# DISCLOSURE OF POSITIVE HUMAN IMMUNODEFICIENCY VIRUS STATUS TO CHILDREN DIAGNOSED WITH THE INFECTION AND ON ANTIRETROVIRAL TREATMENT: EXPERIENCES OF PRIMARY CARE GIVERS AT SELECTED CLINICS IN MOPANI DISTRICT, LIMPOPO PROVINCE

**Dissertation**

by

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# DECLARATION

I**, Muditambi Nathaniel Nndavheleseni,** declare that the research reported in this thesis, **“Disclosure of positive human immunodeficiency virus status to children diagnosed with the infection and on antiretroviral treatment: experiences of primary care givers at selected clinics in Mopani district, Limpopo province”** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Signature Date18/04/2023

## DEDICATION

To my wife Muditambi (Machaka) Phillipine, my children, Muditambi Mutshidzi, Murendeni and Mudodzwa. You inspired, supported, and prayed for me. May God bless you all.

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## ABSTRACT

**Introduction and background**: Disclosure of HIV status remains low in South Africa and globally. Care givers commonly delay the HIV disclosure process until the child is over 10 years of age. The World Health Organization (WHO) reports that disclosure of HIV status to infected children, as the gateway to treatment, has failed to keep pace with the increasing access to ART globally. Non-disclosure if allowed to continue can have negative ramifications for not only the affected children but the entire nation. The study, therefore, envisages determining and exploring the experiences of care givers as they disclose to individual children under their care about their HIV status.

**Methodology:** Qualitative, explorative, and descriptive phenomenological design was utilised to respond to the objectives of this study, to describe the experiences of primary care givers regarding HIV disclosure to children living with HIV. This study was conducted in Mopani District Limpopo Province, South Africa. Sixteen care givers were included in the study. Non-probability sampling was utilised to sample the facility for inclusion and the participants in this study. Semi-structured and face-to-face interviews were conducted to collect data from participants. During data collection, the researcher used an interview guide, and the participants were audio-recorded. Data were analysed using the ATLAS.ti 9 program, according to the thematic method of analysis.

**Results:** Care givers indicated that they have trouble initiating the HIV disclosure process for the child. Care givers also state that they disclosed HIV status to the child because of their individual reasons, they believe is the right of the child to know the truth about their condition and the treatment they are taking. Care givers expressed that HIV disclosure improves child understanding of their condition, the importance of treatment, adherence, and quality of life. Care givers state that non-disclosure of HIV status resulted in children refusing treatment, which will lead them to get sick and increases the risk of HIV transmission to others. Care givers state that they didn’t receive any training or education from healthcare providers.

**Conclusion**: Care giver’s experience suggested that HIV disclosure is a difficult process to initiate and is aggravated by a lack of skills and support from healthcare providers on how to disclose HIV to children. However, care givers acknowledge the importance of HIV disclosure and the complication of non-HIV disclosure. More support from a health provider is required to guide care givers to initiate HIV the disclosure process at an ideal age.

## DEFINITION OF CONCEPTS

### Disclosure of positive Human Immunodeficiency virus status

Disclosure of positive Human Immunodeficiency Virus status (HIV) is a process whereby an individual tells and opens his/her own HIV status to another person, identified as a trusted person to keep confidentiality. A trusted person may include a friend, relative, or sexual partner and potential benefits associated with voluntary sharing of the information include improving emotional and psychological well-being, access to early enrolment for antiretroviral treatment and adherence to treatment (Eustace & Ilagan, 2010; Dessalegn, Hailemichael, Shewa-Amare, Sawleshwarkar, *et al.,* 2018). In this study HIV status disclosure shall include when a child has been told all that is appropriate about his/her own HIV status and is able to take appropriate responsibility for their health in relation to preventing re-infection, infecting others, and adhering to treatment to improve his/her quality of health.

**Human Immunodeficiency Virus (HIV)** is a retrovirus transmitted through direct contact with HIV-infected body fluids such as blood, semen, and vaginal fluids or from a mother who has HIV during pregnancy, labour, and delivery or through breastfeeding from a mother who is infected with HIV (Department of Health and Human Services (HHS), 2018). In this study, Human Immunodeficiency Virus will refer to a viral infection that infected the child through direct contact with the infected body either during pregnancy, delivery, breastfeeding, and any other life interaction which predisposed the child to infection including rape.

### Children

Children include any person between the age of 0 to 14 years of age (National Department of Health, 2016). In this study, children shall include any person aged between 3 and 14 and years diagnosed with HIV infection and on Antiretroviral treatment (ART) in the local area of Tzaneen in the Mopani District.

### Primary Care giver

The parent, legal guardian, or person responsible for providing primary care to the child and adolescent (National Department of Health, 2016). In this study, a primary care caregiver will indicate any person who is a biological parent, a legal or traditionally approved person to be a guardian of the child diagnosed with HIV and on antiretroviral treatment (ART) and residing in the Mopani District.

### Experiences

Experiences – is the participants lived social and interpretation of the phenomenon under study based on live human realities that may have been gained through repetitive emotional formation that they developed as they create meaning to the phenomenon understudy (Daher, Carre, Jaramillo, Olivares & Tomicic, 2017). In this study experience refers to how primary care givers describes their life as they live and provide care to children living with HIV infection that was transmitted by parents encounter about HIV disclosure to children living with HIV and on ART.

## LIST OF ABBREVIATIONS

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Antiretroviral treatment |
| HCP | Health Care Provider |
| HIV | Human Immunodeficiency Virus |
| NDoH | National Department of Health |
| PCG | Primary Care giver |
| PHC | Primary Health Care |
| RBC | Red Blood Cell |
| UNAIDS | United Nations Programme on HIV and AIDS |
| WBC | White Blood Cell |

# CHAPTER 1

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# CHAPTER 1

# ORIENTATION OF THE STUDY

## 1.1 INTRODUCTION

The primary purpose of care givers is to support, guide, apply their knowledge and skills to manage the process of disclosing the diagnosis of Human Immunodeficiency Virus (HIV) positive status to children living with HIV and on Antiretroviral treatment (ART) is imperative. The process is important to improve adherence to ART among these children, including the ability to reduce transmission of HIV infection (National Department of Health, 2016). The ability of primary care givers to disclose and tell children who are HIV positive about their status using age-specific processes as described in the algorithms of HIV and AIDS care for children and adolescents will assist an individual child to adhere to ART and improves their health, physical and social well-being of the child as he or she adjusts the diagnosis and living with HIV and AIDS (National Department of Health, 2016).

The nurses' support empowers the primary care givers with knowledge and skills on how to manage the process of disclosure for individual age-specific, children and adolescents would enable primary care givers to disclose HIV positive status of their HIV-infected children. Thus, to improve the ability of the individual child to adapt, understand and cope with the chronic illness nature of HIV (Britto, Mehta, Thomas & Shet, 2016). The ability of primary care givers to disclose and tell their children's HIV-positive status is an important process of HIV care as it increases the ability of children to adhere to treatment however, living with HIV is a complex challenge for a child who is unaware of their illness and its effect on their bodies. Growing up and reaching adolescence is marked by physical and intellectual growth, including the social growth of the child beyond the family, which further poses a challenge for care givers to decide on when to disclose to a child diagnosed with HIV (World Health Organization, 2011; Britto *et al.*, 2016).

Ideally, HIV disclosure to children of their own HIV status should happen between 6 – 12 years of age, before sexual exploration and complex adolescent development. The ability of the primary care giver to disclose to the child also improves communication among care givers and children may also assist social behaviours that drive HIV infection like the early sexual debut, drug, and alcohol intake of the child to reduce (World Health Organization, 2011; World Health Organization, 2014). Moreover, based on the complexity of the process of disclosure of HIV status to children diagnosed with HIV, the (National Department of Health, 2016) has compiled guidelines that guide health workers and policymakers on how to manage age specific disclosure of children and adolescents with age specific. Since the publication and implementation of the guidelines, in the Mopani district, Limpopo Province, the study that establishes the experiences of caregivers as they reveal and tell individual children about their own HIV status was not undertaken, to identify the strengths and gaps of the guidelines. Identified strengths and challenges of the guidelines would improve the provision of HIV care services that reduce transmission of infection including the acceptability of services that would the alt incidence of HIV. The disclosure of the HIV status of individual children diagnosed with HIV is of clinical importance in children as it will help them comply with the HIV treatment regimen. Children who are informed of their HIV status have higher self-esteem than their peers who are unaware of their status (Doat, Negarandeh & Hasanpou, 2019).

## 1.2 BACKGROUND OF THE STUDY

HIV prevalence rate is approximately 13,5% among the South African population. The total number of people living with HIV is estimated at approximately 7,97 million in 2019 (Statistics South Africa, 2019). Despite excessive progress in increasing access to ART in recent years, HIV positive status disclosure remains low worldwide (National Department of Health, 2016). According to Ekstrand, Heylen, Mehta, Sanjeeva and Shet (2018) primary caregivers reported a low level of HIV status disclosure among children living with HIV both in the South and North Indian. Similarly, in a study conducted in Latin America, the disclosure of HIV positive status to children living with HIV was less than 50% (Lee, Siberry, Alarcón, Vega, Roca, Gutierrez, Succi, Peixoto, Stoszek, Hazra & Harris, 2018).

These results are congruent with studies in Africa and Sub-Saharan Africa, because according to Okechukwu, Offiong and Ekop (2019) indicates that the rate of HIV positive status disclosure to children is low at 29.6% in Nigeria. Moreover, a systematic review was conducted which included several studies in different countries like

Ethiopia, South Africa, Ghana, Kenya, Cote d'Ivoire, Burundi, Cameroon, Democratic Republic of Congo, Uganda, Burkina Faso, and Zambia where the prevalence of HIV-positive status disclosure ranged from as low as 9% to 72% (Doat *et la.*, 2019).

According to Mutumba, Musiime, Tsai, Byaruhanga, Kiweewa, Bauermeister and Snow (2015) caregivers may delay disclosing HIV positive status on children until they are at the average age of 13 years. The healthcare providers disclosure once-off event. Delaying the disclosure of HIV status to children, complicate the process and outcome of disclosure when children are now in adolescence emotional and developmental state (World Health Organization, 2011).

