enhance referrals. There is a need for structured, evidence-based protocols, materials and guidelines for disclosure which will equip the caregivers with knowledge about HIV disclosure to their children living with HIV.

Keywords: Children, caregivers, disclosure, adherence, support

DEFINITION OF CONCEPTS

Caregiver: A parent, legal guardian or person responsible for providing care to the child. This includes the biological parents, adoptive parents, relatives who care for the child, foster parents and legal guardians (National Department of Health, 2016). In this study caregiver refers to biological parents, adoptive parents, relatives who care for the child, foster parents and legal guardians who has a child or caring for a child who is living with HIV at Mohodi community in the Limpopo Province.

Children: The United Nations Convention on the Rights of the Child (UNCRC) defines children as individuals under the age of 18 years (UNICEF). In this study children refers to anyone under the age of 18 years who is living with HIV and living at Mohodi community in the Limpopo Province.

Disclosure: Disclosure is a process whereby a child gains knowledge of his/her HIV positive status or his/her caregiver’s HIV positive status or a gradual process of giving children age-appropriate information regarding their illness (National Department of Health, 2016). In this study disclosure will be used as defined above by the National Health Department.

Human Immunodeficiency Virus Status: The ability to determine whether a person is HIV positive or negative through HIV testing. Being HIV-positive means someone has signs of the human immunodeficiency virus (HIV) in their bodies, discovered through an HIV test (Avert, 2020). In the study, the focus will be on whether the caregivers have made their children are aware of their HIV positive status.

Human Immunodeficiency Virus: World Health Organization (2021) defines HIV as a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). In this study the concept will be used as defined by WHO above.

Living with the Human Immunodeficiency Virus: It means that an individual has the Human Immunodeficiency Virus (HIV) which the human body cannot get rid of completely. Once an individual has HIV, they have it for life, but with proper medical care the HIV is controlled and the individual can live their normal life (Avert, 2020). In this study it will mean children who have tested positive for HIV and are living under the care of their biological parents, caregivers, foster parents and legal guardians.

Perceptions: The act of perceiving or the ability to perceive; mental grasp of objects, qualities, etc. by means of the senses; awareness; comprehension (Collins English Dictionary, 2020. Perceptions within the study will be used, as to how the caregivers view the concept of disclosure towards their children who are living with HIV.

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1. CHAPTER 1: GENERAL OVERVIEW OF THE STUDY

1.1. Introduction and background

Globally, 37.6 million people were living with human immunodeficiency virus (HIV) in 2020 with women constituting about 50% of new HIV infections and 1.7 million of the people living with HIV (PLWH) being children less than 15 years old. Although there is a global commitment to stop new HIV infections and ensuring that everyone with HIV has access to HIV treatment. Moreover, several people do not subject themselves to HIV testing for different reasons or they are children on HIV treatment. However, other people are not aware of their HIV positive status due to non-disclosure of their HIV positive status by their parents or caregivers or adoptive parents. Non-disclosure of HIV positive status to children interferes with HIV prevention, treatment, care and support services for children living with HIV (United Nation AIDS programme, 2021).

Although in 2020 about 84% of pregnant women with HIV worldwide received Antiretroviral Therapy (ART) to prevent transmitting HIV to their babies during pregnancy and childbirth to protect their own health, some children are still born HIV infected. This happens because the mothers had no access to ART or they did not enrol for Prevention of Mother to child transmission program (PMTCT). According to the World Health Organization (2020), 83% of children living with HIV are in the sub-Saharan Africa with 2.1 million children aged 0–14 years. Some countries in this region have not managed to roll out ART to all pregnant women. A total of about 320 000 (15%) of the children living with HIV in the sub-Saharan region are found in South Africa despite the programmes implemented in this country. The new infections, vertical transmissions and acquired immunodeficiency syndrome (AIDS) related deaths are still occurring at an unacceptably high rate in South Africa particularly among young people (Avert, 2020; UNAIDS, 2021). This is despite the programmes that have been implemented in South Africa to deal with the HIV epidemic and prevent vertical transmission include health education. Although a significant change has been observed, but South Africa has not managed to bring down the HIV infections to the levels of other Middle-income countries as would have been expected (Wong, Murray, Phelps, Vermund, & McCarraher, 2017; UNAIDS, 2019; Avert, 2020).

The history regarding the management of HIV epidemic and delays in the implementation of PMTCT and exclusive breastfeeding in South Africa, have been responsible for the challenges related to HIV in South Africa, particularly among children (Avert, 2020). The challenges related to these delays have created a new concern related to disclosure of the HIV positive status to children born with congenital HIV and those who acquired HIV during breastfeed from mothers living with HIV. It was confirmed that these mothers who defaulted or did not have access to antiretroviral (ARVs) and did not use exclusive breastfeeding to prevent transmission HIV to their infants (Avert, 2020). Many children who are HIV positive grow up unaware of their HIV positive status because caregivers are afraid or uncomfortable to inform their children about their positive HIV status. Evidence from some studies have identified non-disclosure of HIV positive status to children as one of the actors that lead to a delay in access to treatment. Non-disclosure of HIV positive status is also one of the most complex challenge facing adolescents who live with HIV/AIDS as some of them have been taking treatment unaware that they were actually on ARVs (WHO, 2019; Wong, Murray, Phelps, Vermund, & McCarraher, 2017).

Some studies conducted in low-and middle-income countries indicate low rates of disclosure to children about their HIV positive status estimated at about 38%, reported full disclosure to children in South Africa, ranges between 7.9% and 9.0%. Delaying the initiation of the disclosure process makes it an increasingly difficult process for the caregivers to inform the children about their HIV positive status. The reasons for these low rates of disclosure are not fully understood. However, they range from, caregivers believing that the child is either not old enough or not ready to comprehend the meaning of their HIV positive status. Some are of the view that the children are not sufficiently mature to cope with their HIV positive status.

Some believe that their children would not manage to keep their diagnosis private and therefore concerned that their children would be exposed to stigmatisation and discrimination in their communities and families. Some mothers living with HIV are of the view that their children will be angry with them for transmitting the virus and making them suffer, because of their mistakes (WHO, 2020).

Avert (2020) argues that non-disclosure of the HIV positive status to children by caregivers has negative impact on the children and the community health workers (CHWs) responsible for providing medication to these children on daily basis without telling them the reasons for giving them the medication. Furthermore, it also hampers the use of teachable moments to teach them about the diseases and living a healthy life with HIV (UNICEF, 2019). All these concerns could be dealt with by using the WHO Disclosure Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (WHO, 2020). These guidelines provide strong evidence that disclosure is central to the overall well-being of children and adolescents. They confirm the psychological and emotional benefits of disclosure to children living with HIV and adolescents, dispelling concerns that disclosure may cause harm (WHO, 2011; Mahlako & Madiba, 2012; Mutambo, Shumba & Hlongwana, 2019; Van Elsland, Peters, Grobbelaar, Ketelo, Kok, & Cotton et al., 2019).

Findings from some studies indicate that informing children about their HIV diagnosis can have positive psychosocial and clinical outcomes (UNICEF, 2019; Mutambo, Shumba & Hlongwana, 2019). Furthermore, it improves adherence to ARVs which is associated with increased survival rates, improved personal health maintenance, decreased psychological effects associated with accidental disclosure and improved HIV prevention (Kiwanuka, Mulogo, Haberer, 2014; Gyamfi Okyere, Enoch & Appiah-Brempong, 2017; Sarkar, Selvaraj, Krishnamurthy, Balasundaram & Lakshminarayanan, 2018). To achieve these, the disclosure of HIV positive status to young people is paramount. It must be safe and appropriate for their age in accordance with the WHO guidelines. This will ensure good physical, psychological and emotional outcomes. Hence the need for caregivers as trusted individuals in the life of their children living HIV to take-up the role to disclose to the children (UNAIDS, 2014; Montalto, Sawe, Miruka, Maswai; Jamieson & Kellerman, 2016; WHO, 2019).

Some researchers argue that the rollout of treatment to children highlight the need to address disclosure. They indicate that children living with HIV in all settings need to know their HIV positive status. They could be informed by their parents, caregivers, and healthcare providers if given permission to do so by the parents or caregivers. Delaying the initiation of the disclosure process makes it an increasingly difficult process for both caregivers and child. These have detrimental to the psychological and emotional well-being of the child and often result in conflicts between the children and parents, and the family at large (Mutambo, Shumba & Hlongwana, 2019; WHO, 2019). It is for these reasons that the researcher wants to conduct a study among caregivers regarding their perception towards disclosure of the children's HIV positive status to them.

1.2. Problem statement

There is a problem in many countries including South Africa where parents or caregivers delay disclosing the HIV positive status to their children that are living with HIV/AIDS. This problem often leads to delays in access to treatment, non-compliance and resulting in treatment failure. Moreover, the delay in disclosure of HIV positive status to children has harmful effects on the well-being of children living HIV. The World Health Organization (2020) has recommended that children living with HIV should be gradually informed about their HIV positive status from six (6) through to twelve (12) years of age with the aim of making them aware of their HIV positive status. By the time they reach adolescent stage, many caregivers and healthcare providers struggle to implement these recommendations (UNICEF, 2019). The biological parents, guardians, adoptive and foster parents are the ones responsible for telling children about their HIV positive status. UNICEF (2019) posits that parents postpone their role of disclosing HIV positive status to children to a point where children discover their HIV positive status on their own in unsafe manner.

Therefore, this discovery is received by parents in an unpleasant manner and can be dangerous to a child as it may result in family conflicts.

The researcher is currently employed as a Social Worker at Mohodi community in the Limpopo Province and is responsible for cases of non-disclosure. When investigating non-adherence among children living with HIV, the researcher discovered that it is most likely that children were not made aware of their HIV positive status. They discovered the condition on their own, which results in psychological harm upon the child. An increase in non-adherence to ARV among children at the above-mentioned community has been observed. This could be due to the delays in informing children about their HIV positive status. It is also not clear how caregivers perceive disclosure as their responsibility or are even aware of this role of disclosure and its importance in the lives of children living with HIV. It is therefore necessary to find out if they are aware and how they perceive this role.

1.3. Preliminary literature review

De Vos, Strydom, Fouche and Delport (2011) describe the purpose of literature as to provide up to date understanding of the subject and identifying significant issues that can lead to further research especially where there is a gap in current knowledge. This means identifying gaps in existing knowledge and practice, articulating the weakness of the arguments of a particular approach or previous studies. This study explored the relevant literature on caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to their infected children.

1.3.1. Disclosure HIV positive status to children

Disclosing HIV status has been a challenge since HIV was discovered, because of the effects it has on the person disclosing the HIV status and the effect on the people who are receiving the news. Although disclosing can be stressful, the love and support that may be received could empower the PLWHA and improve their self-esteem. However, some PLWHA had negative reception and stigmatisation from people they love because of disclosing their status. This has made disclosure to children much difficult among parents and caregivers.

1.3.2. Lack of skills to disclose by the caregivers.

From the literature reviewed, caregivers seem not be skilled on how to disclose the HIV positive status to their children living with HIV. UNICEF (2019) argues that caregivers have no clear guidance on how to disclose their status to children who are living with HIV. The World Health Organization (2020) stipulates that disclosure should be addressed by the health care workers to the caregivers immediately a child is born with HIV. This is expected to create readiness for caregivers to disclose the HIV positive status to the children and to know the age at which it is suitable to disclose to the child about the HIV status and the appropriate steps to take.

1.3.3. The importance of disclosure to the HIV infected children

The increased survival rate of children infected with HIV has made HIV positive status disclosure very important. Studies reveal that healthcare providers, parents, and other caregivers of HIV infected children in resource-limited settings believe that disclosure may have benefits, but they weigh the benefits against feared risks (Turissini, Nyandiko, Ayaya, Marete, Mwangi & Chemboi et al., 2013; UNICEF, 2019).

1.4. Research question

The main research question is: what are the perceptions of caregivers; towards disclosure of HIV positive status to their children living with HIV at Mohodi community in Limpopo Province?

1.5. Aim of the study

The aim of the study is to explore caregivers' perceptions towards disclosure of HIV positive status to children living with HIV at Mohodi community in the Limpopo Province.

1.6. Objectives of the study.

- To discover the insights of caregivers towards disclosing the HIV positive status to their children living with HIV at Mohodi community in the Limpopo Province.

- To determine contributory factors to the delayed disclosure of HIV positive status to children living with HIV amongst caregivers at Mohodi community in the Limpopo Province.

1.7. Research methodology

The qualitative research approach was used to conduct the study to obtain a deeper understanding of the caregivers' perceptions towards disclosure of their children's HIV positive status. Tuffour, (2017) states that qualitative research inquiries make it possible for the research to shed light on meanings that are not easily noticeable to get in-depth understanding of our social complexities.

1.7.1. Study design.

The study used an explorative descriptive design to describe the perception of caregivers towards disclosing the HIV positive status to children living with HIV at Mohodi community in the Limpopo Province. The research design is the plan for obtaining answers to the research questions and for handling various challenges to the worth of the study evidence (Polit & Beck, 2013).

1.7.2. Study Setting

The study was conducted at Mohodi community situated in Molemole sub-district: Capricorn district in Limpopo Province, South Africa. The area is located within Molemole Local Municipality which is in the Northeastern side of Polokwane (Limpopo Province).

1.7.3. Population of the study

The study population is comprised of caregivers caring for children living with HIV at Mohodi community and receive treatment at Mohodi clinic.

1.7.4. Sampling and sample size

Purposive sampling technique was used to select caregivers who are responsible for children living with HIV and did not disclose the HIV positive status to the children. A maximum of 12 caregivers were identified from the list provided by the Social Workers at Mohodi clinic. Only ten caregivers responded to the call to participate in the study.

1.8. Data collection tool

An interview guide was developed and used to collect data for the study. The interview guide was developed guided by other previous studies where questions were tested and accepted as credible and trustworthy for qualitative research.

1.9. Data collection approach

Appointments were made with the identified participants and face to face interviews were conducted at the clinic, in an environment where privacy was ensured.

1.10. Data analysis

Data analysis from in-depth interviewees followed the Thematic content six –step analysis. Themes and codes were developed. Chapter four contains details of the data analysis.

1.11. Trustworthiness

Measures to ensure trustworthiness included credibility, dependability, conformability, Authenticity, transferability to validate the findings.

1.12. Bias

The researcher avoided bias by using purposive sampling where participants can provide relevant in formation according to their experiences and knowledge.

1.13. Significance of the study

The findings of the study highlight gaps in the knowledge of caregivers about the importance of and their role in the disclosure of HIV positive status to children living with HIV at Mohodi community in Limpopo Province. The information gained could be valuable to the social workers when they plan intervention programmes for families and to ensure that disclosure of HIV status to children is not delayed until children learn about it from unreliable sources. The findings of the study regarding the contributing factors towards delay disclosure of HIV positive status to children living with HIV amongst caregivers' families could assisted to ensure that children know about their status and the responsibility they must take to safeguard themselves and others.