Correspondingly, the South African National Department of Health (NDoH) also indicated that there is a low disclosure of HIV-positive status amongst South African children (National Department of health, 2016). Furthermore, the disclosure of HIV-positive status to the children by their caregivers is a challenge. A diagnosis of HIV continues to be potentially life-threatening circumstance associated with a social stigma, especially, in low-income countries. Communities in low-income countries continue to believe and practice complex cultural norms. Poor health coverage, social, educational equality and higher unemployment rates also negatively affect the ability of care givers to initiate HIV disclosure processes (National Department of Health, 2016).

Additionally, the disclosure of HIV-positive status is essential in providing access and adherence to ART. Antiretroviral treatment will enable children living with HIV to survive to an age where disclosure of their HIV-positive status is imperative and appropriate. At some stage, these children become aware of the fact that they have a chronic illness, and they experience the impact of HIV on their bodies and lives. Both primary care givers (PCG) and healthcare providers (HCP) face the stressful process of informing or disclosing to the child about their HIV-positive status (National Department of Health, 2016). The literature evidently substantiates that there is a low level of HIV disclosure to children with living HIV, hence, the researcher envisages exploring the phenomenon within the context of Limpopo Province.

## 1.3. PROBLEM STATEMENT

The problem statement is grounded on the working experience of the researcher, where the researcher observed that there is high number of children living with HIV and taking ART and unfortunately, they are not aware of their HIV-positive status In Limpopo. The researcher's observation is corroborated by findings from the study conducted in Limpopo by Nong, Mothiba, Malema and Bopape (2015), which find that care givers experience difficulty in disclosing HIV status to the infected children. Mafune, Lebese and Nemathaga (2017) also state that care givers experience fears to disclosure HIV status of the child. There are no published studies conducted in Limpopo regarding prevalence of HIV disclosure in perinatally infected children and very few studies address HIV disclosure In children in Limpopo.

However, Van Elsland, Peters, Grobbelaar, Ketelo, Maarten, Mark, Cotton, and van Furth (2019) indicated that out of 190 children only 45 (23.7%) received disclosure about their HIV status, of whom 28 (14.7%) were partially disclosed and 17 (8.9%) were fully disclosed in South Africa. The delays in HIV positive status disclosure are likely to lead to inability of children who are on antiretroviral treatment to adhere to treatment, adjust to the diagnosis, adapt to appropriate health promotion activities that would improve individual quality of health and address problems related to adherence to treatment. Non-disclosure of HIV status indicates the poor implementation of NDoH HIV disclosure guidelines (National Department of Health, 2016). The researcher, therefore, finds it imperative to determine and explore the experiences of care givers as they disclose to HIV infected children under their care about their HIV status in Limpopo.

## 1.4. THE SUMMARY OF LITERATURE REVIEW

A literature review is a process of gathering information through reading, understanding, and making the conclusion of a published topic by scholars who are relevant to the study topic (Brink, Van der Walt & Van Rensburg, 2018). Literature was conducted which assisted the researcher to have a clear understanding of the nature and the depth of the research problem. Various sources globally and locally were reviewed with more relevant details on the disclosure of HIV-positive status to infected children. The literature review was guided by the theoretical framework adopted for this study, detailed in chapter 2.

## 1.5. PURPOSE OF THE STUDY

The purpose of the study is to determine and explore experiences of HIV status disclosure on children living HIV/AIDS among primary care givers in Mopani District Limpopo Province, South Africa

## 1.6. OBJECTIVES OF THE STUDY

The objectives of this study are to:

- To explore experiences, fears, and threats care givers meet related to HIV status disclosure on children living with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa.
- To describe experiences, fears, and threats among care givers on HIV status disclosure on children living with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa.

## 1.7. RESEARCH QUESTION

The study attempts to answer the following research questions

- What are the experiences of primary care givers on HIV status disclosure on children with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa?

## 1.8 THEORETICAL FRAMEWORK

In this study, the Health Belief Model (HBM) will be used, because this is one of the robust psycho-sociological models frequently utilised in assessing beliefs, values, and attitudes towards a wide variety of health-related behaviours. The model was intended to assist the public health service to understand the failure of people to implement disease prevention strategies. The health belief model proposes that a person's belief in a personal threat of the illness or disease together with a person's belief in the effectiveness of the recommended health behaviour or action will predict the possibility the person to implement the behaviour (Strecher, Champion & Rosenstock, 1997). A detailed discussion on the application of the framework will be discussed in chapter 2.

## 1.9 OVERVIEW OF RESEARCH METHODOLOGY

Qualitative, explorative, and descriptive design was utilised to respond to the objectives of this study. Exploratory research describes the whole characteristic of the phenomenon, the nature in which it is manifested and the factors to which is associated with (Polit & Beck, 2017). Explorative design was utilised in this study to explore the experiences to HIV status disclosure on children living with HIV. Descriptive research provides an accurate account of the characteristics of a particular individual or group in real-life situations for the purposes of discovering new meaning and describing what exists (Boswell & Cannon, 2017).

Non-probability sampling was utilised to sample the facility for inclusion and the participants in this study. The self-developed individual interview guide was utilised to gather data from participants. Therefore, semi-structured and face-to-face interviews were conducted to collect data from participants. The researcher used Tech's coding method of analysis which involves eight steps of data analysis. Research methodology detailed in chapter 3.

## 1.10 MEASURES TO ENSURE TRUSTWORTHINESS

Connelly (2016) defines trustworthiness as the degree of confidence in data collection and the interpretation and methods used to ensure the quality of a study. Thus, to enhance the trustworthiness of the research, the researcher used four criteria for trustworthiness which include credibility, dependability, transferability, and confirmability (Polit & Becker 2017). These measures will be explained in detail in chapter 3.

## 1.11 BIAS

Bias is commonly understood to be any influence that provides a distortion in the results of a study (Polit & Beck, 2017). The researcher will implement the sampling methods as indicated on the methodology. During analysis the researcher will not manipulate the results, all raw data will be provided on request. The researcher will ensure that the research participants are independent and treated with respect so that they are protected from exploitation.

## 1.12 ETHICAL CONSIDERATION

Before starting with the research, ethical clearance certificate will be obtained from Turfloop Research Ethics Committee (TREC). The research proposal, ethical clearance certificate and consent form will be submitted to the Limpopo Provincial Department of Health's Research Ethics Committee to request permission to conduct the study (see attached Annexure B). The ethical clearance certificate from the university and a letter of approval from the Limpopo Provincial Department of Health's Research Ethics Committee will be submitted to Mopani District Manager and to the Primary Health care Manager to request institutional permission to conduct the study (see attached Annexure E). The information gained from the institution will be kept confidential and no information will be utilised to exploit an institution.

## 1.13 SIGNIFICANCE OF THE STUDY

The findings of this study contributed to the body of knowledge through determining the experience of care givers on HIV disclosure on children living with HIV. It is the role of the caregiver to initiate HIV disclosure, but the healthcare Provider to support the care giver during the process. The study will provide an in-depth understanding of how primary care givers perceive and understand their roles, responsibilities, and challenges in HIV disclosure process to the child. Recommendation on how to Improve the knowledge of care givers regarding HIV disclosure process will be developed. The study will further assist to identify gaps in the role of healthcare providers in capacitating care givers regarding HIV disclosure process and providing psychosocial support to facilitate smooth disclosure. Recommendation to address gaps related to healthcare provider will be developed like including HIV disclosure topics in basic HIV training for nurses, hence improving nursing practice in HIV disclosure in children. The findings can also generate other research topics for further studies like lack of literature regarding the prevalence of HIV disclosure in Limpopo.

## 1.14. OUTLINE OF THE STUDY

Chapter 1: Overview of the study

Chapter 2: Literature Review

Chapter 3: Research methodology

Chapter 4: Results and Discussion of the Findings

Chapter 5: Integration of results with theoretical framework

Chapter 6: Summary of the study, recommendation, limitations, and conclusion

## 1.15 SUMMARY

This chapter outlined the orientation of the study, a synopsis of the main research study was presented. The following chapter will detail literature review conducted.

# CHAPTER 2

# LITERATURE RREVIEW

## 2.1 INTRODUCTION

The previous chapter presented a synopsis of the study. Chapter 2 will focus on discussion of literature review on the disclosure of positive Human Immunodeficiency Virus status on children diagnosed with the Infection and on antiretroviral treatment. A literature review is a well-organized written presentation of what has been studied and published on the research topic, to orientate the readers on existing knowledge around the research topic (Polit & Beck, 2017; Grove, Burns & Gray, 2016). Moreover, this chapter will describe the literature that assisted the researcher to familiarize themselves with the phenomenon under study.

## 2.2 LITERATURE REVIEW METHODOLOGY

De Vos, Strydom, Fouche and Delport (2011) state that a “literature review presents a scholarship or literature that helps the researcher to see how other scholars have investigated the research problem of interest”. Brink *et al.*, (2018) further state the “literature review assists the researcher to develop a search strategy the researcher needed to achieve the trustworthiness of the review”.

### Identifying Sources of literature

The researcher commenced a literature search on the archives of MEDLINE and PubMed. These databases are considered because they have the greatest abstract and citation databases for peer-reviewed literature, they provide a rich research process for researchers and moreover, and they provide a comprehensive view. Furthermore, the researcher conducted research on the following databases: Allied Health Literature (CINAHL), Ebscohost, WorldCat.org, Wiley Online Library database, Google, and Google Scholar databases.

### Selecting search terms

The following search terms identified related to the research topic were used, “HIV disclosure”, “experience of Caregivers on HIV disclosure”, and “challenges, complication, benefits and barriers of HIV disclosure”. Each of these concepts was searched individually then a Boolean operator ‘and’ or ‘or’ were used by combining the terms. The search results were initially broad and were narrowed down with the use of more specific search topics.

### Inclusion and exclusion criteria

The criteria assisted the researcher to identify the relevant literature sources for the study. All sources not older than 10 years (between 2021- 2010) were included. Literature written in English and appropriate to HIV disclosure in children living with HIV were included. All articles not written in English, older than 10 years and not relevant to HIV disclosure in Children were excluded.

### Findings of the literature search

The findings of the literature search included 08 books, 58 published article, 3 guidelines and 3 published reports reviewed during literature reviewed.

### Topics/themes identified

The following topics identified from literature reviews included on the discussion of literature:

- *The status of HIV/AIDS in children* – To give a brief introduction about the status of HIV/AIDS burden in Children.
- *Disclosure of HIV to children living with HIV globally* – To highlight the global state of HIV disclosure in children.
- *Disclosure of HIV to children living with HIV in South Africa* – To highlight the South African state of HIV disclosure in children.
- Process of disclosure of HIV positive status to children – To describe the standardized process of HIV disclosure in children.
- Theoretical Framework – To discuss the framework adopted for this study and literature theme ground from the theoretical framework.

## 2.3 STATUS OF HIV/AIDS IN CHILDREN

Domek (2010) state that many care givers did not disclose because they share the desire to ‘protect’ children from destructive information that might lead to negative psychological consequences (Domek, 2010; American academy of peadiatric, 1999). In South Africa, the progress on 90-90-90 targets is also behind, because presently, 84.8% of a population have knowledge of their HIV positive status, of whom 70.7%

were linked to ART, with 87.4% of those on ART to have suppressed viral load (Marinda, Simbayi, Zuma, Zungu, Moyo, Kondlo, Jooste, Nadol, Igumbor, Dietrich & Briggs-Hagen, 2020). Worldwide, children under 15 years account for about 5% of all people living with Human Immunodeficiency Virus (HIV), moreover 9% of new HIV infections and 14% of all Acquired Immune Deficiency Syndrome (AIDS)-related deaths are among children. Despite evidence indicating that early initiation of antiretroviral drugs in infants with HIV can save lives, coverage of important intervention among children remains too low (UNIADS, 2020; South Africa, 2016). The prompt initiation of Antiretroviral Therapy can decrease 76 per cent of mortality among children who test positive for HIV (UNAIDS, 2020).

International guidelines advise that urgent antiretroviral therapy is vital, if HIV infection is detected in any child under the age of 5 years (National Department of Health, 2020). Moreover, most children started on treatment programs are older. Delays in HIV status disclosure are likely to lead to a delay in access to treatment or problems related to adherence to treatment. The South African Department of Health indicates that the disclosure that takes place during adolescence can cause non-adherence and subsequent treatment failure (National Department of Health, 2016).

## 2.4 DISCLOSURE OF HIV TO CHILDREN LIVING WITH HIV GLOBALLY

The World Health Organization (WHO) indicates that the disclosure of HIV status to infected children is the key entry to ART program and will improve the quality of their lives. Unfortunately, HIV disclosure in children living with HIV is lagging (WHO, 2011; National Department of Health, 2016; van Elsland, Peters, Grobbelaar, Ketelo, Maarten, Mark, Cotton, and van Furth, 2019). WHO further indicates that the disclosure of HIV status is a vital part of the process of living with HIV and is crucial in HIV care. However, disclosure decisions are challenging when children are involved because of fear about children’s emotional, and attitudinal ability to understand, and to manage the nature of the illness, a stigma, and concerns about social support. Care givers are frequently uncertain about how to counsel about HIV disclosure, and opportunities to provide HIV testing and care, and to help families start the discussion about living with HIV are often missed (WHO, 2011).

The American Academy of Pediatrics recommends that children of school age and all adolescents should be informed about their HIV status. The Academy further emphasizes the significance of implementing a customized approach in the disclosure process. The disclosure of health status to children is a basic human right issue that cannot be overlooked. The United Nations Convention on the Rights of the child indicates that children have the right to decent quality health care, and information to help them stay healthy (United Nation Treaty Collection, 2018). It is, therefore, imperative for care givers to provide sufficient information for children who are HIV positive. The provision of such information would assist to protect the health rights of these children (Gyamfi, Okyere, Enoch and Appiah-Brempong, 2017).

The World Health Organization (WHO) reports that the disclosure of HIV status to infected children, as the age-specific treatment, has not keep-up with the increasing access to ART globally. The WHO also acknowledges that the lack of disclosure eventually affects the well-being of the child, including access to pediatric HIV treatment, care, and adherence to treatment. The WHO recommends that as part of their long-term management, children of school age should be informed about their HIV status and further recommends that HIV disclosure should be done incrementally to accommodate their mental skills and emotional maturity, in preparation for full disclosure (WHO, 2011; National Department of Health, 2020).

Despite evidence about the benefits of developmentally appropriate paediatric HIV disclosure. Many of these children are unaware of their HIV status, do not understand the importance of remaining adherent to antiretroviral therapy, and enter adolescence without the knowledge that they could infect others with HIV (the American Academy of paediatric, (1999); Krauss, Letteney and Okoro, (2016). Nevertheless, Meena, Hemal and Khanna (2018) conducted a study in India which found that the majority (93.8%) of care givers felt that it is imperative to disclose HIV status to children but only 33% of the children were disclosed. A similar result was in a study conducted in China only 32% of care givers reported having to disclose HIV status to their children. However, care givers intended to disclose when children were 14 years or older.

Krauss *et al*., 2016) indicated that it is significant for care givers to disclose a child's HIV status to them, to prevent the child from feeling isolated and finding out their status accidentally in public. However, there are worries about a stigma toward children and care givers were hesitant to disclose to their children (DeSilva, Penwill, Sabin, Gifford, Li, Fujie, Weiwei, Yongzhen, Hongyan, Xuemei Barnoon Gill & Bonawitz, 2018).

In sub-Saharan Africa HIV disclosure in children remains a challenge as well, although full HIV disclosure rates have increased lately (Dahourou, Raynaud & Leroy, 2018). Similar results were found in a study conducted in sub-Saharan countries (Ethiopia, South Africa, Ghana, Kenya, Cote d'Ivoire, Burundi, Cameroon, Democratic Republic of Congo, Uganda, Burkina Faso, and Zambia) on HIV status disclosure in children living with HIV that the prevalence of HIV disclosure was ranging from as low as 9% to 72% (Doat *et al.,* 2019). A similar result was found in a study conducted in Nigeria by Mukhtar-Yola Kuczawski and Oniyangi (2020) found that the prevalence of HIV disclosure was low, full disclosure was 24.5%, partial disclosure 22.7%, with an overall prevalence of 47.2% and the average age at full disclosure was 11 years.

HIV disclosure process is often complicated, because of numerous barriers related to caregivers and to healthcare providers (Dahourou *et al.,* 2018). A study conducted by Finnegan, Langhaug, Schenk, Puffer, Rusakaniko, Choi, Mahaso and Green (2019) in Zimbabwe found that only 26.9% of children knew their HIV status and that they can transmit the virus to others. Care givers who had not disclosed their child's HIV status worry that disclosure would lead to a stigma in the community, causing questions from their child that they would not be able to answer.

Guta, Areri, Anteab, Abera and Umer (2020) conducted a study in Eastern Ethiopia, which revealed that out of 134 (60.6%) of HIV-infected children knew about their HIV status and the average age at disclosure was 10 years. Children who stayed on anti-retroviral for 10–15 years were more likely to know their HIV-positive status compared to those staying on anti-retroviral therapy for less than 6 years. The prevalence of disclosure of HIV-positive status to HIV-infected children is usually low worldwide. Thus, to better understand the reasons for non-disclosure, a qualitative study is recommended for future studies (Guta *et al.,* 2020).

## 2.5 DISCLOSURE OF HIV TO CHILDREN LIVING WITH HIV IN SOUTH AFRICA

In South Africa care givers require confidence and skills to disclose to children with HIV. Moreover, current disclosure guidelines do not provide strategies on how to approach disclosure. The care giver has been identified as a responsible person to disclose to the child, however, they need the support from a healthcare provider (Madiba & Diko, 2021).

Due to inadequate support care givers in South Africa are likely to postpone the HIV disclosure process until the child is over 10 years of age. Moreover, the reported full disclosure of children living with HIV in South Africa varies between 7.9% and 9.0% (van Elsland *et al.,* 2019). Additionally, a study conducted in Johannesburg, South Africa found that HIV disclosure is initiated only to 4% of children aged 5 years. Some of the care givers who had not disclosed, 42% reported having always discussed illness in general with the infected child, and 17% reported ongoing discussions about illness with the infected child (Murnane, Sigamoney, Pinillos, Shiau, Strehlau, Patel, Liberty, Abrams, Arpadi, Coovadia, Violari & Kuhn, 2017).

A study conducted in South Africa, Mpumalanga by Madiba and Mokgatle (2017) found that the prevalence of disclosure was 27%. Care givers reported that they disclosed to promote ART adherence (26%) and others stated that because it was the child's right to know their status (43%). The authors further indicate that care givers who did not disclose had worried that children were too young and would not understand the implications of HIV diagnosis or would not keep the HIV status a secret. Over half of the care givers intended to disclose HIV status when the child is aged between 12 and 15 years (Mutumba *et al.,* 2015). Moreover, care givers indicated that when the child questions about HIV medication, caregivers exchanged HIV with other less stigmatizing conditions (Madiba & Mokgatle, 2017).

The South African National Department of Health has pledged to priorities support, guiding primary care givers and healthcare providers in the HIV disclosure process. This approach aims to ensure the physical, emotional, cognitive, and social well-being of the child. South Africa is legally required to certify that appropriate disclosure becomes an incorporated component of complete HIV management. The disclosure impacts various children's rights, and by not disclosing, the rights of those children are violated (National Department of Health, 2016). South Africa has seen an increasing population of children and adolescents accessing antiretroviral treatment (ART) in the past seven years (UNAIDS, 2020). Many of these children are growing to an age where they should know their HIV diagnosis (National Department of Health, 2016).

There is a dilemma regarding HIV/AIDS disclosure in children born and living with HIV/AIDS, hence, there is a low HIV disclosure to children in South Africa. HIV status disclosure is a broad but critical process as it strengthens children's ability to adhere to medication and dismisses anxiety and suspicion within themselves around their status. Proposals relate to community education and awareness program; policy and practice changes and makes suggestions for future research (Dube & Smith, 2016).

## 2.6 PROCESS OF DISCLOSURE OF HIV-POSITIVE STATUS TO CHILDREN

The South African National Department of Health (NDoH) states that HIV disclosure should adhere to a plan or process. The disclosure does not have a fast reached endpoint; therefore, disclosure should be treated as a recurrent process, which gets repeated as new information is shared with the children (Cantrell, Patel, Mandrell, Grissom, 2013).