1.14. Format of the report

Chapter 1: Introduction

This chapter introduces the study area and provides the background of the study and the research problem in the study.

Chapter 2: Literature review

This chapter explores the literature review, focusing on local and global perspective of the study.

Chapter 3: Research methodology

This chapter focus on the Methodology used by the researcher in this study.
It included aims and objectives of the study, research approach, research design, sampling and population, data collection, data analyses and quality criteria.

Chapter 4: Data presentation, analysis, and interpretation of findings

This chapter will present the data collected, analysis of the data, and interpretation of the findings.

Chapter 5: Interpretation and discussion of findings.

This chapter presents the summary of findings based on the analysis of the data gathered from participants drawn from the findings, and the generated recommendations.

Chapter 6: Summary, Recommendations, Limitations and Conclusions

This chapter presents the summary of the entire study, recommendations, strengths, and limitations of the study.

1.15 Conclusion

The introduction and the background provide insight regarding the perceptions and experiences of caregivers caring for HIV positive children regarding disclosure of HIV status. Participants shared their concerns and their experiences regarding this phenomenon. The next chapter will focus on the full review of literature for the study. The chapters in this document are aligned as follows:

2. CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

The previous chapter dealt with the outline of this study. In this chapter, the literature was reviewed in line with the objectives of the study. A systematic review starting at international, continental, national and local levels was done to cover aspects related to disclosing HIV status. This challenge has been an issue since the arrival of this disease. This literature review chapter illuminates obtainable and current literature on caregivers' perceptions towards disclosure of HIV positive status to children living with HIV.

2.2. Historical overview of human immunodeficiency virus

(Corey, Gilbert, Jurask, Montefiori, Morris, Karuna , Edupuganti, 2021) postulate that AIDS was first identified in the United States in 1981. In 1984, three years after scientists identified AIDS, they discovered its cause which is he virus known as HIV (World Health Organization, 2019). Scientists believed that HIV comes from chimpanzees, in West Africa during the 1930s, and the virus was originally transmitted to humans through the transfer of blood during hunting (Moss, Bacchetti, 1989; Henrard et al. 1995 and Melhuish, Lewthwaite, 2018). Researchers estimate that about 100,000 to 300,000 people worldwide lived with HIV pre-1980 (Psomas et al. 2018; Green, 2019 and Dowd et al. 2020). It is believed that HIV-1, the most common form of the virus, was spread from chimpanzees to humans not later than 1930, during bush meat trading (Corey et al.2021)

The World Health Organization (2019) indicates that over the decades, the virus spreads through Africa, and to other parts of the world. However, the situation was different until the early 1980s, when rare types of pneumonia, cancer, and other illnesses were reported until the world became aware of HIV and AIDS (Kumar, Tanna, Shetty, and Stosor, 2020). The researcher posits that as time unfolds, some of the major events and discoveries in HIV and AIDS surfaced. The HIV, the virus that leads to acquired immunodeficiency syndrome (AIDS), remains the cause of one of the largest epidemics in the world today. Sub-Saharan Africa (SSA) remains the region most affected by the HIV epidemic. Almost three quarters (69%) of the 23.5 million people infected worldwide reside in this region. More countries in SSA report a generalized epidemic with pockets of concentrated epidemics in key populations. South Africa remains the country with over 6 million people reported to be infected with HIV. It was found that Swaziland has the highest adult prevalence rate of 26.5% followed by South Africa, Namibia, and Mozambique at 17.9%, 13.3% and 11.1% respectively (Ramjee and Daniels, 2013).

The HIV and AIDS were first reported in South Africa in 1983. A report in the South African journal described two cases of AIDS in the male homosexuals. In the early part of the epidemic in South Africa, HIV/AIDS was mainly associated with the homosexuals who were diagnosed with AIDS related opportunist infections. In most of Africa, AIDS first became apparent as an urban phenomenon in South Africa, but it spreads rapidly through to rural areas.

2.2.1. Disclosure of HIV positive status to children

A study conducted by Fauci, Redfield, Sigounas, Weahkee, and Giroir, (2019) indicates that identifying why PLWHA may or may not decide to disclose their HIV status is important if interventions that seek to promote safe disclosure decisions, positive disclosure outcomes and secondary prevention of HIV are to be effective. Furthermore, the researcher is of the view that understanding the reasons for disclosure and nondisclosure and how these reasons may differ depending on the recipient of the disclosure may be essential for tailoring intervention strategies. Yet most studies on HIV disclosure in Africa have focused almost entirely on the disclosure to spouses and sex partners, especially among women (UNICEF, 2019). Therefore, it is evident that few have examined disclosure of HIV clients (male or female) to others in the social network and how reasons for disclosure and nondisclosure may differ by the gender and age of the one disclosing, and the nature of the relationship to the recipient of disclosure.

Studies regarding HIV disclosure in Africa show that most people (approximately 80%–90%) have disclosed to someone, but more meaningful is whether someone is able to disclose to key members of their social network (Kalembo, Kendall, Ali, and Chimwaza, 2018). A review by Medley and others in the studies conducted in sub-Saharan Africa, found that disclosure rates to sexual partners ranged from 17% to 86%. The World Health Organization (2020) estimates that 52% of PLWHA disclose their status to their sexual partners in Africa. More recent studies of disclosure to sexual partners or spouses in Africa have reported rates ranging from 24% to 91%. In Uganda, the study by King and colleagues reported a disclosure rate of 62% to sex partners. Although limited, emerging data on disclosure to members of a person's social network other than spouses or sexual partners, such as family, children, and friends, indicate that rates of disclosure to these members of the network are much lower than disclosure to sexual partners (World Health Organization, 2020).

Approximately one third had disclosed to family or relatives, In Ethiopia and only 6% to children and 7% to neighbours. Evidence is beginning to emerge that there are different rates of disclosure across different segments of a person's social network, and men and women may differ regarding to who they disclose to (World Health Organization, 2020). For example, HIV-positive parents did not disclose as much to their children as they did with other adults. In Uganda, King et al. (2019) noted that men were most likely to disclose their status to their sexual partners and brothers, while women were more likely to disclose their status to their sisters. Similarly in Kenya, established that men were more likely to disclose to their wives than other family members, while women were more likely to disclose to family members.

Women preferred to disclose to female network members who were believed to also be HIV positive (World Health Organization, 2020). However, establishing gender disparities is complicated by the fact that the above-mentioned studies were either female specific or women constituted the bulk of the respondents. From a Public Health perspective, HIV disclosure has been advocated primarily because of its contribution to reduced risk of HIV transmission as disclosing HIV status, especially to one's sexual partner, encourages the partner to engage in preventive behaviours such as condom use and HIV testing (Avert 2020).

HIV disclosure is also thought to contribute to reduction of HIV stigma in the community and enhance awareness as well as the importance of HIV prevention. Conversely, community support especially from groups of PLWHA is thought to encourage disclosure of HIV status to family members (UNICEF, 2019). Those who are self-focused, also have the need for social support, which is often the reason for disclosing to family members; deterioration of physical health and the need to access medical care and treatment; the need for spiritual support, which is often associated with disclosing to pastors; the nature of the relationship, especially with one's spouse; and the need to be understood by others, which is often associated with disclosure to family and friends (World Health Organization, 2020).

Those who are other-focused, include whether the disclosure target is believed to be HIV positive; concerns about how the disclosure target will respond to the information; and the desire to protect others from contracting HIV, especially in disclosure to spouses and to children (Avert, 2020). While there are many advantages to, and reasons for disclosing one's status, there are also risks and reasons for deciding not to disclose (Miller and Rubin, 2018). The researcher is of the view that most of these reasons, relate to the negative aspects that may potentially arise from disclosing one's HIV status. These include fear of discrimination, anticipated disruption of relationships or even abandonment, fear of emotional and physical abuse, and to avoid stigma. The predominance of these themes is in part attributed to most studies that focused on women and disclosure to spouses (UNICEF, 2019). Less is known about reasons for nondisclosure to other social groups such as children, relatives, and friends. In this study, we explored the reasons why PLWHA in care decide to disclose or not disclose their HIV status, and how these reasons vary by gender and age, and the nature of the relationship to the person being disclosed to (World Health Organization, 2019).

Disclosing HIV status has been an issue since the discovery of this disease, because of the effect it has on the person disclosing his//her HIV status and the effect on those that the People Living with HIV/AIDS (PLWHA) is disclosing to (Wu, Chen, Scott, & McGoogan, 2019). Although disclosing can be stressful, the love and support that may be received could empower the PLWHA and improve their self-esteem (Melhuish and Lewthwaite, 2018). However, some PLWHA have received negative reception and stigmatisation from people they love by disclosing their status. This has made disclosure to children much difficult among parents and caregivers.

The fear of seeing their children not be accepted by other people and children including family members has caused delays in disclosing the HIV status of children to the children living with HIV but continue giving them ARTs (Turissini et al., 2013). There is a need for caregivers to be provided with general guidance on the process of disclosure for HIV status to their children with the support of healthcare workers where needed (UNICEF, 2019). It is important for caregivers who have disclosed the status to their child to share their experiences with those that are still contemplating to disclose the HIV positive status to their children. Many care givers who have disclosed the HIV status to their children experience less depression compared with those who did not. Disclosure tends to have positive impacts to the child, caregiver or parents, and the family (Glaser, 2016).

According to Osingada, Okuga, Nabirye, Sewankambo and Nakanjako (2017), there are many barriers that prevent caregivers of children living with HIV from disclosing to their children the positive HIV status. The following are some of the barriers indicated: perceptions that children are too young to understand what HIV infection means, fears of secondary disclosure by the children, the children might get scared, cry and fear of rejection and blaming of the caregiver.

Osingada et.al. (2017) also argue that when children know their status, they become adherence to medical care and become helpful in the household. In their view it is important that each country develop their own guidelines that will assist parents and caregivers to improve the process of parental HIV disclosure to their children living with HIV and how to deal with the immediate psychological challenges associated with the disclosure (Osingada et al., 2017).

Fauci, Redfield, Sigounas, Weahkee, and Giroir, (2019) argue that the introduction of ART for the treatment of HIV infection has dramatically reduced the number of HIV-associated deaths. In 2019 about 24.5 million people had access to ART. The statistics indicates that in 2018, 62% of all people living with HIV were accessing treatment and 54% of them were children aged 0-14 years having access to treatment. Also 82% of pregnant women living with HIV had access to ART through the prevention of mother-to-child transmission programme to prevent transmission of HIV to their children in 2018 (UNAIDS, 2019; Avert, 2020). Disclosure involves giving children age-appropriate information regarding their illness, ideally progressing to full disclosure of their HIV infection when the child has the cognitive, emotional, and psychological maturity to process this information (UNICEF, 2019).

There is a clear relationship between age and disclosure, with older children (11-17 years) more likely to know their HIV positive status (WHO, 2020). The South African National Department has on several occasions committed to prioritise support and guide primary caregivers and health care assistance for disclosure to children living with HIV (National Department of Health, 2016). Disclosure should be an on-going process, one that takes account of the readiness of the caregiver and family and the developmental level of the child, along with input and guidance from the healthcare worker, as appropriate and as needed. Disclosure should not be seen as a one-time event; rather it is a process that begins before the child knows the term HIV and continues with on-going support even after full disclosure of HIV positive status has occurred (World Health Organization, 2020; UNICEF, 2019 & Fauci et al., 2019).

With the advent of antiretroviral therapy (ART), people living with HIV and AIDS (PLWHA) can now plan to live, instead of planning for death (UNICEF, 2019). As HIV becomes more of a chronic disease and PLWHA live longer, disclosure of HIV status is encouraged to reduce sexual risk behaviour and transmission of the virus, decrease stigma associated with HIV, and increase access to support and care (World Health Organization, 2020). However, there are also several potential negative consequences associated with HIV disclosure such as domestic violence and abuse, abandonment, and discrimination, which can serve as viable reasons for nondisclosure (Avert, 2020).

2.2.2. Lack of skills to disclose HIV status by the caregivers.

Caregivers may not be skilled on how to disclose the HIV positive status to their children living with HIV. UNICEF (2019) argues that caregivers have no clear guidance. While studies have looked at background, views, what is disclosed and the effects of disclosure, beyond recognizing its challenges, is little understood. However, the World Health Organization (2020) stipulate that disclosure should be addressed by the health care workers to the caregivers immediately a child is born with HIV. This should assist the care giver to prepare and know that at what age is suitable to disclose to the child about their positive HIV status and what are the appropriate steps to take. The literature reviewed revealed that non-disclosure is one of the causes of many deaths amongst children and the adolescents due to non-adherence to treatment. The literature also revealed that even though the caregivers are aware of the advantages and disadvantages of disclosure they are still not comfortable to disclose. Capacity building on disclosure to care givers should be given priority, they could be knowledgeable but without creating an enabling environment as one of the principal areas of health promotion embedded in Ottawa charter and the implementation plans, caregivers might never utilise and apply the knowledge they have about disclosure.

2.2.3. The importance towards disclosure to the HIV infected children

The increased survival rate of children infected with HIV has made HIV positive status disclosure very important. Studies reveal those healthcare providers, parents, and other caregivers of HIV infected children in resource-limited settings believe that disclosure may have benefits, but weigh these against feared risks (Turissini, Nyandiko, Ayaya, Marete, Mwangi, Chemboi, Warui, and Vreeman, 2013 and UNICEF, 2019). They also believe that disclosure could lead to better ART adherence improve the child's long-term HIV care or equip children to better protect themselves and others by preventing HIV transmission. However, caregivers fear that the child will subsequently disclose their HIV positive status to others resulting in stigma and social isolation. They also worry that disclosure will negatively impact the children's psychological or emotional health (Turissini et al., 2013).

2.2.4. Psychological Effects

Due to the psychological implications of disclosure to the child, caregivers may be reluctant to reveal the child's HIV status. As indicated by Turissini et al. (2013) this is their own way of protecting the child from harmful negative reactions and psychological disturbances. In a study by John-Stewart, Wariua, Beima-Sofie, Richardson,Farquhar, Maleche-Obimbo, Mbori-Ngacha, Wamalwa, (2019) involving already-hospitalized children, parents' reasons for nondisclosure hinged on their fears that knowledge of HIV status might worsen the child's condition. The researcher supports the above-mentioned sentiments that at times the knowledge of HIV status might worsen the child's condition due to circumstances such as acceptance and the awareness of HIV status. The inability of children to keep a diagnosis to themselves was given as a reason for nondisclosure in several studies (UNICEF, 2019). This was also attributed to the child's age. Caregivers felt that, due to the vulnerability of the child at that age, they might openly discuss their HIV status with peers, friends, schoolmates, or the community at large (World Health Organization, 2019).

It is well known that HIV patients are discriminated against and stigmatized in society. As a result, caregivers would not want their children to be faced with these negative societal reactions. Hence, the reason for non-disclosure to the children, as observed in the following studies (UNICEF, 2019). Heeren et al. (2017) observed that the ripple effect of stigmatization of the child could lead to isolation, fear of blame, guilt, and gossip. Murnane, P.M.; Sigamoney, S.L.; Pinillos, Shiau, Strehlau, Patel, Liberty, Abrams, Arpadi, Coovadia, (2018) observed that another adult living in the same household as the caregiver and the child who was unaware of his or her status made it more challenging for the caregiver to disclose disease status to the child for fear of the child spreading the news, which might lead to stigmatization.