### 2.6.1 Steps in the disclosure process

South African HIV disclosure guideline outlined four steps in the disclosure process (South Africa, 2016).

*Preparation and planning stage*

During this stage, the health care facility is equipped with the correct policies, tools, documentation, and referral networks. The healthcare provider is equipped with the skills, tools, and language to assist both the children and the primary care giver. The primary care giver is fully engaged to understand the benefits of disclosure and is equipped with a plan and language to share with the children (National Department of Health, 2016). Care givers of an HIV-infected child should be counselled by a knowledgeable healthcare provider about HIV disclosure to the child (the American academy of paediatrics, 1999; National Department of Health, 2020). In a study conducted by Vaz, Maman, Eng, Barbarin, Tshikandu and Behets (2011) regarding patterns of disclosure of HIV-status to Infected children in a Sub-Saharan African, found that nearly one-third of care givers saw no benefits to informing the child of her/his HIV status. Most care givers felt that they themselves were the best to disclose to the child, but some needed support from health care providers. Hence, children should receive a disclosure service with a prepared primary care giver and in a friendly space assisted by a qualified health care giver (National Department of Health, 2016).

### *Pre-disclosure assessment stage*

During this stage, caregivers explore how the children are functioning emotionally, cognitively, socially, and economically (National Department of Health 2016). The American Academy of peadiatric also recommends that disclosure of HIV infection status to children should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context (American Academy of peadiatric, 1999). It is important to assess whether a child is ready to be disclosed and/or the extent to which the disclosure is important. The assessment should take place in a discussion with the primary care giver or other family members where possible. The Pre-disclosure assessment should not be conducted in front of the child (National Department of Health, 2016).

### *Actual disclosure session*

Once the child is comfortable and relaxed, the care givers need to utilize the tools provided to discuss the health of the child and use age-appropriate terminologies. Allow the child to ask questions and answer as truthfully as possible, using pictures and tools to ensure that the child understands and allows the child to express emotions (National Department of Health, 2016 & 2020). However, Kiwanuka, Mulogo and Haberer (2014) conducted a study on caregiver perceptions and motivation of HIV disclosure and found that care givers deceive children regarding the correct HIV and ART information. It is important to assess the levels of disclosure and support required at each follow-up with the children. The disclosure follow-ups process can take place informally in clinical follow-up sessions, but if it is evident that the children require more time or has questions, then a referral to a counsellor is recommended to take the disclosure further. If the child does not initiate questions or issues, regular follow-up sessions are scheduled to build the relationship and allow more time for child to digest the information (National Department of Health, 2020).

The American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children. The process for disclosure should be discussed and planned with the care giver and may require several visits to assess the child's knowledge and coping capacity. A significant effort should be directed to facilitating and managing the child in coping with the illness. Symptomatic children, particularly those requiring hospitalization, should be informed of their HIV status. The possibility of children accidentally learning about their status in a hospital setting is high. Moreover, the disclosure should optimally be conducted in a controlled situation with care givers and knowledgeable professionals (American academy of peadiatric, 1999; National Department of Health, 2016).

### 2.6.2 Level of Disclosure

Most importantly, to make the disclosure process easy NDoH has recommended different levels of disclosure. Non-disclosure is when the child is unaware of their illness and its effect on their body, partial disclosure is when the child is made aware of their illness without naming HIV (National Department of Health, 2020). Aderomilehin, Hanciles-Amu and Ozoya (2016) indicated that partial disclosure is appropriate for children up to early adolescence. Full disclosure is when the child is made aware of their illness which is named HIV. Health-promoting disclosure is when the child knows everything about their disease that is appropriate for their age (National Department of Health, 2020). The complete disclosure process is when the child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure within a children's rights framework (national Department of Health, 2016).

Children who are fully disclosed become self-motivated and are more likely to adhere to Antiretroviral Therapy (ART) and overcome external adherence challenges. Therefore, for ART to be successful, sustained, and optimum adherence is required (Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa & Mupepi 2018).

### 2.6.3 Types of Disclosure

There are 5 types of HIV disclosure outlined in South African HIV disclosure guideline. In prepared disclosure, the primary care giver and the child are fully prepared for the disclosure process. Unprepared disclosure is when either the healthcare provider, the primary care giver or the child are not fully prepared for the disclosure process. Involuntary disclosure is when the primary care giver is forced into disclosing to the child due to circumstances. Accidental disclosure the child becomes aware of their illness purely through an unplanned occurrence (National Department of Health, 2016). WHO strongly recommends that the children should receive prepared disclosure, to avoid other types of disclosure because they do more harm psychologically and emotionally (Abegaz, Walle & Tilahun 2019; American academy of peadiatric,1999).

### 2.6.4 Development and age-appropriate disclosure

Furthermore, to implement age-appropriate HIV disclosure, the South Africa HIV disclosure guideline outline step by step guide to facilitating disclosure in children. However, it remains a difficult process for all the parties concerned. Effective conversations are dependent on the age and understanding (developmental level) of the child. The purpose is to build up a body of knowledge in the child that leads to the point of disclosure of HIV diagnosis. The fundamental step is to find out what the child already knows (WHO, 2011; National Department of Health, 2020; American academy of peadiatric, 1999).

*Very young (age 0 – 4 year)*

There is no disclosure at this stage, developmental level depends on adult for all needs and information and child needs comfort, support, and most of all security. The care giver and healthcare provider need to carry on consultation with child present. At this stage the child is too young for direct information about HIV but explanations to the caregiver about how HIV cannot affect the child remain important. The Healthcare providers need to help the care giver to support the child in taking medicine and congratulate the child on taking medicines well. Healthcare providers need to address care giver anxieties, build a relationship with the child through play/singing and provide a safe and welcoming clinic. This is because the purpose of this stage is to build up the confidence of a child in caregivers, healthcare provider and medicine taking (National Department of Health, 2020).

*Young child (pre-school) 5 – 7 Years*

Early disclosure is initiated at this stage because the child can understand concrete-based ideas e.g., real events in the present and past and thinking is based on the present (National Department of Health, 2020). However, many care givers prefer the age to initiate HIV disclosure to be above 10. When the child's age is 10 and above, he/she has 80% more likely to be informed about his/her status (Shallo & Tassew, 2020). The child can take the lead from confidence of care giver interactions with healthcare provider, and they begin to link the role of medicines and health. The child needs to learn about illness but not HIV by name yet. Introduce ideas of good and bad health by eating healthy food, keeping clean, exercising, and looking after teeth. The child learns that medicines help to keep a body healthy and strong. Care givers need to introduce infections as 'germs' that can hurt or damage the body/make you sick or hurt. Introduce (white) blood cells as the part of the body that looks for and kills infections or germs, state that some germs hide, and you need to take medicines to help fight the germs. At this stage, the child starts to understand that medicines support the body to keep you well (National department of Health, 2020).

*School-going child (8 – 11 years)*

Partial disclosure is done at this stage because the child can hold onto ideas and apply them to new situations, and can understand the past, present, and future. However, a study conducted in India by Meena *et al.,* (2018) found that Forty-seven percent of care givers believed that the most appropriate age for HIV disclosure should start between 10-12 years. The child has social and moral awareness about right and wrong behavior. They are beginning to be more curious and take some control over their lives. The care giver needs to explain that the germ concerned is a virus. Viruses are 'clever germs' which can damage white blood cells. If medicines are not taken correctly, the virus can get stronger and stop the medicines from working (resistance). The naming of the virus as HIV may occur but is not essential, there is a need to explain that information is private and should only be shared with those agreed with the care giver. The child is assisted to identify who they can talk to about their health or HIV. The disclosure to symptomatic school-age children is strongly encouraged (National Department of Health, 2020).

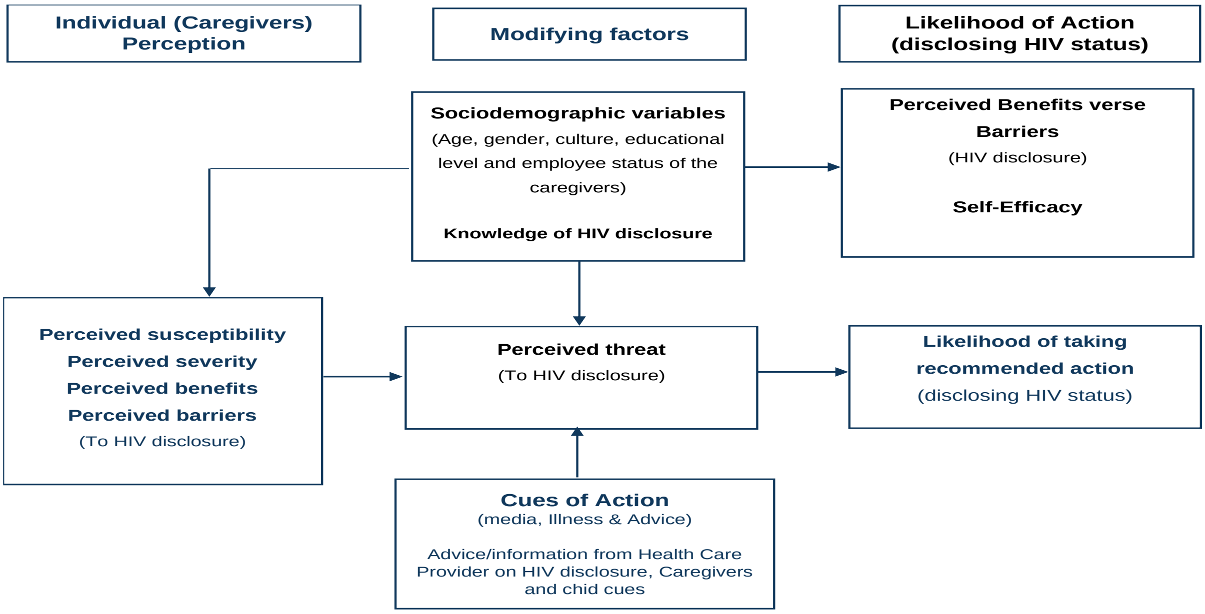
*Teenager (11 – 14 Years)*

Full disclosure is done during this stage because the child has more abstract thinking, increasingly making decisions on their own regarding identity, independence, school, and career. Moreover, children depend less on caregiver and importance of relationships with friends increases. Moreover, children who are informed of their HIV status they make appropriate decisions about treatment, participation in clinical treatment trials and consequences for many aspects of their health, including sexual behavior (American Academy of peadiatric, 1999; National Department of Health, 2016). The child needs to understand the responsibility for not transmitting HIV i.e., safer sex, and their rights i.e., family planning and confidentiality. The child needs to be prepared for the future and encourage direct involvement in discussions and decisions. Advise the child on the benefits of attending an adolescent support group. The outcome of this stage is for the child to fully understand their rights and responsibilities, and the ability to negotiate their healthcare (National Department of Health, 2020).

## 2.7 THEORETICAL FRAMEWORK

The theory is a systematic, abstract explanation of some aspects of reality. “Therefore, theories and conceptual models are the main tools used by researchers to consolidate findings into a wider conceptual context” (Polit & Beck, 2017). The researcher identified the HBM as a theoretical framework to the study as its aligned to the problem statement and objectives of the study. The concepts related to the theoretical model also assisted the researcher to perform a literature search and also to conceptualize the study within the context of the topic. HBM have six contracts which are factors that determine health behaviour as a person perceived threat to illness (perceived susceptibility), belief of consequence (perceived severity), possible positive benefits of action (perceived benefits), perceived barriers to action (perceive barriers), exposure to factors that prompt action (cues to action), and confidence in capacity to succeed (self-efficacy) (Strecher *et al*., 1997). Tarkang and Zotor (2015) state the HBM has part which include Individual perception, modifying factors and Structural variables.

The researcher utilized all the six constructs to align the theory to the topic under study. Additionally, the researcher also explored perceived threat or the fears that care givers have when they plan about starting HIV disclosure processes. Moreover, the researcher utilized Health Belief Model to guide the development of interview guide for data collection. Below is a diagrammatic representation of the HBM:



*Source: HBM diagram, Adapted from Stretcher, Champion & Rosenstock (1997)*

Figure 2.1 The Health belief model.

## 2.8 PERCEIVED THREAT TO NON-DISCLOSURE OF HIV POSITIVE STATUS

Refers to an individual perception on how the outcome will be severe if the condition will occur (Joseph, 2018). Domek, (2010) states that children will feel the psychosocial stress of a serious illness whether disclosed or not. Non-disclosure may even cause poor psychosocial change. Non-disclosure of HIV status has been identified as one of the possible risks to optimum adherence, especially in children. “Non-disclosure is related to poor adherence, which would lead to treatment failure, increased viral load, increased risk of early disease progression or dramatic changes in the clinical course of HIV infection, and consequently decreased survival time of these children” (National Department of Health, 2016; WHO, 2011).

Moreover, children living with HIV and are non-adherent on ART, they could potentially transmit drug-resistant virus to their sexual partners through unprotected sex, thereby increasing HIV spread (Hayfron-Benjamin *et al.,* 2018; Van Elsland *et al.,* 2018). “Delaying disclosure contributes to children’s refusing to take their medication in future, leads to the accidental disclosure of HIV, give rise to anger and resentment towards the caregiver, increases the risk of secondary transmitting of HIV, and poor health outcomes” (Madiba & Diko, 2020; National Department of Health, 2016). Non-disclosure if allowed to continue would have negative results for not only the affected children but the entire Nation. This is because non-disclosure will lead to non-adherent and consequently poor treatment outcomes such as treatment failures, increasing drug resistance strains, increased viral load, and associated risk of HIV transmission to the general population (Hayfron-Benjamin *et al.,* 2018).

## 2.9 PERCEIVED BENEFITS OF HIV DISCLOSURE TO CHILDREN

This refers to an individual perception on the importance of engaging in good health behaviour to reduce risk of the disease (Onoruoiza, Musa, Umar, & Kunle, 2015). Children who know their HIV status have higher self-esteem than children who are unaware of their status (American academy of peadiatric, 1999; National Department of Health, 2016). South African HIV disclosure guidelines also highlighted that disclosure of HIV status to children reduced mortality and morbidity, increases psychosocial functioning of child and family, and improves child health and welfare (National Department of Health, 2011). “According to peadiatric HIV disclosure process-oriented framework indicate that disclosure decreases anxiety, improves self-esteem, does not negatively affect the child’s quality of life, and promotes independent medication practices” (Cantrell *et al.,* 2013).

In Tanzania, a study conducted by Bulali, Matthew, Bonaventura and Mpondo (2018) found that HIV status disclosure was associated with ART adherence and increased the odds of having good quality of life. Disclosure also provides the child with information and knowledge, decreasing stigma and victimization, less secrecy, better adherence to medication, less anxiety, improved attitudes, and quality of life. Children become a part of their health management plan and as a result, their opinions are considered. Children develop responsibility for their own health and proactive health-seeking behavior. Empowered with vital information led to better self-care and decision-making around health and prevention of transmission (American academy of peadiatric, 1999; Cantrell *et al.*, 2013).

Sariah, Rugemalila, Somba, Minja, Makuchilo, Tarimo, Urassa and Siri, (2016) also state that “disclosure increases the use of antiretroviral therapy in low-resource settings, children with HIV/AIDS tend to live longer. Children who are aware of their HIV-positive status have better abilities to seek social support, improved coping skills and practice safer sexual practices to prevent secondary transmission”. A similar study conducted in Uganda found that the benefits of the disclosure include good adherence, improved healthcare and better dialogue among adolescents, care givers, and healthcare providers (Namasopo-Oleja, Bagenda & Ekirapa-Kiracho, 2015).

Many care givers state that after HIV disclosure children had increased adherence to medication after learning about their infection. There was a supportive and trusting relationship with the care giver and the child sought ways of dealing with stigma as opposed to situations where the care giver had to force or bribe the child to take his/her medications for those who did not disclose the illness to their child (Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui, 2010). A study conducted in Kinshasa, the Democratic Republic of Congo by Phiri and Chilemba (2015), found that care givers reported that they felt sad and worried about stigma. However, the same author indicated that care givers state that children expressed relief; felt it is necessary and important to know as they would not worry anymore and expressed that knowledge helps to avoid being sicker and enabling to protect others (Phiri & Chilemba, 2015).

The UNESCO's strategy for HIV and AIDS also states that as these children grow older into adolescents, the knowledge about their disease will enable them to make safe and healthy life choices about relationships, sex, and reproduction (UNESCO, 2011; Hayfron-Benjamin *et al.,* 2018). HIV/AIDS disclosure becomes more significant because of the multiple benefits for the children and their caregivers. Disclosure is related to good or improved adherence to ART medications and influences children's participation in healthcare decision-making. It also enables children to understand HIV infection and make sense of their disease-related experiences as well as the importance of adherence (Tamir, Aychiluhem & Jara, 2015).

## 2.10 PERCEIVED BARRIERS TO HIV DISCLOSURE TO CHILDREN

This refers to a person's feelings on the obstacles to performing a recommended health action (Onoruoiza *et al*., 2015). Understanding the major barriers to HIV disclosure is necessary to prepare HIV-positive children for the HIV disclosure process. It is often assumed that children are 'not old enough' to comprehend the nature of a terminal illness. However, children are aware of the seriousness of their illness long before it is disclosed to them (American academy of peadiatric, 1999; Domek, 2010). Children may understand others' behavior toward them as meaning that they are ill. They also learn from overheard conversations between care givers and healthcare providers (Domek, 2010).

Therefore, some of the barriers to HIV disclosure indicated by care givers is that children are ‘not ready for disclosure because they have not been asking questions (Mweemba, Musheke, Michelo, Halwiindi, Mweemba and Zulu (2015). Children may decide not to ask questions about their illness for several reasons. Additionally, it is an expectation in many cultures that children will not ask questions. This is because children are at the bottom of the societal hierarchy. It is often inappropriate for a subordinate to question anyone in a superior social position. Simply because children are not asking direct questions about HIV does not mean that they are not ready to begin discussing their illness (Domek, 2010).

Care givers also avoid disclosure because they fear that children might accidentally reveal the diagnosis to other family members. The anticipated negative outcomes related to stigma may delay or prevent disclosure (Wariri, Ajani, Raymond, Iliya, Lukman, Okpo & Isaac, 2020). While these fears are very real, they should not override the multiple benefits of disclosure and open communication with children. The care giver may be quite surprised by how much their child already knows because children learn a lot by observations (Domek, 2010).

Care givers often struggle with the issues of when and how to begin the disclosure process (Baker, Bayer, Kolevic, Najarro, Viani & Deville, 2018; Domek, 2010; Mandalazi, Bandawe & Umar, 2014). Same authors further state that care givers are fearful of stigma and fear that children might not accept the information. It has been found that lower prevalence rates of HIV disclosure are related to fear of stigma and discrimination by the family members who are not aware or/and care givers who perceive they are not emotionally prepared. Care givers fear that once the HIV-positive status has been disclosed to a child they will disclose to others causing stigma and discrimination against the family. Other fears from caregivers include fear of isolation, and a child’s negative emotional reactions such as suicide, guilt and blame related to the perception that HIV is transmitted by promiscuousness (Doke, 2010). “Disclosure counselling to the care givers is important because it prepares and enables them to support disclosure in their children” (Sariah *et al.,* 2018).

A critical review of the literature conducted by Phiri and Chilemba (2015) in Soweto, South Africa, revealed that care givers reported discrimination, being judged as promiscuous, social rejection, isolation and disclosure being emotionally and psychologically challenging has led to Non-disclosure of HIV status. Additionally, care givers in South Africa indicated that they feared that the child would discuss his/her infection with other people. Phiri and Chilemba also indicate that in Kenya care givers "reported fear of negative psychological consequences after disclosure and the possibility of the child disclosing to other people" (Phiri & Chilemba, 2015).

Thus, for HIV disclosure to be successful, a favorable environment needs to be created. In this environment, we need to maximize facilitators and overcome Barriers to HIV disclosure. This would help improve their skills in peadiatric disclosure, leading to positive health outcomes for children infected with HIV (National Department of Health, 2016).