2.2.5. Insufficient Knowledge of the Caregivers

Research shows that insufficient knowledge and skills among caregivers were a hindrance to disclosure (Melhuish, Lewthwaite, 2018; Wu, Chen, Scott, and McGoogan, 2019). It was observed that most of the caregivers had limited knowledge and expertise on how to disclose HIV status to a child. Paintsil, E.; Renner, Antwi, Dame, Enimil, Ofori-Atta, Alhassan, Ofori, Cong, Kyriakides, (2018) pointed out that the literacy level of the caregiver was another factor that affects disclosure of the HIV status to children. Caregivers who had a higher level of education were more likely to reveal the child’s status and those with less knowledge were most likely not to reveal (UNICEF, 2019). Basic knowledge about HIV/AIDS appears to be limited in African countries. For example, in a study from Nigeria, only 15% of people surveyed were able to describe HIV/AIDS as a deadly disease and 69% of young women from Burkina Faso were aware that AIDS was deadly (World Health Organization, 2020). Many African women incorrectly believe that AIDS can be cured (UNICEF, 2019). Most African people are aware now that HIV can be transmitted through unsafe sex (Corey, Gilbert, Juraska, Montefiori, Morris, Karuna, Edupuganti, Mgodi, deCamp, Rudnicki, and Huang, 2021).

The home-based care guidelines in South Africa stipulate comprehensive knowledge requirements for home-based caregivers on HIV/AIDS. This is useful at the community level, including, the basic information on HIV/AIDS, and the definition of HIV as Human Immunodeficiency Virus (UNICEF, 2019). The modes of transmission are clearly stipulated, ranging from unprotected sexual intercourse, transmission through blood transfusions and contaminated instruments such as needles and skin-piercing instruments, as well as transmission from an infected mother to her child (World Health Organization, 2020). Therefore, the home-based caregivers should be able to differentiate HIV from AIDS. The knowledge about the importance of an HIV test, the meaning of HIV positive and negative results, opportunistic infections, basic nutrition for an HIV/AIDS person, and positive living can assist the caregivers to take an informed decision regarding the disclosure of HIV status to children.

The knowledge and practices of home-based caregivers play a vital role in mobilising communities to access healthcare services for information on HIV/AIDS and treatment (Paintsil, Renner, Antwi, Dame, Enimil, Ofori-Atta, Alhassan, Ofori, ICong, and Kyriakides, 2018).

Hayfron-Benjamin, A., Obiri-Yeboah, Ayisi-Addo, Siakwa, and Mupepi (2018) observed that, because caregivers are not open to discuss sex with the children, for fear of being asked how they got infected, they might decide not to disclose the child's status.

2.2.6. Factors that Promote Disclosure

It was observed that the advancing age of the child was a key motivation for caregivers to disclose disease status. Most caregivers preferred to disclose the HIV status to older children because they believed they would understand the nature of the diagnosis and keep it secret (UNAIDS, 2021). Murnane et al. (2016) observed that the number of children whose status had been disclosed to them increased with increasing age (UNICEF, 2019). This was corroborated by Meless, Aka-Dago-Akribi, Cacou, Eboua, Aka, Oga, Bouah, Eugene, Moh, Arrive, (2019) and Alemu et al. (2020). Being on ART was observed as a reason for disclosure of the child’s status. This was observed in (World Health Organization, 2019). Alemu, Berhanu and Emishaw, (2017) observed that disclosure status in children increased with the length of time on ART (UNAIDS, 2019). This is supported by Meless et al., (2020) who observed that HIV disclosure was significantly higher in adolescents with a history of ART treatment (UNICEF, 2019).

2.2.6.1. To Promote Adherence

Promoting adherence to HIV treatment was also cited as a main motivation for caregivers to disclose the child’s status to them. Since the HIV positive children should stay on the ART medication for the rest of their lives, caregivers believe that promoting adherence to treatment is prudent to disclosure of the child’s status to them with the hope that they will adhere to medication regimen (World Health Organization, 2020). This notion was also supported by John-Stewart et al. (2019) and Montalto et al. (2018).

On the contrary, Kallem et al. (2017) observed that the lack of adherence to ART was a motivation for disclosure of the child’s status. Though caregivers’ reason for disclosure of HIV status to. Children was promote adherence Newman, Kamgaing, Nduwimana, Obama,Bukuru, Kariyo, Niyongabo, Mbaya, Mukumbi, and Akam, (2016) observed that there was no association between disclosure of status and ART adherence.

2.2.6.2. Enquiries by HIV positive children

The children’s quest to know why they are constantly falling sick and have to take medication, was part of the reason why some caregivers opted to disclose the

HIV status to the children (UNICEF, 2019). Some studies observed that when a child asks questions or becomes curious about the condition, that is a motivating factor for HIV status disclosure (Wong et al., 2017; Van Elsland et al. 2019 and UNAIDS, 2019). A caregiver describes how a child kept asking questions about his illness and constant intake of medication as he was growing up. Acts of this nature prompted caregivers to disclose a child's status. There were other factors associated with disclosure in some of the studies. The religion of the caregiver, the caregiver being a family member, the frail health of the child, the level of education of the child, the death of the biological father, improved immunological status, someone in the child's school having knowledge of his or her status, adherence crisis, and the importance of medication were among the factors cited.

2.2.6.3. Timing of Disclosure

Timing of HIV disclosure is an important component in the management of children living with the disease. Abebe et al. (2018) observed that most caregivers delayed disclosure until children were much older because some of them believed that the children were too young to understand, would share the information with others, and would suffer negative emotional consequences at a younger age. Most caregivers agreed that HIV status should be disclosed to children much later, between the ages of six and 20. This was corroborated by Madiba et al. (2017), Kallem et al. (2011) and Heeren et al. (2012). Alemu et al. (2017) also observed that most caregivers preferred to delay the disclosure until the child was 10 or older. This assertion was also observed by Myer, Moodley, Hendricks, and Cotton (2006).

Dusabe-Richards, Rutakumwa, Zalwango, Asiimwe, Kintu, Ssembajja, and Seeley, (2016) observed that children whose status was disclosed to them were able to take control of their healthcare, visiting a health facility unaccompanied and ensuring that their medications were taken regularly and on time, they communicated freely about their physical health, and were able to ask questions and access help from caregivers. Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal, and Ross, (2014) observed that disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. Hejoaka (2009) also observed that HIV status disclosure to children helped them to develop strategies to conceal the medicines and the disease. Mburu et al. (2014) postulate that disclosure of HIV status lead to children becoming anxious, depressed, and blaming themselves, and occasionally creates strained adolescents' sexual relationships.

Parents'/caregivers' decision to disclose or not disclose children's HIV status hinged on the age of the child. Caregivers feared the psychological implications of disclosing HIV status to children, and worried that young children might reveal the diagnosis to others, which could lead to unwarranted discrimination (UNICEF, 2019). As such, it is observed that the prevalence of disclosure to younger children is much lower than that of the older children based on literature.

A study conducted by Simelela and Venter (2014) found that caregivers believe that delaying disclosure until the child was much older would help the child accept the diagnosis and keep it a secret. This assertion is corroborated by a study by Oberdorfer, Puthanakit, Louthrenoo, Charnsil, Sirisanthana, and Sirisanthana, (2006) it was observed that caregivers preferred to delay disclosure because due to fear of negative emotional consequences for the children and that the children might not be able to keep it a secret, but they were ready to disclose the child's status when the child was much older. Kouyoumdjian et al. (2018) also observed that caregivers were concerned that if the children knew the HIV status, they might tell other people in the community, which would lead to stigma and discrimination towards the child and family.

HIV status disclosure to children has its merits as well as demerits, as observed in this review. Most of the findings reported that children whose status was disclosed to them took charge of their own care. There was an improvement in medication adherence and a reduced risk of HIV transmission to others, and they could communicate freely about their health and seek help from caregivers when necessary. This assertion is supported by the study conducted by Vreeman et al. (2021) whose findings revealed that HIV status disclosure to children improved ART adherence, children's well-being, and their social relationships. They also developed strategies to conceal their status from persons whom they felt should not know about it. Disclosure also brought relief to caregivers/parents, who often had to provide alternative, misleading answers to questions posed by the affected children. However, disclosure also had a negative effect on children who got to know their status either through caregivers/parents or accidentally through healthcare providers or other family members. Some were furious for a time, while some felt anxious, and others became depressed. This agrees with the findings by (Okawa et al., 2018).

2.3. Summary of the chapter

This chapter dealt with the literature that was reviewed, comparing the findings, outlining differences and similarities from previous studies. The literature was reviewed in line with the aims and objectives of the study. This mini-dissertation focus on the magnitude of issues of caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to children living with HIV. The following chapter will explore the research methodology used for this study.

3. CHAPTER THREE: RESEARCH METHODOLOGY

3.1. Introduction

Research Methodology encompasses the way one intends to carry out the study (Salmons, 2021). This section brings to the fore the qualitative research methodology that was used to carrying out this study. The key discussions centre around the aim, , objectives, and the research approach, of the study.

3.2. Research design

The research design is the plan for obtaining answers to the research questions and for handling various challenges worth to the study evidence (Polit and, Beck, 2013). An exploratory descriptive design was used to reflect a naturalistic perspective and to understand a phenomenon in a natural setting, emphasizing the exploration of ascribed meaning from individuals who are involved. Such an approach offers a rich description of a phenomenon about which little is known.

According to McCombes (2019), an exploratory descriptive research design aims at accurately and systematically describing a population, situation or a phenomenon. Moreover, it can use a wide variety of research methods to investigate one or more variables. Descriptive research was found fit for the study because it helps and allows the researcher to answer what, where when and how questions. According to Hancook, Algozzine, and Lim (2021), a descriptive design assists and allows the researcher to describe, analyse and interpret the research findings. The selected design was found relevant to explore and describe perceptions of caregivers in relation to the disclosure of HIV status to the children living with HIV.

3.3. Study Site

Study setting refers to the place and condition or circumstances where and within which the research study takes place (Pilot and Beck, 2012). The study was conducted it Mohodi community situated in Molemole Sub-District: Capricorn District. The village is 10 kilometres away from Dendron community and 74.4 kilometres from

Polokwane City. The area is located within Molemole Local Municipality which is located in the Northeastern side of Polokwane, Limpopo Province. The majority of the people are Africans (98.1%) with a minority of whites and Indian population (Census, 2011). Mohodi community is 3347km^2. Mohodi has nine villages, namely Fatima, Sekakeng, Mohodi Newstands A to D, Maponto and Madikana. Job creation and poverty alleviation remains an important challenge to be addressed. The population of Mohodi is under the King Manthatha, they come from Botlokwa and relocated to Mohodi in 1977.

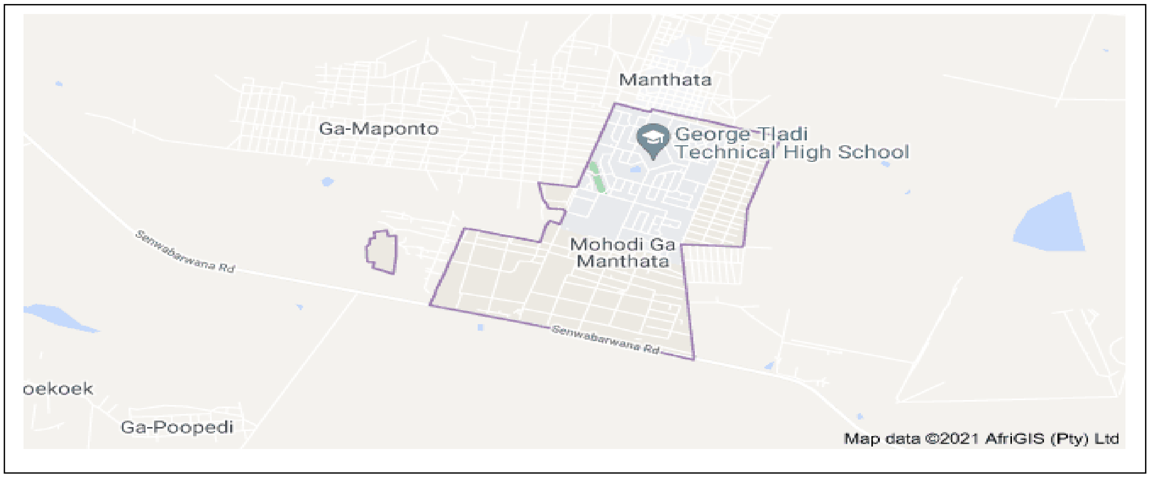

Figure 1: Showing Mohodi community in Limpopo Province Source: Maps (2021) from Molemole Municipality Website.

Mohodi community has one clinic that services all the villages making the clinic always overcrowded. There are five social workers in Mohodi community who work with caregiver's including the biological parents, foster parents and relatives taking care of children living with HIV.

3.4. Population

The population refers to an aggregate or totality of all the objective, or members that conform to a set of specification (Polit and Beck, 2013). The population of this study includes all caregivers caring for children living with HIV at Mohodi community and receive treatment at Mohodi clinic. The researcher was aware that there is a list of children, their caregivers' names and contact details which consist of 87 children from the clinic records and 67 caregivers and foster parents at social workers' offices attached to the clinic. The list was used to identify caregivers who have not disclosed the HIV positive status to their children. This information is readily available at the researcher's workplace where families and caregivers are assisted to disclose the children's HIV positive status to their family members and those close to them.

3.5. Sampling Method

Sampling is the process of selecting a portion of the population to represent entire population. A sample is a subset of population element. In qualitative research the sample should be large enough to obtain sufficient data to describe the problem or phenomenon that the researcher wants to study and to address the research questions (Polit and Beck, 2013). Purposive sampling technique was used to select caregivers using the following criteria: the caregivers were females and males living with a child who is HIV positive, the child receives HIV treatment and the care givers did not disclose the positive status to the child. The study interviewed 10 participants who were caregivers of children living with HIV at Mohodi community in the Limpopo Province.

Purposive sampling also known as judgmental sampling, is a form of non-probability sampling in which the researcher relies on her/his own judgment when choosing members of the population to participate in the study (Polit and Beck, 2013). The researcher used purposive sampling based on her judgement and the purpose of the study. The list of HIV positive children was obtained from clinic and contact details of caregivers were identified and used to recruit twelve caregivers who agreed to participate in the study.

A purposive sample of ten (10) participants was selected for this study which consisted of six (6) females' caregivers and four (4) male caregivers living with children who are HIV positive. The participants were selected from the four categories, there was a list of the foster parents staying with children living with HIV and they did not disclose, the biological mothers, the brothers, and the aunts. Out of the four categories, more participants were from foster parents, who were part of a long list of the foster parents who did not disclose to their grandchildren. One biological mother was selected, one from the brothers list and one from the aunts list. During interviews, saturation point was reached on the 10th participant when no more new information was coming forth.