## 2.11 PERCEIVED CUES FOR HIV DISCLOSURE TO CHILDREN

This is the internal and external stimulus needed to trigger the decision-making process to accept an indorsed health action (Glanz, Rimer & Viswanath, 2015). Unfortunately, many care givers feel unprepared to disclose to their children due to lack of knowledge about HIV infection, transmission, and treatment and would like guidance on how to disclose (Baker *et al.,* 2018). Care givers who believed that disclosure had benefits to children living with HIV, were 10 times more likely to disclose their HIV status to their children. However, care givers expressed deep-seated feelings of guilt and self-blame, HIV-related stigma, and cultural sensitivity around HIV (Wariri *et al.,* 2020).

Care givers who had disclosed indicated that they disclose because of healthcare providers' advice, children's desire to know and concerns that children might initiate sexual activity before knowing or discovering their HIV status by accidental (Beck-Sagué, Pinzón-Iregui, Abreu-Pérez, Lerebours-Nadal, Navarro, Ibanez, Soto, Halpern, Nicholas, Malow & Dévieux, 2015). "Non-disclosing care givers worried that children would be traumatized by disclosure or stigmatized if they revealed it to others" (Beck-Sague *et al*., 2015)

Sarkar, Selvaraj, Krishnamurthy, Balasundaram and Lakshminarayanan (2018) state that most care givers manage with deception to avoid or delay disclosure until they feel their own readiness to disclose (Kiwanuka, Mulogo, Haberer, 2014; Namasopo-Oleja *et al.,* 2015). “Care givers state that they do disclose HIV status only if the child starts to ask why they were taking medication, threats by children not to take HIV medication, desire to promote treatment self-efficacy amongst children as well as facilitating the adoption of safe sexual behavior among adolescents. The disclosure processes were conducted either at the home or at the clinic” (Mweemba *et al.,* 2015).

## 2.12 PERCEIVED SELF-EFFICACY TO INITIATE HIV DISCLOSURE TO CHILDREN

This refers to the level of an individual's confidence in his or her ability to successfully execute a behavior (Strecher et al., 1997). South African HIV disclosure guidelines highlighted those care givers have little knowledge regarding disclosure issues, and they do not feel prepared to initiate the HIV disclosure process (South Africa, 2016). Thus, to promote the appropriate implementation of procedures for HIV disclosure to children, it is important to understand the capacity of caregivers in HIV disclosure to children (Madiba, 2016).

A study conducted in Botswana and South Africa by Madiba (2016) found that care givers had knowledge that children should be told of their HIV-positive status even though none had disclosed this information to the children. Moreover, the same author further stated that some caregivers reported a lack of HIV knowledge, lack of communication skills on HIV, lack of skills on how to conduct HIV disclosure and disclosure skills. Care givers believed they are mainly responsible for HIV disclosure to children and required support from healthcare providers during the disclosure process. They believed that counselling on how to approach disclosure and training on when and how to disclose will make the disclosure process easier. Healthcare providers have a crucial role to play in promoting disclosure to perinatally infected children (Madiba, 2016; Hayfron-Benjamin *et al.*, 2018).

Due to lack of knowledge care givers expressed uneasiness and apprehension with the disclosure conversation, whether they had already told their child that he or she had HIV (Mandalazi *et al.,* 2014). Care givers who had not told their children recounted that they had contemplated starting the conversation but could not gather enough courage to follow through with those thoughts. Care givers cited the fear of robbing their child of the happiness of living without the knowledge of being positive, fear of making their own status known to more people, and fear of confrontation or creating enmity with their child as barriers to disclosing their child’s positive HIV status to him or her (Mandalazi *et al.,* 2014). Moreover, HIV-positive children have indicated that the reasons why their caregivers do not talk to them earlier about their HIV status include not knowing enough about the disease symptoms, diagnosis, and treatment (Sariah *et al.,* 2016).

In sub-Saharan Africa, Madiba and Diko (2020) found that care givers delay HIV disclosure because of lacking disclosure skills or knowledge of how to disclose. Hence caregivers feel unprepared even to answer some of the questions from children. These have been identified as major barriers to the early initiation of HIV disclosure to children. As such, WHO recommends that many caregivers require assistance from healthcare providers to prepare them to initiate and facilitate disclosure to their children. WHO Suggest that the lack of care giver readiness has redefined the role of healthcare provider to that of educating, empowering, and persuading caregivers about the importance of HIV disclosure (WHO, 2011; Madiba & Diko, 2020).

Most of the children’s care givers prefer disclosure by a health professional than themselves. This is due to a lack of clear guidelines on the roles and responsibilities of healthcare providers and standardized training in peadiatric HIV disclosure. Care givers’ lack of skill in how to disclose is a contributing factor to poor disclosure of the HIV status of the child (Shallo & Tassew, 2020).

## 2.13 SUMMARY

The literature review was conducted to provide a comprehensive insight on HIV disclosure in children globally and nationally. It is evident that further studies on the topic of interest within South African context will contribute to the body of knowledge. The following chapter will detail the research design and methods used in the study to respond to the objectives of the study.

# CHAPTER 3

# RESEARCH METHODOLOGY

## 3.1 INTRODUCTION

The previous chapter detailed literature reviewed related to the research question. Several literatures indicate that HIV disclosure in children is inevitable and significant to improve the overall health outcomes for the child. This chapter detailed a research design and methods that were applied during the implementation, to fulfil the purpose of the study namely, to determine and explore the experience of care givers on the disclosure of positive human immunodeficiency (HIV) virus status on children diagnosed with the infection and on antiretroviral treatment, at selected clinics in Mopani district, Limpopo province. This chapter will provide a comprehensive description of the research approach, design, setting, population, sample, sampling technique, data collection technique, data collection tool, and data analysis. This chapter also highlights ethical issues and measures taken to ensure the trustworthiness of the study. The reasons behind the choices of methods and design were further explained in this chapter. A qualitative exploratory descriptive study was conducted to answer the research question.

## 3.2 RESEARCH SETTING

According to Brink *et al.,* (2018); Polit and Beck (2017); Grove *et al.,* (2016) a research study setting is defined as a specific environment where the information is obtained. The researcher conducted this study in a real life setting in Mopani District Limpopo Province, South Africa. Mopani District is one of the five districts of Limpopo province in South Africa. Mopani District is situated in the North-eastern part of the Limpopo Province, 70 km and 50km from Polokwane along provincial roads R81 and R71 respectively. Mopani District consists of five subdistricts namely, Greater Tzaneen, Giyani, Letaba, Ba-Phalaborwa and Maruleng, as depicted on the map below (see the figure 2 below). However, the study was conducted in 4 selected ART clinics in greater Tzaneen subdistrict as indicated in an arrow pointing.

**Figure 3.1** *Mopani District Map (Source: Muscoosa.co.za)*

## 3.3 RESEARCH DESIGN

Polit and Beck (2017); Babbie and Mouton (2009); Creswell (2013) state that research design is the complete strategy for responding to a research question, including the plan for enhancing the study's integrity. The researcher utilized the design to organise a research project in such a manner that the eventual research findings are strengthened.

The researcher applied qualitative, explorative, and descriptive design to respond to the objectives of the study. Qualitative research is a systematic, subjective approach which describes the deepest life experiences and circumstances from the perspective of the participants, in the context where the action takes place (Hyejin, Sefcik & Bradway, 2017; Grove *et al*., 2016). No interventions were introduced, the setting was not controlled, and the data from care givers were collected in the natural environment (Polit & Beck 2017). The researcher only focused on the assessment of the experience of caregivers rather than my personal knowledge De Vos, Strydom, Fouché and Delport (2011).

Phenomenology is a qualitative research technique utilised to describe a lived experience of a phenomenon. It was inspired by the branch of philosophy that concerns the phenomenon of human consciousness (Polit & Beck 2017). Phenomenological studies attempt to deeply understand human nature and individuals' perspectives on a given situation; that was, describing really lived experiences.

### 3.3.1 Exploratory research design

Exploratory research describes the whole characteristic of the phenomenon, the nature in which it is manifested and the factors to which is associated with (Polit & Beck, 2017). The researcher used explorative design in the study to explore the experiences to HIV status disclosure to children living with HIV.

### 3.3.2 Descriptive research design

Descriptive research provides an accurate account of the characteristics of a particular individual or group in real-life situations for the purposes of discovering new meaning and describing what exists (Boswell & Cannon, 2017). The researcher used descriptive design in the study, to describe experiences of primary care givers regarding HIV disclosure to children living with HIV. Boswell and Cannon (2017); Brink *et al*., (2018) further state that descriptive studies may be used to diagnose problems with current practice or to justify or determine current practice, and to make judgements or to generate theory. Using the design, the researcher was able to gather comprehensive and accurate information from care givers through face-to-face interviews. The design was appropriate in addressing the objectives of the study because the purpose of the study is to determine and explore experiences of HIV disclosure to children living with HIV among primary care givers.

## 3.4 RESEARCH METHODOLOGY

Polit and Beck (2017); Grove *et al*., (2016) explain the research method as a set of techniques a researcher utilises to structure a study and gather information relevant to the research question. Babbie and Mouton (2009) further state that research methods refer to all the measures followed by the researcher to collect and analyse data in a study. The researcher below detailed a method that was applied to structure the study to collect information that was relevant to respond to study questions.

### 3.4.1 Population

Population refers to the people with characteristics, knowledge, or experience of which the researcher was interested De Vos *et al*., (2011). The researcher was interested on the people who have the characteristics that are of significant to the study. However, due to the large sizes of populations, the researcher did not interview every individual in the population because it was going to be too expensive and time-consuming (De Vos *et al*., 2011). Polit and Beck (2017) differentiate the two categories of population, namely the target and accessible population. The target population refers to the aggregate of cases about which the researcher would like to generalise, while the accessible population is defined as the aggregate of cases that conform to set criteria and are available as subjects for a study.

The researcher had access to primary care givers of children living with HIV and on ART in Greater Tzannen subdistrict. Purposive sampling was utilised to select clinics with high numbers of children on ART, namely Grace Mukden Health Centre (103 children on ART), Motupa clinic (62 children on ART), Carlotte Clinic (91 children on ART) and Dan Village clinic (78 children on ART). The researcher only collected information from a particular population who met a set criterion through eligibility criteria (Moule, Aveyard & Goodman, 2017).