3.5.1. Inclusion criteria

All caregivers at Mohodi community both male/females who are living with children that tested HIV positive and did not disclose the HIV status to the children were the participants within the study.

3.5.2. Exclusion criteria

The caregivers who are women and men and caring for a child and children living with HIV and have not disclosed the HIV positive status of their children and are taking care of a very ill child were excluded. The caregivers that are absent at Mohodi community during the time of the study were also excluded. Caregivers who have also disclosed to their children about their HIV positive status were excluded.

3.6. Data collection tool

Data was collected through in-depth face-to-face interviews conducted among the caregivers of children living with HIV. The data collection tool used was an interview guide which was validated with the approved questions on it. The interview guide was developed by the researcher in English and was translated to Sepedi which is the local spoken language (Appendix A) and (Appendix B). The researcher was guided by the journals on how the interview guide should be structured. According to Legard, Keegan and Ward (2003), in depth or unstructured interviews are one of the main methods of data collection used in qualitative research. The significance of the in-depth interview is talking to people to grasp their point of view and personal accounts are seen as having central importance. The researcher used the information about the in-depth interview to formulate her own interview guide, with open-ended questions and it was used to guide the interviews. The interview guide had, two sections, and is attached as Appendix A and Appendix B. Section A of the guide required Demographic data of the participants whilst Section B consisted of the central questions and follow-up questions.

A pilot study was conducted at a separate area from the research site among few participants, to test the relevance, for clarity and appropriateness of the questions. It also helped to identify potential problems or difficulties that could arise during the interview process and to measure the duration of the interviews. Confusing questions and terms were rectified, and ambiguous questions were corrected. No problems or difficulties were encountered during pilot study. The interviews were conducted for 30-45 minutes per participant. Therefore, the interview guide used was credible as the researcher was able to collect the information required to respond to the objectives of the study.

3.7. Data collection

Data collection refers to a process of gathering and measuring information on variables of interest, in an established systematic approach that enables one to answer stated research questions, hypotheses and evaluates outcomes (Kabir, 2016; Bhandari, 2021). Firstly, the researcher scheduled appointments with the participants telephonically. The participants were called to the office on the first appointment to give them the background of the study and to request their permission to participate in it verbally. Sepedi language was used during interviews as a locally spoken language in the study area.

The participants were informed that on the next appointment, which was scheduled for 15 May 2022, interviews will be conducted . The consent forms were signed by all participants to indicate that they agreed to be part of the study. The Semi-structured face to face interviews were conducted in a private space provided by the clinic to ensure that participants feel comfortable and free. The process allowed confidentiality and the researcher made follow ups and probes on certain issues shared by participants to enrich the data. This gave the researcher a comprehensive picture of participant's daily life and perceptions, and daily life experiences. All interviews were recorded using a voice-recorder and notes were taken to record non- verbal cues and the demographic data of participants.

3.8. Data analysis

A general inductive approach for qualitative data analysis was followed. This study sourced primary data from interviews and secondary data was obtained through literature, which shared insight into the current study. Thematic Content Analysis was used to identify, analyse, and report technique for the subjective interpretation of the data through the systematic classification process of coding (Annexure I) and identification of themes or patterns. The Researcher conducted the six phased Thematic Content Analysis as outlined by Braun and Clark (2011).

3.8.1. Step one: Familiarizing oneself with data.

After conducting interviews, the researcher transcribed data from audio recordings to the scripts, then read and re-read through the transcripts to be familiar with data, making notes of initial ideas.

3.8.2. Step two: Generating initial codes.

After the researcher has familiarised herself with data, a list of notions was generated. This step involved the production of initial codes from the data. The codes identified data that is thought-provoking to the researcher and referred to the most basic elements of the raw data. All real data extracts were coded and organized together within each code. Codes of analysis that explain the perceptions of caregivers in relation with the disclosure HIV status of their children living with HIV were determined.

3.8.3. Step three: Searching for themes.

This involved careful reading of the data to extract themes.

After data were coded and collated, different codes were organised and identified into credible themes. All the relevant coded data was assembled within the identified themes. The researcher then analysed the codes and considered how different codes could be combined to form the all-comprehensive theme. Thereafter, the themes were arranged into themes and sub-themes. Three different themes and seven sub-themes identified for the study.

3.8.4. Step four: Reviewing themes.

The themes that were developed from the data were then re-examined and advanced. The researcher instigated the re-examination of themes to polish them and remained with fascinating and significant themes. All assembled extracts for each theme were read and considered to see whether they appeared to form a coherent pattern.

3.8.5. Step five: Defining and naming themes.

Themes were defined and further refined. The researcher ran theme names and clear working definitions that outlined the essence of each theme briefly. The researcher examined each theme and then put it into writing. Themes that relate to the perceptions of caregivers in relation with the disclosure HIV status of their children living with HIV are captured in a separate table 4.2. The refining and defining of themes is all about identifying the essence of each theme and determining aspects of the data for each theme that was developed.

3.8.6. Step six: Producing the report.

A final analysis of the themes and sub themes was made by the researcher and was verified by the independent coder. A report was compiled as part of chapter four for analysis in the study. The researcher provided a concise, coherent, logical, non-repetitive, and interesting account of the story from the data, within and across the themes.

3.9. Trustworthiness

Trustworthiness refers to the degree of confidence that the researcher has that their qualitative data and findings are credible, transferable, and dependable the following criteria were applied to determine the trustworthiness of qualitative research.

3.9.1. Credibility

The researcher adopted a qualitative research method which is recognised to ensure durability and debriefed the participants to describe the phenomenon under scrutiny (Sheton, 2004). As outlined by De Vos (2011), the criterion reflects the truth and value of the information and findings from the participants, as well as the context in which the study has been undertaken. The researcher immersed herself in the participant's world, views and the feelings which assisted in understanding the challenges they experience, eliminating distortions of information that arise due to her presence in the field. Recorded data from interviews was transcribed verbatim and used to generate themes and sub-themes. Therefore, credibility helped to establish reasonable information drawn from participant's data findings which represent reasonable information drawn from participants' original data and interpretation of the participants' point of view.

3.9.2. Transferability

According to Glaser, Kyle, Onwuegbuzie and Whittermore (2013), transferability alludes to the generalisation of the study and findings to other situations and contexts. The results of this study may not be generalised or applied, other comparable settings, populations, circumstances because individuals may have different perceptions based on different backgrounds and influences and HIV program implementations and application of health policies and circumstances. The number of the participants and duration of each interview ensured transferability in a sense that each participant was given enough time to express their perceptions hence saturation was reached by the 8th participants. The findings of the study were therefore based on the participant's circumstances and their current situations, it was not the opinion of the researcher.

3.9.3. Conformability

Conformability is the degree to which results of the study can be confirmed or corroborated by others). The researcher recognised shortcomings in the research methods and minimised the shortcomings by conducting the interviews similarly, for instance, administrator bias, which meant that she had to conduct the interviews as similarly as she could (Shenton, 2004). The researcher enhanced conformability by documenting all procedures used to check and recheck the data throughout the study. Critical to this process is the audit trail, which allows any observer to trace the course of the research step- by-step, decisions made, and procedures described. Belief underpinning decisions made, and methods adopted were acknowledge within the research report, and reasons for favouring one approach when others could have been taken were mentioned.

The researcher also used data triangulation whereby comprehensives data was gathered from the participants to understand the researcher's research question. All the findings of this study were from the participant's reports but not of the research's opinion.

3.10. *Ethical consideration*

As stipulated by De Vos et al. (2011), all studies should be guided by acceptance, agreements, promises, mutual trust, cooperation and well-accepted prospects between all parties involved. Having done so the researcher has accordingly complied with the relevant ethical considerations. Ethics has to do with behaviour that is considered right or wrong. Ethics is an important consideration in research, particularly which involves humans and animal (Bertram and Christiansen, 2014). No harm to human was encountered during the interviews. In the current study, the researcher was guided by the following ethics:

3.10.1. Permission to conduct the study.

Prior to the commencement of the study, the researcher obtained Ethical clearance from Turfloop Research Ethics Committee (TREC) of the University of Limpopo. The researcher also attained permission from the gate keepers at The Department of Health (see Appendix A) which covers Mohodi Clinic in Limpopo Province. The researcher also obtained permission from gatekeepers at the Department of Health, which covers Mohodi Clinic. Thereafter, ten (10) participants were interviewed by the researcher from Mohodi Clinic using a list of questions carefully constructed. A total response rate of hundred per cent (100%) was successfully achieved. An audio recording device was utilised with the permission from participants to record their responses. The researcher also used field notes to back up the interview process.

3.10.2. Privacy, anonymity, and confidentiality

Privacy suggests the element of individual privacy, while confidentiality infers managing information in a confidential way (De Vos et al., 2011). The researcher conducted the interview in a private and separate office in the clinic. The researcher also ensured that the participant's information is entrusted, and their identity remained anonymous by replacing their real names with the word participant. In addition, respondent's information was secretly marked and informed the participant that it will be made available to the supervisor for guidance and purpose of the study.

3.10.3. Informed Consent

In this study, the participants were provided with all the details of the study and their consent was obtained. The researcher informed participants about what the study is about and its intentions after its completion so that they can freely participate in the research. According to De Vos et al. (2011), this makes participants fully aware of the possible dangers and advantages of the study. Participants were required to sign a consent form (See appendix C). As outlined by the De Vos et al. (2011), locating informed consent suggests that all important procedures were followed, and participants are fully of the research proceedings.

3.10.4. Avoidance of harm to participants

The significant ethical rule of social research is to gather information or discover knowledge not previously known to verify existing data without bringing any harm to participants. The researcher fully prepared the participants for the interview and the nature of the study itself to enable them to be open and to be free to share their experiences in details and information.

3.10.5. Voluntary participation

Participation in this study was voluntary and no one was forced to participate Participants were not coerced to engage in the study without their consent. All important information and processes involving their participation in the study were explained. They were required to sign consent form prior to the commencement of data collection (See Appendix C).

3.11. Bias

In this study, the following safeguards were taken to minimise bias:

The researcher was guided by the supervisor from time to time. The researcher did not assist or give signals on how the questions should be answered. The researcher listened sensibly to the participants and recorded all responses. The researcher complied with the ethical standards when interpreting data as well as during the period of interviews.

3.12. Summary of the chapter

The chapter focused on the Methodology that was employed to guide the researcher in this study. Aims and objectives of the study, research approach, research design, sampling and population, data collection, data analyses and quality criteria processes were followed addressed,

4. CHAPTER 4: PRESENTATION OF FINDINGS AND INTERPRETATIONS.

4.1. Introduction

This chapter reports on the findings of the study and the related literature that supports the findings. The purpose of this chapter is to present, analyse and interpret findings of the Caregivers' perceptions towards 'disclosure' of Human Immunodeficiency Virus positive status to their infected children, at Mohodi Community in Limpopo Province. *Participant* is the term used to substitute real names of individuals who took part in this study. Social Workers were also interviewed, as they were identified as key informants. Biographical information of participants was collected so that their socio-economic and socio-cultural background can be understood within the context and perceptions of the subject.

4.2. Demographic profile of participants and key informants

This study comprises of ten participants who are the caregivers of the children living with HIV. There were more females than the male participants, all from Mohodi Clinic area. One group of participants was between the age of sixty and eighty-five, while the rest were from the age of thirty-five to fifty-five. Caregivers who took part on the study include the foster parents, a biological mother, brother, and aunt. Some of the foster parents who took part in the study are married, while others are single parents. The biological mother, the sister and the brother are also not married.

Key informants were identified to provide in-depth information that supports and clarify some of the statements provided by the caregivers. Three Social Workers, two females and one male who holds an Honours degree in Social Work and are employed at Mohodi clinic, served as Key informants. The Social Workers interact with all patients/clients at Mohodi clinic. They provide counselling to those who are to disclose their status, keep records of those who disclosed and those who have not disclosed HIV status and provide social-welfare services to all carers who are raising children that are living with HIV.

Table 4.3 Demographic profiles of participants and key informants

Participants	Age	Gender	Marital Status	Educational Aspects	Occupational Aspects
Participant 1	86	Female	Married	Primary Level	Retired
Participant 2	55	Female	Married	Primary	Unemployed
Participant 3	52	Male	Married	Secondary	Employed
Participant 4	72	Female	Married	None	Unemployed
Participant 5	36	Female	Single	Secondary	Unemployed
Participant 6	35	Female	Single	Secondary	Employed
Participant 7	40	Female	Single	Secondary	Unemployed
Participant 8	66	Male	Single	Primary	Unemployed
Participant 9	60	Male	Single	Primary	Self -employed
Participant 10	45	Male	Single	Secondary	Unemployed
Participant 11(SW)	40	Female	Married	Social Work Honours Degree	Employed
Participant 12(SW)	36	Male	Single	Social Work Honours Degree	Employed
Participant 13(SW)	39	Female	Single	Social Work Honours Degree	Employed

4.2.1. Themes and Sub-Themes

A summary of themes and sub-themes is provided on table 4.2 below. Data analysis reflects three themes and seven sub-themes. The themes in qualitative data analysis serve as theoretical relationships that emerged from the study following data analysis, categorising, and sorting of elements into groups and to look for patterns (Burns and Grove, 2013). The summary of the findings raised the following themes and sub-themes:

Table 4.2 Themes and sub-themes

Themes	Sub-themes
1. Theme 1: It is challenging to disclose HIV positive status to children.	1.1.. Care givers fear of rejection and blame by children when they find out about their HIV positive status
	1.2. Fear of stigma from other peers as children may disclose status.
	1.3. Uncertainty of the right age to disclose to the children.
2. Theme 2: Lack of skills to disclose HIV positive status to infected children.	2.1. Lack of strategies by the caregivers to disclose HIV status to infected children.
	2.2. Readiness of children to know about their HIV status.
3. Theme 3: Benefits of disclosure of HIV positive status towards infected children	3.1. Disclosure encourages better adherence to medication.
	3.2. Disclosure builds trust and strengthens relationship between the caregivers and children.

4.2.1.1. Theme 1. Inability to disclose HIV status to children.

Data was analysed and coded, it was found that caregivers are unable to disclose the HIV status to the children who are HIV positive. Most participants reported that they are aware of the status of their children, but they are unable to disclose their own HIV status due to fear of rejection and blame that can emanate from their children. The participants cited challenges that come with disclosure. Under this theme, the following sub-themes emerged: the participants mentioned the fear that children might start resenting, rejecting, or blaming them. They also felt that the children are still young, therefore, they may not have the intellectual capacity to understand HIV and how it spreads from one person to the next. It was also cited that children might start telling their peers about their illness, which will create stigma for them. Key informants also supported the information provided by the caregivers. The sub-themes that were developed are discussed below:

4.2.1.1.1. Sub-theme 1.1. There is fear of rejection and blaming of the caregiver by the children.

The studies revealed that most caregivers are unable to disclose to their children because of fear of rejection and blame by their children. Care givers have a tendency of telling lies to the children about the medication they are taking on daily basis. According to Osingada et al. (2017) when children know their status, they become serious regarding adherence to medical care and they become helpful and co-operative in the house. Some caregiver's challenges are reflected on the statement below:

> **Participant *3:*** *"I feel like the child will start to cry and blame me for the disease, I'm also afraid that the child might start to resent me for keeping it as a secret for a long time".*
>
> ***Participant 6:*** *"it is difficult to tell the child about the illness that you do not know much about, the child might start hating you and blame you for the disease even though it is not your fault.*"

The Social Worker indicated that caregiver's fear rejection from their children and as such they are unable to disclose the HIV status to the children living with HIV. Below is the extract with the confirmation by the Social Worker:

> ***Participant 13 (Social Worker):*** *''No, the clients are unable to disclose as they fear that their children will start to blame them for the disease. Some it is due to age and maturity of the children''.*

> ***Participant 12: (Social Worker):*** *''most of the clients that I know are unable to disclose as they are afraid of the rejection from their children or their grandchildren''.*

According to Osingada, Okuga, Nabirye, Sewankambo and Nakanjako (2017), the children might get scared and crying there is fear of rejection and blaming of the caregiver. Most care givers live with a guilty feeling of not disclosing to their children on daily basis. They sometimes wait until children go into the adolescence stage without disclosing.

As a result, caregivers would not want their children to be faced with these negative societal reactions. Hence, the reason for nondisclosure to the children, as observed in the following studies (UNICEF, 2019). Heeren et al. (2017) observed that the ripple effect of stigmatization of the child could lead to isolation, fear of blame, guilt, and gossip.

4.2.1.1.2. Sub-theme 1.2. Fear of stigma from other peers as children may disclose status.

This study revealed that most caregivers who are HIV positive are not only stigmatised by the society but also by their family members. Therefore, stigma has negatively affected the caregivers to an extent that they do not want to see their children going through the same pain. Below are how the participants expressed themselves:

> **Participant 02:** *“I’m afraid to tell the child as he might tell other children and other children might start calling him names. One of child from our street committed suicide after one of the boys he was playing with started to tell him about his illness”.*

> *Participant 4: “The child will start to be rejected at school by her peers, this might affect her grades at school, I’d rather wait until he is old enough to disclose to her.*

This was confirmed by one of the key informants, a Social Worker that the clients are mostly afraid of stigma towards their children from their friends and other community members.

> **Participant 13 (Social Worker):** *‘’parents are afraid of stigma, trauma that comes with isolation children lack confidentially and they might tell their friends”.*

> **Participant 11 (Social Worker):** *“Most of the clients are afraid that due to the children’s age, and lack of understanding of HIV children might tell others while playing about their HIV positive status’’.*

Some caregivers received negative reception and stigmatisation from people they love for disclosing their status. This has made disclosure to children much difficult among parents and caregivers. The fear of seeing their children not accepted by other people, fellow learners, other children out of school, by the community including family members has caused delays in disclosing the HIV status of children to the children living with HIV but continue giving them ARTs (Turissini et al., 2013).

4.2.1.1.3. Sub-theme 1.3. Uncertainty of the right age to disclose to the children.

Participants reported that they believe age plays a key role in their culture as children are not supposed to be told sensitive issues. Participants have the perception that children are too young to understand HIV infection pathophysiology. Below are the perceptions of the participants.

> ***Participant 2:*** *'the child should know when they are 15 years of age. He is not mature enough to know about his status".*
>
> ***Participant 1:*** *"He should know when he is 18 years of age* and above. They will be able to understand the disease''.
>
> ***Participant 6:*** *"The child should know when he is 20 years of age* and above".

The quotes above were confirmed by the Social Workers who also reported that their clients did not disclose due to age restriction, fear of rejection and lack of confidentiality from the children.

> ***Participant 11 (Social Worker):*** *''the clients mentioned that children are still young and not mature enough to understand the dynamics of HIV, they are also afraid that children might tell other children while playing''*
>
> ***Participant 13 (Social Worker):*** *''our clients are unable to disclose as they fear that their children will start to blame them for the disease. Some it is due to age and maturity of the child''.*

> The Social Workers indicated that it is important to be mindful of the age, maturity and the developmental stage of the children as recommended by the Children's Act 38 of 2005. Most caregivers lack information that a child as young as four years, can be told about the status even though the term HIV may not be used at that stage. The stages of disclosure are not known by the caregivers; hence they delay disclosure until the child reaches adolescences stage.

Timing of HIV disclosure is a vital component in the management of children living with the disease. Abebe et al. (2018) observed that most caregivers delayed disclosure until children were much older because some believed that the children are too young to understand, and would share the information with others, then later suffer negative emotional consequences at a younger age. Most caregivers agreed that HIV status should be disclosed to children much later on, between the ages of six and 20. This was corroborated by (Madiba et al., 2019), (Kallem et al., 2017) and (Heeren et al., 2021).

4.2.2. Theme 2: Lack of skills to disclose HIV positive status to infected children.

Participants indicated that they lack full knowledge about HIV and the disclosure of the status to children; they only know about the medication their children are taking and that the medication should not be missed. The caregivers also mentioned that the children are still young and not ready to hear about such critical news. However, the World Health Organization (2020) stipulates that disclosure should be addressed by the health care workers to the caregivers immediately when the child is born with HIV. The following sub-themes emerged:

4.2.2.1. Sub-Theme 2.1. Lack of strategies by the caregivers to disclose HIV status to infected children.

UNICEF (2019) argues that caregivers have no clear guidance. While studies have looked at the background, views of what is disclosed and the effects of disclosure beyond recognizing challenges, is less understood. However, the World Health Organization (2020) stipulates that disclosure should be addressed by the health care workers among the caregivers immediately when a child is born with HIV. The participants reported the following:

> **_Participant 1:_** "*I think that I need to know what to say to the child, and also I need to know where to start and when the right time to tell the child is. I believe that if the child is ready and prepared he might not think or harming himself".*

> **_Participant 6:_** *"I don't think I will tell the child alone I will need nurses to help tell him as I do not how to tell and what exactly to tell the child. I'm afraid that I might hurt the child's feelings".*

Research indicates that insufficient knowledge and skills among caregivers are a hindrance to disclosure (Melhuish, Lewthwaite, 2018; Wu, Chen, Scott, and McGoogan, 2019), while most of the caregivers had limited knowledge and expertise on how to disclose HIV status to a child.

4.2.2.2. Sub-theme:2.2. Readiness of children to know about their HIV status.

A study conducted by Simelela and Venter (2014) found that caregivers believed that delaying disclosure until the child was much older would help the child accept the diagnosis and keep it a secret.

> **_Participant 01:_** *"I think that I need to know what to say to the child, and also, I need to know how to start and when the right time to tell the child is. I believe that if the child is ready and prepared, he might not think or harming himself."*

> ***Participant no 4:*** *“Parents should wait for their child to grow up a little bit and they can tell them. Parents should be not harsh and rude towards their children’’.*

Parents’/caregivers’ decision to disclose or not disclose children’s HIV status hinged on the age of the child. Caregivers fear the psychological implications of disclosing HIV status to children, and they worry that young children might reveal the diagnosis to others, which could lead to unwarranted discrimination (UNICEF, 2019). As such, the prevalence of disclosure to younger children was much lower than that of older children in this study.

4.2.3. Theme 3: Benefits of disclosure of HIV positive status towards infected children.

Participants believe that the more the children know about their status the higher is the possibility of taking their medication on time every day. Since the child is expected to stay on the ART medication for the rest of their lives, caregivers believe that to promote adherence to treatment among the children, it is prudent to disclose the child’s status to them (World Health Organization, 2020). Caregivers also believe that telling the child about his/her illness will create a comfortable environment for the child to talk about the disease. It will build trust and strengthens the caregiver and child relationship. The child will also become resilient and confident to take charge of their lives. Below are more sub-themes derived from the participants’ perceptions

4.2.3.1. Sub-theme 3.1. Disclosure encourages better adherence to medication.

HIV status disclosure to children has its merits as well as demerits, as seen in the literature. The findings indicate that children whose status were disclosed to them, took charge of their own care. There was an improvement in medication adherence and a reduced risk of transmission of HIV to others, and they could communicate freely about their health and seek help from caregivers when necessary. Participants reported the following:

> ***Participant 10:*** *“yes, the child will drink the medication on time without supervision”.*
>
> ***Participant 4:*** *“Children will know about their dates to go and take their medication at the clinic. They will drink their medication on time”.*
>
> ***Participant no 5:*** *‘’yes, disclosure will have a positive impact on the child. The child will be able drink their medication on time’’.*

Dusabe-Richards et al. (2019) observed that children whose status was disclosed, to them took control of their healthcare, visiting a health facility unaccompanied and ensuring that their medications were taken regularly and on time, they communicate freely about their physical health, and they are able to ask questions and access help from caregivers. Mburu et al. (2018) observed that disclosure creates opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. Hejoaka (2016) also observed that HIV status disclosure to children helps them to develop strategies to conceal the medicines and the disease.

4.2.3.2. Sub-theme 3.2. Disclosure builds trust and strengthens relationship between the caregivers and children.

Disclosure to children can strengthen the relationship amongst the care giver and the child. It can also create levels of support and build resilience on the side of the child. Caregivers believe that the child should be informed about the illness with the support of health care professionals and Social workers.

> ***Participant 3:*** *"Telling the child is to prevent her hearing about it from the street and the child will gain more trust in you than other people. If she is not informed by you she will feel pain and resent you".*

> ***Participant 05****: "I should be the one to tell the child before anyone and professionals such as nurses should also be available to support me with information. This would generate trust and support between me and the child".*

The Social Workers also confirmed that it is the responsibility of the caregivers to tell the children about their HIV positive status as it will generate trust amongst them.

> ***Participants 12 (Social Worker):*** *'' a suitable person here it's a parent, if parents are unable to disclose to their children they should approach professional such as social workers to assist them with the disclosure but parents are the ones who should disclose to the children about their status''*

> ***Participants 11 (Social Worker):*** *'' the clients themselves so that they can strengthen the relationship between the children and themselves''.*

According to the Social Worker, disclosure is supposed to be done by the caregivers in the presence of the Social Workers guiding them. The age of the child and the maturity of the child to be considered before disclosure so that the child will no experience harm. One of the studies revealed that many care givers who have disclosed the HIV status to their children experience less depression compared with those who did not. Disclosure tends to have positive impact to the child, caregiver or parents, and the family (Glaser, 2016).

4.3. Conclusion

From the extracts by the Social Workers and the caregiver's disclosure towards the children it is still a challenge among the caregivers. The study found that most children are lied to about the medication they are taking on daily basis. Caregivers are not ready and they lack strategies to disclose the status to their children.

5. CHAPTER 5 INTERPRETATION AND DISCUSSION OF FINDINGS

5.1. Introduction

This chapter focuses on the interpretation and the discussion of major findings of the study. It will further interpret and discuss the perceptions of care givers regarding the disclosure of the HIV status to the children living with HIV. All the themes and sub-themes derived from data analysis will be unpacked. The paragraphs below show interpretation and the discussion validated by the findings from the participants, key-informants and the previous research literature. The findings of the study are based on the participants' reports.

Most literature explored for this study in Chapter 2, reflected data that focus on the perception of care givers regarding the disclosure of HIV status to children by the care givers/parents. It was clear that disclosure of the parent's HIV status is a serious challenge and for this reason, the children who are HIV positive have no idea why they have to continue taking treatment when they know nothing about the diagnosis. Many of them were lied to by parents and adults who take care of them regarding the reason why they have to continuously take treatment. The HIV pandemic has reached a period where new challenges must be addressed, because the HIV positive children who are not aware of their status may simply and unknowingly continue to spread the infection.

The National HIV Testing Services Policy (2016) highlights that knowing one's HIV status is critical for the achievement of HIV prevention and treatment goals, which were developed from the National Strategic Plan 2017-2022 goal 03 and 04. Furthermore, South Africa has adopted the Joint United Nations programme for HIV and AIDS 90-90-90 strategy, which requires that 90% of all people at risk of being HIV positive are tested and diagnosed, 90% of the people diagnosed with HIV receive ART and 90% of those on treatment are virally supressed by 2020. This includes all the children living with HIV. Based on the high number of children who do not understand the importance of treatment adherence caused by lack of disclosure by care givers in South Africa, the 90-90-90 strategy did not reach its purpose as the planned goals and objectives were not reached by 2020.

Care givers who boldly disclosed their HIV status to the children indicate how it was not easy, however, there was acceptance, adjustment later and adherence to treatment among HIV positive children was strengthened. Similar to the requirements for the disclosure of the HIV positive status by care givers, the Health Policy requires strong social support and positive approaches of dealing with stigma across different sectors.

5.2 Interpretation of the themes and sub-themes

Theme 1: Inability to disclose HIV positive status to children.

As the care givers confirmed the inability to disclose their HIV positive status to the children who are HIV positive, it is clear that they need empowerment on how to successfully speak to children about how HIV spreads from one individual to the other including the spread from mother to child. Some of the children could have got infected because their mothers did not enrol for the PMTCT programme as recommended by the Department of Health in South Africa.

5.2.1.1 *Sub Theme: Care givers fear rejection and blame by children when they find out about their positive status.*

Fear of care givers to disclose HIV status to HIV positive children may be a sign of self-blame, which makes it difficult to face and accept responsibility and be ready to handle challenges that accompany this situation. Disclosing HIV infection is a challenging task because of potential blame, stigma, shame, and fear associated with HIV infection.

One participant felt that the children can cry and blame the parent for the situation. There was fear of resentment for keeping the HIV status as a secret for as long as the child was growing. Another participant, a Mother, indicated that:

"*I feel like the child will start to cry and blame me for the disease, I'm also afraid that the child might start to resent me for keeping it as a secret for a long time*."

Some mothers living with HIV are of the view that their children will be angry with them for transmitting the virus and making them suffer, because of their mistakes (WHO, 2020). The statements from the participants were also supported by the Social Workers indicating that caregiver's fears rejection from their children, as such they are unable to disclose their HIV status to their children living with HIV. The caregivers believe that the less families talk of HIV, the better as it will not alarm the closest relatives and other people who can start judging them.

5.2.1.2 *Sub –theme fear of stigma from other peers as children may disclose status*

It was reported by the participants that one of the reasons care givers are unable to disclose is the fear that children lack confidentiality, and they may start telling their best friends about their HIV positive status. According to the participants, this might bring about stigma and discrimination against them. Stigma delays HIV testing, treatment care and support as people shy away from testing and this may lead to failure to disclose. HIV and AIDS related stigma has been reported in children living and those perceived to be living with HIV, which are known causes for prejudice, rejection, negatives views about illness and negative view about themselves. Some individuals have been reported to isolate themselves from friends and family members to avoid stigma. High levels of depression also have been reported (Health Disclosure Guidelines: 2016) as individuals face challenges related to disclosure of their HIV status.