### 3.4.2 Eligibility Criteria

Eligibility criteria define who should be included or excluded in the population of the designed study (Polit & Beck 2017). The researcher had a specific criterion that define which population to be included in this study as the outline below (Creswell & Poth 2018).

*Inclusion criteria*

Grove *et al* (2016) describe inclusion criteria as all attributes significant for inclusion in the target population. Primary care givers of children who are infected with HIV, collecting ART in 4 selected clinics in Greater Tzannen Subdistrict, who have been living with the child since the child is 5 year old and are willing to participate in the study were included in the study.

*Exclusion criteria*

Exclusion criteria define who should not be included in the study (Leedy & Ormrod 2010). Primary caregivers of children who are not living with HIV and not on ART in selected clinics and those who are not willing to participate in the study were not included in the study.

### 3.4.3 Sampling

Polit and Beck (2017) define sampling as a process of selecting a part of the population to represent the entire population. Creswell and Poth (2018) also state that sampling is the process of selecting a small portion of the total set of objects in a way that represents the population of interest.

The researcher used non-probability sampling to sample the facility for inclusion and the participants in the study. The purposive sampling method was used to select the sample, which involves selecting people or settings with varying dimensions of interest to the researcher (Polit & Beck 2017). Purposive sampling was done based on specific characteristics of the participants, the participants based on the judgement of the researcher provided knowledge by virtue of knowledge or experience (Etikan Musa & Alkassim 2016).

### 3.4.4 Data saturation

In a qualitative study the size is determined by data saturation, which occurs when more data does not lead to more information or adding more participants does not result in obtaining additional information (Polit & Beck, (2017); Vasileiou, Barnett, Thorpe & Young, (2018). Polit and Beck (2017). The researcher interviewed 16 participants and realised data saturation was reached because there was no new information given by participants, the information sounded the same. Phenomenological studies typically rely on small samples of participants – usually 10 or fewer (Polit & Beck 2017).

## 3.5 DATA COLLECTION

According to Grove *et al*., (2016), data collection is an accurate, systematic assembly of information relevant to the research aim or the specific objectives and questions of a study. The researcher had a predetermined plan on how to collect data and to avoid disorganising the facility and participants not in the facility.

### 3.5.1 Data collection method and Approach

Qualitative interviews are either open or structured and when you are conducting semi-structured the researcher needs to prepare the interview guide which included predetermine questions (McGrath, Palmgren & Lileah, 2018). Data collection methods are distinguished by three different dimensions: structure, researcher obtrusiveness and objectivity. The structure of the data collection is either structured or unstructured. If the data collection is structured, the researcher collects data from participants in a comparable and pre-specified way (Polit & Beck 2017). In the study, the researcher used semi-structured and face-to-face interviews to collect data from participants. The approach allowed the researcher to control how and what information to be collected. However, the researcher allowed the participants to be free to explain their experiences without restrictions.

The researcher conducted an interview more like a discussion between the researcher and participants. The researcher developed questions in an open-ended to avoid leading the participants or channelling their responses. The open-ended questions were not based on predetermined answers, this allowed caregivers to provide richer and more diverse information. The semi-structured face to face interview method was interactive to enable participants to give deep, rich, and detailed information.

### 3.5.2 Data collection instrument

Polit & Beck (2017) state that to successfully conduct an interview, there should be an interview guide which is used as a data collection instrument to guide the interview process. The researcher used self-developed interview guide to gather data from participants. The researcher wrote questions to cover all areas required. During the proposal stage, the researcher have written the interview questions in English and submitted them to the supervisors, got feedback and changes were made and the interview guide was translated into Tsonga and Sepedi. See attached Interview questionnaire (Appendix H).

### 3.5.3 Pilot study

De Vos *et al*., (2011) describe the aim of piloting as to see if the data collection tool addresses the research questions and to see if the participants will be able to understand the questions. Pilot study is whereby the researcher learns about his or her own level of interviewing skills and is familiar with the questions to be asked (De Vos *et al*., 2011). Nevertheless, no matter how well the sampling and analysis are done, an ambiguous questions lead to wrong responses and ultimately to incorrect conclusions.

The researcher piloted the interview guide in a similar environment to that of the actual study. A pilot was done at the Lenyenye clinic which was not part of the clinics to be used in the main study. The researcher conducted a pilot to investigate the practicability of the main study and to identify the possible pitfalls of data collection instruments that need revision (Brink et al., 2018). During the pilot the researcher selected participants meeting the selection criteria to conduct interviews. Study information was given in the waiting area of the ART clinic and 4 caregivers volunteered to participate in the pilot. Information regarding the study was provided to individuals, and a consent form was signed. The interview question that opened the conversation with individual participant “The interview took an average of 35 – 45 minutes to complete the interview session including the use of probing question session. At the end of the pilot, the researcher requested participants to give honest feedback on the questions to identify challenges experienced during the process. The results of the pre-test did not form part of the actual study; however, the aim was to enlighten the researcher against the time, clarity, and sensitivity of the interview guide. The researcher identified that there were two similar questions, one was removed and replaced by a different question. A gap was identified when interviewing a caregiver who already disclosed, so two additional questions when added to explore more from these care givers.

### 3.5.4 The data collection process

The researcher collected data during the days that the care givers were accompanying their children collect treatment. The dates and time for data collection were communicated with the participants. At the beginning of data collection, the researcher welcomed each participant on entering the room, the researcher introduced himself then briefly explained the participant’s eligibility criteria to clarify to participants as to why they were selected to participate in the study. The aim of the study was explained, ethics clearance, Provincial and District permission letters to collect data will be shown to participants. The researcher also explained the process of data collection and management, including the ethical considerations in maintaining anonymity, privacy, and confidentiality. The researcher informed participants about their rights to refuse to participate or to withdraw their participation without explanation or consequence. The participants voluntarily participated in the study. Participants volunteered to participate by signing the prepared consent form, see attached consent form (Appendix G).

After the participants show interest, the researcher explained the importance of obtaining informed written consent from the participant as a means of an agreement that he or she is willing to participate. The researcher has obtained permission from the participants to audio-recorded the interview using the prepared consent form. The researcher was also writing field notes during the interview to capture the original accounts of the participants' responses and to verify their interpretations by referring to the original responses. The details that made up the interview context such as reactions, confidence in answering questions, hesitations, and the tone of participants were recorded in the notes, and they formed part of the data. Each sheet of paper was given a code so that the actual names of the participants were not written to maintain confidentiality.

The interviews were conducted in Tsonga and Sepedi in a private, quiet, and a comfortable consultation room at the facility. The researcher used a range of communication skills such as attentive listening, clarifying, paraphrasing, and probing to improve understanding and to direct the participants to explain more in their responses. The interview lasted between 12:58 – 15:26 minutes to complete. All data were stored safely in a locked cupboard. Moreover, data was saved on the computer with a password at the researcher's home. At the end of each interview, the researcher summarised what the participants indicated and requested the participants to confirm it is the true reflection of what they had said.

## 3.6 DATA ANALYSIS

Polit and Beck (2017) state that data analysis is the systematic organisation and synthesis of research data. Data analysis is conducted to reduce, organise, and give meaning to data (Grove *et al*., 2016). Analysis of data in qualitative studies, therefore, includes an examination of words rather than numbers, as is done in quantitative studies (Brink *et al.,* 2018). In qualitative research, data collection and data analysis usually occur concurrently rather than after the data has been collected as in quantitative studies (Polit & Beck, 2017). The researcher used thematic analysis which is a search across a set of interview data to discover repeated patterns of meaning. Data were analysed using the ATLAS.ti 9 program, according to the thematic method of analysis. The researcher and coder followed the following steps of data analysis:

### 3.6.1 Transcription of interviews

The researcher listened to the recording several times, soon after the interview and the recorded information was also compared with the field notes taken on the same day to identify any common important relationships that could be considered in developing codes, and themes. The recording was transcribed or typed verbatim into a word document.

### 3.6.2 Reading and re-reading

The transcribed data and the notes made during the interview were read and re-read several times so that the researcher can be more familiar with the data. The audio recordings of the interviews were listened to again to verify and confirm the precision of the transcription. The entire sets of transcripts were read also to distinguish irrelevant units from the participant's description of the experience under study.

### 3.6.3 Coding

The researcher and the independent coder read the transcript to identify specific or repeated words, phrases, sentences, and paragraphs to create headings. Some codes were repeating show emerging categorizes. Meaningful segments were located, and codes were assigned to them. Whenever the researcher identifies a meaningful segment of text in a transcript, a code was assigned to signify that segment. The process was continued until all the data have been segmented and initial coding was completed. See the attached independent coder certificate (Appendix I).

### 3.6.4 Creating categories and building themes

Categories were created by the linking codes which had similar meanings. Categories were reduced and grouped together to show that they were related and main features of the themes and sub-themes from the data were produced as tables. Evidence from the interview and quotations which the researcher felt best captured the essence of the participants' experiences regarding HIV disclosure to children living with HIV were extracted.

## 3.7 MEASURES TO ENSURE THE TRUSTWORTHINESS IN THE STUDY

Connelly (2016) defines trustworthiness as the degree of confidence in data collected and the interpretation and methods used to ensure the quality of a study. Therefore, to enhance the trustworthiness of the study, the researcher used four criteria for trustworthiness which include credibility, dependability, transferability, and confirmability (Polit & Beck, 2017).

### 3.7.1 Credibility

Credibility is a criterion for evaluating data quality in qualitative studies, referring to confidence in the truth and interpretation of the data (Polit & Beck 2017). Credibility was achieved by the extent that which the research methods produce confidence in the truth of the data and in the researcher's interpretations of the data (Grove *et al* 2016). Credibility was maintained by prolonged engagement; the researcher spent enough time with participants when collecting data and by listening to the audio-recorded interview several times and reading and re-reading transcripts to be fully engaged with the data. The researcher applied the following steps in promoting confidence in the study.