> Participants explained that they are afraid that their children will also be rejected and stigmatised by the society, some participants who are the foster parent of a child living with HIV mentioned that :
> *"I'm afraid to tell the child as he might tell other children and consequently, other children might start calling him names. One of child from our street committed suicide after one of the boys he was playing with started to tell him about his illness*", whereas the other participant added that:
> "*The child will start to be rejected at school by her peers, this might affect her grades at school, I'd rather wait until he is old enough to disclose to her*."

Participants did not indicate at what age children can be ready to know about their status and how they got infected. Kouyoumdjian et al. (2018) also observed that caregivers were concerned that if the child knew his/her HIV status, s/he might tell other people in the community, which would lead to discrimination towards the child and family. This assertion is corroborated by a study conducted by (Oberdorfer et al., 2018) in which they observed that caregivers preferred to delay disclosure of their HIV status because they feared it would have negative emotional consequences for the children and that the children might not be able to keep it a secret, but they were ready to disclose the child's status when the child was much older.

5.2.1.3 *Uncertainty of the right age to disclose to the children.*

Disclosure is a process whereby the children gain knowledge of their HIV positive status. It is not a once off event or conversation but a process with multiple child centred discussions over time depending on the need and circumstances of the children. It requires continuous support and is naturally progressive, allowing for provision of age-appropriate information to the child regarding their illness and leading to full disclosure when the child has cognitive and emotional maturity to process the information. There are different ways of understanding a child's developmental journey into adolescence, as well as adulthood. As a child grows into adolescence and adulthood, they can think, feel and relate to others in a more complex way. Childhood development is thus seen as a process of gaining increasing abilities within physical, cognitive, social and emotional areas that lead to meaningful participation within the family and society. Most children receiving treatment do not know what is wrong with them and why they are receiving treatment. According to the department of Health Disclosure Guidelines (2016) there is low disclosure rate amongst orphans and vulnerable children, adolescents, and youth (OVCAY) in South Africa

The caregivers are not sure of the right age to tell their children about their HIV positive status, most of them reported that from 15 years upwards might be the right time to tell the child. According to the participants, telling the child from fifteen years will be appropriate as they will be matured and could understand the disease. One participant said that "*the child should know when they are 15 years of age. He is not mature enough to know about his status*". The other participant also reported that "He should know when he is 18 years of age and above. They will be able to understand the disease''.

Social Workers also indicated that, according to the Children's Act no 38 of 2005 section 133(1)2) no person may disclose the fact that a child is HIV positive without consent. Consent to disclose that a child is HIV positive may be given by the child if the child is 12 years of age or older or under the age of 12 and is of sufficient maturity to understand the benefits, risks and social implications of such disclosure. The sufficient maturity can be a subjective issue, which makes it difficult to assess if the child is ready or not. Different standards for sufficient maturity are indicated from different perspective.

However, the Children's Act states that disclosure should be done or can be done to children as long as they are mature enough to understand the concept of HIV. As far as the guidelines for Social Service Practitioners for HIV testing services is concerned, disclosure can start from the age of four (4) years upwards and the practitioners who is handling the disclosure should be able to assess the child age and child's developmental stage. The child should be made aware that they are taking the medication for a reason, other than being lied to by their caregivers, even if the child is 4 years the illness can be called a germ as to replace the term HIV to maintain confidentiality.

Theme 2 lack of strategies to disclose HIV positive status to infected children.

More capacity building on disclosure among care givers should be given priority, knowledge might be there but without the implementation plans caregivers will never utilise the knowledge.

Sub-theme: 2.1. Lack of skills by the caregivers to disclose HIV status to infected children.

Insufficient knowledge and skills among caregivers were found to be a hindrance to disclosure (Melhuish, Lewthwaite, 2018; Wu, Chen, Scott, & McGoogan, 2019). It was observed that most of the caregivers had limited knowledge and expertise on how to disclose HIV status to a child. Paintsil et al. (2018) pointed out that the literacy level of the caregiver was another factor. Caregivers who had a higher level of education were more likely to reveal the child's status and those with less knowledge were most likely not to reveal (UNICEF, 2019).

> Most of the participants were the grandparents of the children living with HIV, they lacked basic education or have only finished their primary and secondary school level. The participants reported that even if they want to tell their children about their HIV positive status, they will not know what to say. One participant who is the grandmother of the child living with HIV reported the following *"I think that I need to know what to say to the child, and also I need to know where to start and when is the right time to tell the child. I believe that if the child is ready and prepared, he might not think of harming himself*".
>
> Another participant who is a secondary school dropout sister to the child living with HIV, mentioned that *"I think that I need to know what to say to the*

child, and also I need to know where to start and when the right time to tell the child is. I believe that if the child is ready and prepared he might not think or harming himself".

The literature also revealed that even though the caregivers are aware of the advantages and disadvantages of disclosure they still do not disclose. More capacity building on disclosure for care givers should be given priority. Care givers could be knowledgeable but without the implementation plans caregivers can never utilize the knowledge.

Although the developmentally-guided disclosure of HIV status is widely recommended, there are few specific frameworks to guide primary caregivers, families, and healthcare providers through this disclosure process. The WHO Disclosure Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (2011) provides strong evidence that disclosure is central to the overall well-being of the children and adolescents. These guidelines confirm the psychological and emotional benefits of disclosure to HIV-positive children and adolescents, dispelling concerns that disclosure may cause harm if done by a person who lacks knowledge about it and who is not well informed about HIV.

Sub-theme: 2.2. Concerns regarding readiness of children to know about HIV status.

A study conducted by Simelela, and Venter, (2014) found that caregivers believed that delaying disclosure until the child was much older would help the child accept the diagnosis and keep it a secret. Timing of HIV disclosure is an important component in the management of children living with the disease. The participants reported that the children are still young and not ready to know about their status. The child readiness according to participant is defined by age and maturity of the child. The participants reported that the child is likely ready when they are from the ages of 15 years and above as they will have the mental capacity to understand the disease.

One of the participants mentioned that: “I think that I need to know what to say to the child, and also I need to know how to start and when the right time to tell the child is. I believe that if the child is ready and prepared he might not think or harming himself.” The above statement was supported by the other participant who the foster parent is mentioning that “Parents should wait for their child to grow up a little bit and they can tell them. Parents should be not harsh and rude towards their children’’.

Abebe et al. (2018) observed that most caregivers delayed disclosure until children were much older because some of them believed the children were too young to understand, would share the information with others, and would suffer negative emotional consequences at a younger age.

5.1.1 Theme 3: Benefits of disclosure of HIV positive status towards infected children

5.1.1.1.Sub-theme 3.1.Disclosure encourages better adherence to medication.

Mburu et al. (2018) observed that disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. Hejoaka (2016) also observed that HIV status disclosure to children helped them to develop strategies to conceal the medicines and the disease.

The participants reported the following “yes, the child will drink the medication on time without supervision”. The other participant who is also the foster parent mentioned that “Children will know about their dates to go and take their medication at the clinic. They will drink their medication on time”.

The above statements were also supported by the Social Workers who mentioned that the most advantage for disclosing is that adherence is a psychosocial and health issue. The significance of adherence to treatment and retention in care has become recognized as a vital part of successful management of HIV and the child's response to therapy. Non- adherence can lead to treatment failure, high viral load and drug resistant HIV strains, risk of contracting opportunistic infections and ultimately progression to AIDS.

HIV status disclosure to children has its merits as well as demerits, as seen in this review. Most of the findings reported that children whose status was disclosed to them took charge of their own care. There was an improvement in medication adherence and a reduced risk of transmission of HIV to others, and they could communicate freely about their health and seek help from caregivers when necessary. This assertion is supported by the work of Vreeman et al. (2021) whose findings revealed that HIV status disclosure to children improved ART adherence, children's well-being, and their social relationships.

5.1.1.1. Subtheme 3.2. Disclosure builds trust and strengthens relationship between the caregiver and child.

In sub-Saharan Africa, open sex education is commonly perceived as a taboo. Hence, it is not common to find parents discussing this aspect with their children. Hayfrom-Benjamin et al. (2018) observed that, because caregivers are not open to discuss sex with the child, for fear of questions on how they got infected, they might decide not to disclose the child's status. This was also observed by (Mburu et al., 2017). The participants reported that if your child is aware of their HIV status it will be much easier to talk to them about sex and protection. The conversation can strengthen the child's relationship with the caregiver. The other part is that if the disclosure is done by the caregiver on a one-on-one conversation, it is believed that the process will build and strengthen the trust. The child will be able to go and ask about any sexual misconceptions they hear from their peers.

One participant reported that “*Telling the child is to prevent her hearing about it from the street and the child will gain more trust in you than other people. If she is not informed by you she will feel pain and resent you”*. Whereas the other Participant said that “*I should be the one to tell the child before anyone and professionals such as nurses should also be available to support me with information. This would generate trust and support between me and the child’’*.

Most of the participants reported that it will be better for them to disclose to their children than someone else’s child. The caregivers also reported that support is needed for them to disclose as they fear that they will harm the children’’. The studies revealed that many care givers who have disclosed the HIV status to their children experience less depression compared with those who did not. Disclosure tends to have positive impacts to both the child, caregiver or parents, and the family (Glaser, 2016).

5.2. Conclusion

The Health care providers have a critical role to play in HIV disclosure to HIV positive children, considering the caregivers' expressed desire to be prepared for the disclosure. It is also the role of the social service practitioners to partake in disclosing to the children and provide psychosocial support to the families raising children living with HIV.

CHAPTER 6 SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS

5.3. Introduction

Chapter five discussed the research findings and the literature control. Themes and sub-themes were also discussed in the previous chapter regarding the caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to children living with HIV at Mohodi community in the Limpopo Province. This chapter will highlight the summary of the entire study, recommendations, strengths, and limitations encountered whilst conducting the study.

5.4. Summary and interpretation of the research findings.

The study focused on the caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to children living with HIV. The researcher was able to get insights of caregivers towards disclosing the HIV positive status to their children living with HIV and the contributory factors to the delayed disclosure of HIV positive status to children living with HIV. The qualitative study, in which purposive sampling technique was used to select participants and to conduct open ended interviews to probe to answer the research questions and to meet objectives of the study.

Thematic context analysis was used to organise and manage data. All data collected was transcribed from the tape recordings verbatim. Data collected in the local language was translated into English and analysed. Lack of knowledge, fear of blame and stigma about HIV and lack of guidelines about the disclosure to children who are living with HIV were some of the main challenges cited by the caregivers for their non-disclosure. Chapter 4 of the study focused on findings of the study and the literature was used to control the findings, within the chapter themes and sub-themes that emerged.

Most caregiver's stressed that the reason for their non-disclosure of the HIV positive statuses of their children is that as parents they lack more information about the disease. Children living with HIV spend their childhood without knowing their status and some even reach the stage of adolescence without anyone informing them of their medical condition. The WHO guidelines encourage professionals to assist care givers to inform the infected children at an earlier stage, but the expected disclosure rate is very low worldwide and, in some cases, it is forced.

In one of the studies, thirty-eight articles published in English-language journals prior to 2011 were reviewed regarding disclosure process, reasons for disclosure/nondisclosure and impacts of disclosure/non-disclosure; it was found that disclosure rate was low worldwide. The decision making of disclosure or non-disclosure was affected by children's development level, stigma, consideration of children's benefits, and parenting practices. Unintentional and forced disclosures were common. Findings regarding the impacts of disclosure/non-disclosure were mixed but disclosure tended to have long-term positive impacts on the well-being of children, parents, and family in general (Qiao, Xiaoming Li, and Stanton: 2013).

Participants reported that even though they were to be equipped with knowledge on HIV, they will still need to be told step by step and guided on where to start and at what age should the disclosure happen. The participants reported that they are afraid of harming their children, whereas the aim is to protect them. The Age of the children was also highlighted as one of the barriers to disclose the HIV status to the children. According to the participants, children have no mental capacity to know which news are confidential and which ones are not. The fear is that they might tell other kids and those kids can in turn, start victimising them. The age for disclosure should clearly be specified, and it should be known from the onset. Another question is what do participants want to know and what exactly are they supposed to say to the children when they disclose. Participants highlighted that the word 'HIV' might frighten the children.

5.5. Recommendations

The Department of Health and the Social Development should assume the responsibility of educating all caregivers about HIV and provide the guidelines required for the disclosure to happen. Behaviour change programmes such as ‘Chommie’, ‘Zazi’ and ‘YOLO’ should be introduced in schools and institutions of higher learning to provide children with information on HIV. Disclosure should be an ongoing process from early age and until the child reaches adolescence, there should also be a post disclosure session which will monitor that children are always supported. Caregivers should also be educated through dialogues, support groups and awareness campaigns on HIV and disclosure. Psychosocial support and nutritional support should be available and accessible for parents who are raising children living with HIV.

5.6. Strength and limitations of the study

5.6.1Strength

The researcher was able to interview all the caregivers staying with the children infected with HIV and who did not disclose to them. The caregivers were able to highlight on where they need support as parents to accept the responsibility of disclosing the HIV status to their children. The caregivers are also aware that disclosure has more positive impact towards the children than negative impact.

5.6.2 Limitations

The study was conducted during lunch times at work, most participants arrived earlier before one, as the researcher wanted to avoid disturbances from colleagues and other clients, and participants were not interviewed by the time they arrived at but as per appointment time which was one. Other participant’s interviews were not prolonged because they have been waiting for a long time.

5.7. Conclusion

This chapter highlighted the summary, recommendations, the strength, and the limitations of the study. The researcher was able to answer the research question and objectives. The aim and objectives of the study were adequately met.

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APPENDICES

APPENDIX A: INTERVIEW SCHEDULE/GUIDE

Caregivers' perceptions towards 'disclosure' of Human Immunodeficiency Virus positive status to their infected children, at Mohodi Community in Limpopo Province.

Section A: Demographic details

1.Tick the appropriate in the box:

Aunt	Sister/Brother	Mother	Grandmother	Foster parent

2. Sex

Male	

Female	

3. Age

4. Marital status

Single	Married	Divorced	Widow

5. Educational status

None	Primary	Secondary	Tertiary

6. Occupational status

Employed	Unemployed	Retired

7.Does your child receive treatment for HIV?

YES	NO

Section B

8. Are you aware of the HIV status of the child you're looking after?

- If yes, briefly explain how you learnt about it.

9. What is your understanding of the concept HIV disclosure?

- Does the child that you're looking after knows about his/her status?
- If no, when do you think is the right time to inform the child and why?

10. Would you disclose your HIV status if it will benefit someone next to you? Please explain how you will go about informing them about your HIV status.

11. In your view, why is it important for children living with HIV to know about their HIV positive status? Why? Explain further.

12. In your view, at what age should children living with HIV be told about their HIV positive status? Why?

13. Who should disclose to children living with HIV their HIV positive status? t Why? Tell me more about it.

14.There are those who are of the view that disclosure of the HIV positive status to children living with HIV will have a positive impact on the child. What is your view and why? please elaborate.

15. There are those who are of the view that disclosure of the HIV positive status to children living with HIV will have a negative impact on the child. What is your view and why? please elaborate.

16. In your view, what makes it difficult for caregivers to disclose the HIV status to their children?

17. What needs to be done to assist caregivers to take up this responsibility of informing their children about their HIV status?

18. For you to be comfortable to take up the role of to disclose to your child about their positive HIV what skills would you need? What are those skills?

19. There are those people who are of the view that health care practitioners and/or social workers should be the ones who disclose to the children living with HIV their HIV positive status. What is your view about this?

20. How will you feel if someone besides you as a parent/guardian/foster parent/adoptive parent tells your child about her/his HIV positive status?

21. In your view, how will the children benefit from knowing their own status?

22. In your view what are the challenges that children who are living with HIV may face by not knowing their HIV status?

23. What challenges do families that did not disclose to their children their HIV positive status face when the child learns about it outside the safety of her/his home environment? Why?

24. What did you tell your child/ren about medication they are taking?

25. What makes it difficult for you to disclosure your child's HIV status to them? Why?

26. In your view what would your child prefer to learn about her/his status from you or an outsider? Why?

27. What needs to be done to assist you to take up this responsibility of informing your children about their HIV status?

Thank you for participating in this interview.

APPENDIX B: SEPEDI IN-DEPTH INTERVIEW SCHEDULE/GUIDE

Caregivers' perceptions towards 'disclosure' of Human Immunodeficiency Virus status to their infected children, at Mohodi Community, Molemole Municipality Capricorn district. Limpopo

Karolo ya A: Demographic details.

1Thala mothalo gare ga lepokisi leo le swanetsego:

Mmane	Mma	Koko	Foster parent

2. Sex

Monna		Mosadi	

3. Megwaga

4. Maemo a Lenyalo

Single	Nyetswe	Hladile	Mohlologadi

5. Boemo ba thuto

None	Sekolo sa mathomo	Sekolo sa mahareng	Thuto ya godimo

6. Boemo ba mosomo

Go Shoma	Gose shome	Go hlogela mosomo

7. Na o tseba boemo ba gago ba HIV? Ka kgopelo hlalosa gore o tsebile kabona bjang?

8. O kwisisa bjang taba ya go utullela ngwana mabalele seemo sagage sa bolwetsi, , o bona golebohlokwa gore ngwana a otulllelwe ka semo sa gagwe sa bolwetsi.

9. Na oka utulla boemo ba gago ba HIV geeba botla thusa motho Yo aleng leloko lewena? Ka kgopelo hlalosa gore oka ba tsebixa bjang ka boemo bagago ba twatsi ya HIV.

10. Goya le ka pono ya gago o bohlokwa gore bana baphelang a twatsi ya Hiv ba tsebe ka boemo ba bona ba twatsi na? gobaneng? Hlalosa goya pele.

11. Goya le ka pono ya gago bana ba belegweng le twatsi ya HIV ba swanetse go botswa ka boemo ba bona ba tswatsi. Gobaneng? Ke mang analeng maloka ago ba bots aka seemo sabona , gobaneng?

12._Goya le ka mogopolo wagago na go utullela ngawana ka seemo sa gage sa bolwetsi ba gagwe eka ama ngwana gampe goba gbotse na? re kgpela o hlalose ka botlalo

13. Goa leka mogopolo wag ago keeng seo sedirang gore obe boima gore batswadi ba ban aba palelwe ke go botsa bana ba bona seemo sabona sa twatsi.

14. Keeng se sehlokegang go dirwa go thusa bahlokomedi ba bana go tsea maikarabelo ago tsebixa ban aba bona ka seemo sa bona sa twatsi ya HIV?

15. Na onale tsebo ya go utulla seemo sa ngwana ka twatsi ya gagwe, ke tsebo efe yeo?

16. Go na le batho ba nang le maikutlo a gore basumi ba tsa maphelo goba basomi ba odirela leago ke bona swanetsego go tsebisa bana boemo ba HIV. Maikutlo a gao ke afe ka see?

17. Oka ikutlwa bjang ole motswadi, ge eba motho fela ntle lewena a ka botsa ngwana wa gago ka seemo sa gagwe sa bolwetsi?

18. Go ya ka wena bana batlo holega bjang ge ba tseba seemo sa na sa HIV?.

19. Go ya leka pono ya gago ke mathta afe ao ban aba phelang ka twatsi ya HIV b aka kopang lewona ge bas a tsebe seemo sa bona sa twatsi ya HIV?

20. Ke mathata afe ao malapa asa tsebisang ngwana gore o na le twatsi ya HIVa hlakanang le ona, ge ngwana a thoma go tseba ka twatsi ka ntle le polokeho ya gae? Gobaneng?

21. Na ngwanago o tsea dihlare tsa gagwe tsa HIV?

22. Ekaba oboditse ngwana eng ka di hlare tseo a dinwago?

23. keeng seo sedirang gore obe boima go wena gore o tsibise ngwana wagago ka seemo sa gagwe sa twatsi? Gobaneng?

24. Goya le ka mogopolo wag ago ngwana wag ago aka nyaka go tsebiswa ke mang ka seeno sa gage sa bowetsi eka ba gotswa go wena goba mothofela na? gobanebg?.

25. Go swanetse gore odirwe eng seo seka le thuxsang kago re le tsee maikarabelo a go tsebisa bana lena kaseemo sa bona sa HIV?.

Kea leboga..

APPENDIX C: CONSENT FORM

Informed consent of a voluntary participation in an interview the perceptions of caregivers towards disclosure of HIV positive status of their children living with HIV.

I…………………………………….. agree to participate during the interview regarding my perception as a caregiver towards disclosure of HIV to children living with the disease. The research project has been fully explained with clear and simple language to me, therefore I do understand that to take part means I willingly giving consent to:

- Attend the interview about the above-mentioned research topic
- Make myself available for further interview, should a need arise
- I also understand that information provided by me shall remain confidential
- My participation is voluntary
- I can choose not to participate in any part of the research project
- I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

Signed by the caregiver…………………… signed at: …………..date……………………..

Signed by researcher…………………… signed at: …………..date………………………..

Signed at ………………………………….signed date……………………………………

APPENDIX D: SEPEDI CONSENT FORM

Nna ke le.............................. Ke dumela go tsea karolo go botsisweng dipotsiso ka ga kgopolo yaka jwale ka mohlokomedi wa Bana bao ba phelago ka twatsi ya HIV, mabapi le g o ba tsebisa maemo a bona a lephelo. Projeke ye ya dinyakisiso ba nhlaloseditse yona ka sepedi, ke a kwesisa ebile ke dumela go:

*Tsea karolo mo dipotsisong go ya ka thlogotaba

*Go iponagatsa nako le nako ge go hlokagala gore ke be gona

*ke dumela le go kwesisa gore tseo ke di bolela go di tlo ba sephiri

*Go kgatha Tema gaka ke maithaopo

*Nka ikgethela go se tsee karolo mo projekeng ye

*Nka kgetha go tlogela go tsea karolo mo projekeng ye nako engwe le engwe ge ke se sana kgahlego go se na kotlo

Signed by the caregiver…………………… signed at: …………..date……………………..

Signed by researcher…………………… signed at: …………..date………………………..

Signed at ………………………………….signed date………………………………………

APPENDIX E: REQUISITION TO CONDUCT A STUDY AT DEPARTMENT OF HEALTH, LIMPOPO PROVINCE

P O Box 2464

Letswatla

0849

The senior manager Department of health

Private Bag X 9302

Polokwane

0700

Dear sir/Madam

Request for permission to conduct a research study

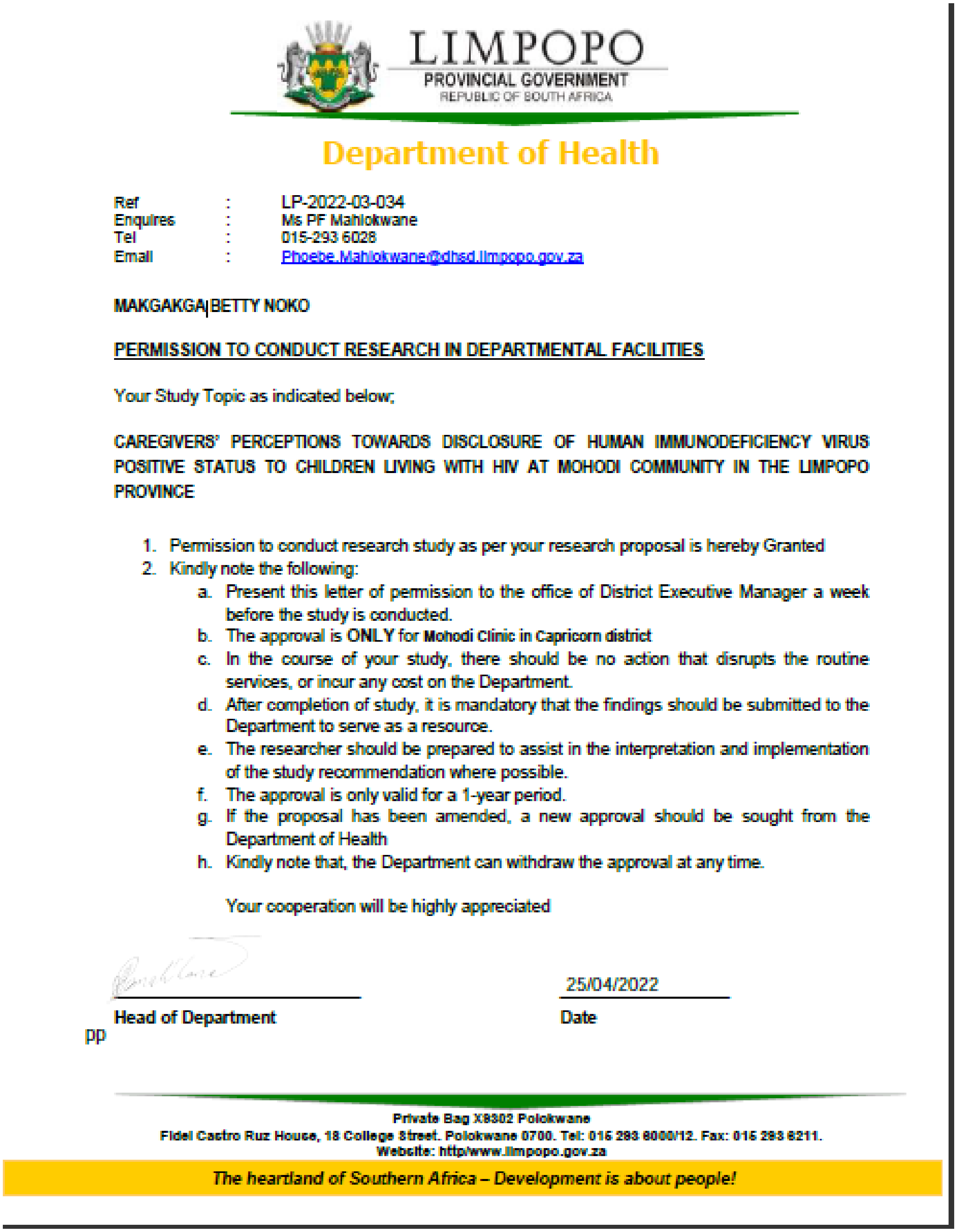
I am a student at the University of Limpopo (UL) currently registered for a Master's degree in public health. I hereby request permission to conduct a research study at Mohodi community clinic. The study is entitled: **Caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to their infected children, at Mohodi community in Limpopo Province**

The aim of the study is to explore caregivers' perceptions towards disclosure of HIV positive status to children living with HIV at Mohodi community in Limpopo Province. Thank you in anticipation of a positive response and for the efforts to be taken to assist me in this regard.

Best Regards,Betty Noko Makgakga

Email: Naominoko9@gmail.com Cell: 082 837 1050

APPENDIX F: permission from department of health, limpopo province to conduct a study



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP-2022-03-034
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Phoebe.Mahlokwane@dhsd.limpopo.gov.za

MAKGAKGA BETTY NOKO

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

CAREGIVERS' PERCEPTIONS TOWARDS DISCLOSURE OF HUMAN IMMUNODEFICIENCY VIRUS POSITIVE STATUS TO CHILDREN LIVING WITH HIV AT MOHODI COMMUNITY IN THE LIMPOPO PROVINCE

1. Permission to conduct research study as per your research proposal is hereby Granted
2. Kindly note the following:
    a. Present this letter of permission to the office of District Executive Manager a week before the study is conducted.
    b. The approval is ONLY for **Mohodi Clinic in Capricorn district**
    c. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    d. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    e. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    f. The approval is only valid for a 1-year period.
    g. If the proposal has been amended, a new approval should be sought from the Department of Health
    h. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Head of Department
pp

25/04/2022
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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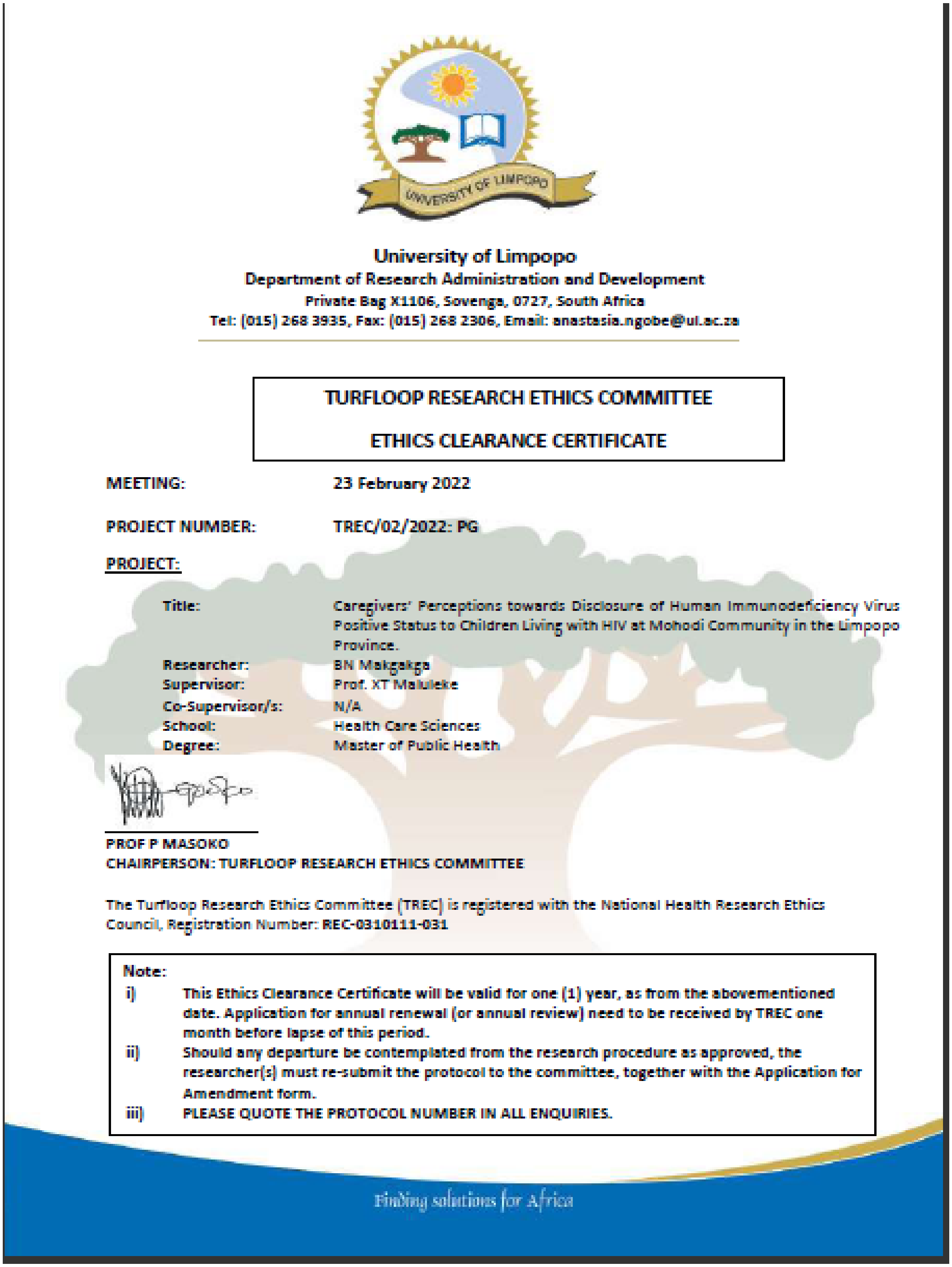
APPENDIX G: Ethical approval from University of Limpopo



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3935, Fax: (015) 268 2306, Email: anastasia.ngobe@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: 23 February 2022

PROJECT NUMBER: TREC/02/2022: PG

PROJECT:

Title:	Caregivers' Perceptions towards Disclosure of Human Immunodeficiency Virus Positive Status to Children Living with HIV at Mohodi Community in the Limpopo Province.
Researcher:	BN Makgakga
Supervisor:	Prof. XT Maluleke
Co-Supervisor/s:	N/A
School:	Health Care Sciences
Degree:	Master of Public Health

PROF P MASOKO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:

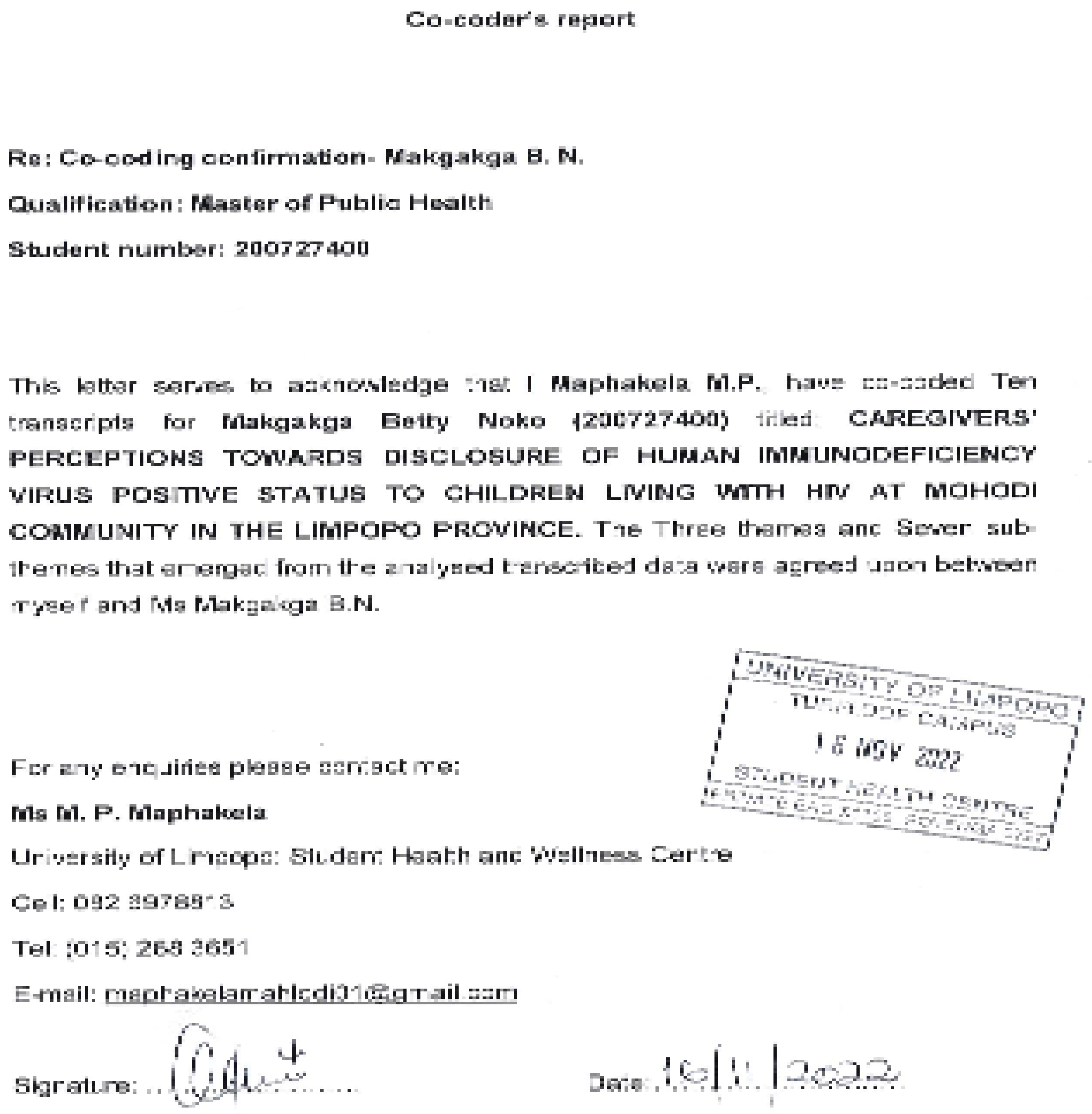
i) **This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.**

ii) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.**

iii) **PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.**

Finding solutions for Africa

APPENDIX H: Conformation of co-coding by independent coder



Co-coder's report

Re: Co-coding confirmation- Makgakga B. N.

Qualification: Master of Public Health

Student number: 200727400

This letter serves to acknowledge that I **Maphakela M.P.** have co-coded Ten transcripts for **Makgakga Betty Noko (200727400)** titled: **CAREGIVERS' PERCEPTIONS TOWARDS DISCLOSURE OF HUMAN IMMUNODEFICIENCY VIRUS POSITIVE STATUS TO CHILDREN LIVING WITH HIV AT MOHODI COMMUNITY IN THE LIMPOPO PROVINCE.** The Three themes and Seven sub-themes that emerged from the analysed transcribed data were agreed upon between myself and Ms Makgakga B.N.

UNIVERSITY OF LIMPOPO
TURFLOOP CAMPUS
16 NOV 2022
STUDENT HEALTH CENTRE

For any enquiries please contact me:

Ms M. P. Maphakela

University of Limpopo: Student Health and Wellness Centre

Cell: 082 3978813

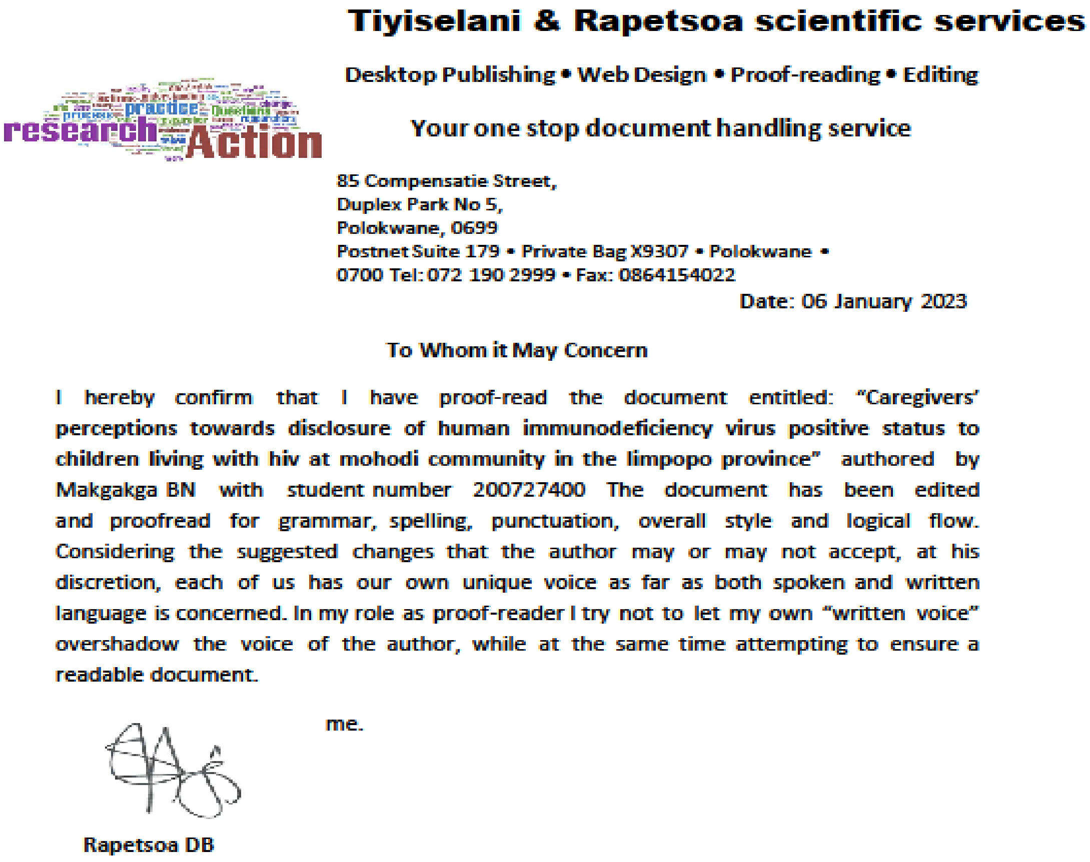
Tel: (015) 268 3651

E-mail: maphakelamahlodi01@gmail.com

Signature: ....

Date: 16|11|2022

APPENDIX I: Language editor certificate for confirmation of language editing for the report



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Date: 06 January 2023

To Whom it May Concern

I hereby confirm that I have proof-read the document entitled: "Caregivers' perceptions towards disclosure of human immunodeficiency virus positive status to children living with hiv at mohodi community in the limpopo province" authored by Makgakga BN with student number 200727400 The document has been edited and proofread for grammar, spelling, punctuation, overall style and logical flow. Considering the suggested changes that the author may or may not accept, at his discretion, each of us has our own unique voice as far as both spoken and written language is concerned. In my role as proof-reader I try not to let my own "written voice" overshadow the voice of the author, while at the same time attempting to ensure a readable document.

me.

Rapetsoa DB

ANNEXTURE J: INTERVIEW TRANSCRIPT

Participant 02 (female 55)

	Question and answers
Researcher	Are you aware of the HIV status of the child you're looking after? If yes, briefly explain how you learnt about it.
Participants:	The child's mother told me ab0ut t before she assed n.
Researcher	What is your understanding of the concept HIV disclosure? Does the child that you're looking after knows about his/her status? If no, when do you think is the right time to inform the child and why?
Participant:	The child does not know about his status, I think will inform him when he is 15 years he will be old enough to understand.
Researcher	Would you disclose your HIV status if it will benefit someone next to you? Please explain how you will go about informing them about your HIV status.
Participant:	yes, i would tell trusted family members about my status, i will call them and seat them down and start telling them about my disease.
Researcher	In your view, why is it important for children living with HIV to know about their HIV positive status? Why? Explain further.
Participant:	Yes, it is important so that they can be able to make their own decisions about their illness.
Researcher	In your view, at what age should children living with HIV be told about their HIV positive status? Why?
Participant:	The child should know when they are 15 years of age. He is not mature enough to know about his status

Researcher	Who should disclose to children living with HIV their HIV positive status? Why? Tell me more about it.
Participant:	i believe that nurses can tell the children about the disease as they are professionals, there is no problem.
Researcher	There are those who are of the view that disclosure of the HIV positive status to children living with HIV will have a positive impact on the child. What is your view and why? please elaborate.
Participant:	yes, disclosure will have a positive impact on the child. The child will be able to protect themselves by going to fetch their medication n their own.
Researcher	There are those who are of the view that disclosure of the HIV positive status to children living with HIV will have a negative impact on the child. What is your view and why? Please elaborate.
Participant:	Yes, if the child is told at an early age they might tell their peers.
Researcher	In your view, what makes it difficult for caregivers to disclose the HIV status to their children?
Participant:	Am afraid to tell the child as he might tell other children and other children might start calling him names. One of child from our street committed suicide after one of the boys he was playing with started to tell him about his illness.
Researcher	What needs to be done to assist caregivers to take up this responsibility of informing their children about their HIV status?
Participant:	Nurses should be able to assist us so that we can be able to tell our children, as they know more about the disease.
Researcher	For you to be comfortable to take up the role of to disclose to

	your child about their positive HIV what skills would you need? What are those skills?
Participant:	I do not know, i think i need to be polite and calm before telling him, also need to know what to tell him first as might be able to tell him well.
Researcher	There are those people who are of the view that health care practitioners and/or social workers should be the ones who disclose to the children living with HIV their HIV positive status. What is your view about this?
Participant:	Yes, they know more about the disease than us.
Researcher	How will you feel if someone besides you as a parent/guardian/foster parent/adoptive parent tells your child about her/his HIV positive status?
Participant:	i told my children their they should only listen to me as their care giver but not strangers.
Researcher	In your view, how will the children benefit from knowing their own status?
Participant:	I think they will start taking their medication on time and also do follow ups on their next appointment at the clinic.
Researcher	In your view what are the challenges that children who are living with HIV may face by not knowing their HIV status?
Participant:	Mmm....the child might default, as they do not have the reason of drinking their medication.
Researcher	What challenges do families that did not disclose to their

	children their HIV positive status face when the child learns about it outside the safety of her/his home environment? Why?
Participant:	I always fear that if the child hears it from someone else they will start to hate me and blame me for not telling them.
Researcher	What did you tell your child/ren about medication they are taking?
Participant:	AAA...i told him that, the medication gives him life if he stops drinking it, we will lose him as a family.
Researcher	What makes it difficult for you to disclosure your child's HIV status to them? Why?
Participant:	The child is still young and will not understand anything about the disease, am also not sure what to tell him and where to start.
Researcher	In your view what would your child prefer to learn about her/his status from you or an outsider? Why?
Participant:	I think he will not have a problem hearing it from the nurses, i will request them to assist when the time its right.
Researcher	What needs to be done to assist you to take up this responsibility of informing your children about their HIV status?
Participant:	I really do not know much about the disease, i do not know what i will start telling him. I need help form the nurses if m the one who should tell hm.

Thank you for participating in this interview.