*Member check*

The researcher frequently checked whether the participants' responses were interpreted correctly by reflecting at the end of each interview. The researcher used communication techniques to verify paraphrasing by stating participants' words to enhance meaning and reflecting on something that the participant has just said. The researcher checked and verified participants' information on the spot and at the end of an interview session. The researcher played out to each participant what was collected to ensure that it is correct, and that the information reflects what they shared with the researcher. Participants also were asked if there is anything they wanted to be removed or added. Data was also coded by an independent researcher who is an expert in the subject matter. See attached independent coder certificate (APPENDIX I).

*Tactics help to ensure honesty in participants when contributing to data*

The researcher allowed each participant to refuse to participate or withdraw from the study at any point in time. The method guaranteed that the data collection involved only participants who were sincerely prepared to take part and were ready to offer data freely.

*The thick description of the data*

The researcher kept a comprehensive description of the environment where the study was conducted, the participants' expressions when being asked questions and when answering, and the whole steps that the study followed to convey the actual situations and the situations that surround them, to also allow academics, the reader of the final account and the peers to determine the extent to which the general findings are true.

### 3.7.2 Transferability

Polit and Beck (2017) define transferability as the degree to which the findings of a qualitative study can be used by other populations. The researchers provided adequate descriptive data so that the readers can evaluate the applicability of the data to other contexts. The researcher provides a comprehensive discussion of the research methods, setting, data collection, data analysis, and interpretation of research findings in this study. The thick description included the nature of the study participants, their reported experiences and the researcher's observation during the study. The researcher provided sufficient information to permit judgement about the transferability of the research findings. Purposive sampling of participants who had enough experience of living with HIV-infected children was done.

### 3.7.3 Dependability

Polit and Beck (2017) state that dependability indicates that the techniques, if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be attained. The researcher has used audit trails in which approaches to data collection, decisions about the type of data to be collected and analysis of data were carefully documented. In the study, a recording device during the interview was used. To ensured that data was kept real as it was directly narrated by the participants and there is no way the data can be altered. The researcher explained in detail the research design, its implementation, describing what was planned and executed and the operational detail of the data collection process. Coding was done by an independent coder, which was not part of the research.

### 3.7.4 Confirmability

Confirmability refers to the assurance of the findings, conclusions and recommendations are supported by the data, and that there is an internal agreement between the investigator's interpretation and the actual evidence. (Brink *et al* 2018). The researcher used open-ended questions to avoid leading the participants to answer specific questions. Thus, to improve confirmability in the study, the researcher got confirmation from the participants that the information captured was a true reflection of their responses after the interview. All the interview transcripts were reviewed by the researcher's supervisor to confirm the actual process of data collection, and analysis up until the conclusion and recommendations. The researcher kept all the raw data for save in case other peers request them, including written field notes, recorded interviews, interview scripts, data reduction and analysis products.

## 3.8 ETHICAL CONSIDERATION

There are fundamental ethical principles that guide the researcher during the research process: respect for persons, beneficence, and justice (Brink *et al*., 2018) the researcher applied principles that are based on the human rights that need to be upheld during research, which includes: fair treatment, privacy, anonymity, confidentiality and being protected from harm or discomfort (Burns & Grove, 2016).

### 3.8.1 Rights of the participants

Health research to be considered ethical, it must respect all four of these principles: autonomy, justice, beneficence, and non-maleficence.

*Autonomy*

Autonomy is the freedom to decide what to do (Polit & Beck, 2017). The researcher explained to the participants that they can withdraw their participation at any time without any reprisal. Individuals were given right to decide whether to participate in a study, without the risk of penalty or prejudicial treatment (Brink *et al*., 2017). The researcher treated the participants fairly; even if the participants refused to participate, they received the same care and respect as those who participated. All the participants were identified by the study number for anonymity so that no information was to be traced back to the participants.

*Justice*

Polit and Beck (2017); Creswell and Poth (2018) referred to justice as treating participants fairly and equitably. The principle of justice was kept by the researcher to ensure that research participants' rights to fair selection and treatment and their right to privacy were maintained to overcome any psychological harm. All appointments and schedules with participants were honoured, and punctuality was observed. The rights, interests, and wishes of participants were always assured, and the researcher collected only necessary information on the experience of caregivers on HIV disclosure.

The researcher respected the rights of the participants by ensuring that participants were given a consent form to sign before participating in the study. The participants were given all the relevant information regarding the study such as voluntary participation, the purpose of the study, the significance of their participation and the risks related to participating in the study. A choice to participate was made without coercion. They were given the choice to freely withdraw from the study should they feel uncomfortable continuing. Moreover, all the information is kept confidential, and it will never be utilised against the participants. See attached study information sheet (Appendix F).

### 3.8.2 Beneficence

William and Anderson (2018) define beneficence as the principle of doing to participants. The researcher provided the participants with information about the importance of the study so as not to deceive the participants in any way. During data collection, the principle of beneficence was maintained by the researcher that the rule of doing no harm and potential benefits of the study was maintained throughout the study. All the records of the interview are kept in a locked cupboard at the researcher's home before analysis. The researcher gave participants an information sheet for further reading and the contact details of the researcher will be given if they wish to contact the researcher for further explanation. During the interview process, the researcher was monitoring any non-verbal behaviour and mannerism indicating stress by the participant, however, nothing out of ordinary was observed. After the interview, the researcher asked the participants if they have any questions or misinformation to correct them.

### 3.8.3 non-maleficence

Non-maleficence is defined as reducing harm (Polit & Beck, 2017). The researcher maintained that the research participants were never subjected to any harm. The researcher has avoided any questions or probing which might deliberately harm the participants emotionally. No intervention was introduced during the study or any physical examination.

### 3.8.4 Confidentiality and Anonymity

Polit and Beck (2017) define confidentiality as a manner to protect the study participants so that information provided will never be divulged publicly. The researcher ensured confidentiality and anonymity at all levels of the study by avoiding the use of names of participants and unique identifiers were used. Moreover, the researcher kept the records secured by password-protected files, and encryption when sending information over the internet. The interviews were conducted in a private consultation room in the facility. No information about the interview was discussed with the facility staff.

### 3.8.5 Rights of the institution

Before starting with the research, ethical clearance certificate was obtained from Turfloop Research Ethics Committee (TREC). The researcher submitted the research proposal, ethical clearance certificate and consent form to the Limpopo Provincial Department of Health’s Research Ethics Committee to request permission to conduct the study. The ethical clearance certificate from the university and a letter of approval from the Limpopo Provincial Department of Health’s Research Ethics Committee were submitted to Mopani District Manager and to the Primary Health care Manager to request institutional permission to conduct the study. The information gained from the institution was kept confidential, and no information was utilised to exploit the facilities. See attached ethical clearance certificate from the university (Appendix A), approval from Limpopo Provincial Department of Health’s Research Ethics Committee (Appendix C), and letter from Mopani District to conduct Research (Appendix E).

### 3.8.6 Scientific integrity of research

The aim of the researcher is to uphold respect for the scientific community by protecting the integrity of scientific knowledge. The researcher has the responsibility to maintain ethical standards during research and the reporting of results. This can be achieved by being competent, accurate and honest while conducting the study Brink *et al*., (2018); Polit & Beck, (2017). The researcher has knowledge, skills, and experience in the field of HIV management. The researcher adhered to the principles and methodology of research as outlined in the proposal which prohibits plagiarism and fabrication. All documents regarding the study were made available to the supervisors to check for fabrication and plagiarism if any. The researcher administered all questions in the same way as approved by the Provincial Department of health ethics committee and a pilot study was done. The participants were included according to the predetermined criteria and those who did not qualify were not part of the exclusion.

## 3.9 BIAS

Bias is commonly understood to be any influence that provides a distortion in the results of a study (Polit & Beck, 2017). The researcher implemented the sampling methods as indicated on the methodology. During analysis the researcher did not manipulate the results, all raw data will be provided on request. The researcher ensured that the research participants are independent and treated with respect so that they were protected from exploitation. The results were shared with participants to check whether the researcher’s interpretations seem to be representative of experiences raised by participants. The researcher supported the findings with more literature to ensure the legitimacy of the results. The findings will be shared or presented to research peers to provide affirmation of the conclusion of the study.

### 3.9.1 Selection bias

Selection bias can be introduced by the selection of individuals, groups of participants in such a way that is not representative of the population intended to be studied. The researcher selected the participants based on the method approved in the proposal. Thus, to reduce selection biases the consistency of findings was compared with other research results, participants were given an opportunity to review the findings and the conclusion were reviewed by peers.

## 3.10 SUMMARY

This chapter was describing the research design and methodology to be employed by the researcher in carrying out the study. The chapter discussed the design and methods to be used, and the procedure for data collection, and analysis. Ethical considerations of the study and measures to ensure trustworthiness were also discussed. The following chapter is on data analysis.

# CHAPTER 4

# RESULTS AND DISCUSSION OF FINDINGS

## 4.1. INTRODUCTION

The previous chapter focused on the research design and methods utilized to determine and explore the experiences of primary care givers on disclosure of positive human immunodeficiency virus (HIV) status to children diagnosed with the infection and on antiretroviral treatment at selected facilities in Mopani District Limpopo Province. A comprehensive description of the research design, population, sample, sampling technique, data collection technique, data collection tool, data analysis and procedures are taken to ensure the trustworthiness discussed. The focus of this chapter is the analysis, presentation, and description of the findings. Furthermore, the demographic characteristic of 16 participants and the results according to themes and subthemes derived from data analysis are presented below.

## 4.2. DEMOGRAPHIC DATA

The demographic characteristics of the participants are presented in the table below:

Table 4.1: Demographic Characteristic of Participants

| Participants | Relationship to the child | Participant's age | Gender | Participants Level of education | Participants Employment status |
|---|---|---|---|---|---|
| 1 | Parent | 40 | Female | Grade 5-11 | Employed |
| 2 | Parent | 43 | Female | Grade 1-4 | Unemployed |
| 3 | Parent | 42 | Female | Grade 5-11 | Unemployed |
| 4 | Parent | 33 | Female | Matric | Unemployed |
| 5 | Parent | 38 | Female | Grade 5-11 | Unemployed |
| 6 | Parent | 38 | Female | Grade 1-4 | Unemployed |
| 7 | Guardian | 60 | Female | Never attended school | Unemployed |
| 8 | Parent | 32 | Female | Grade 5-11 | Unemployed |
| 9 | Parent | 48 | Female | Matric | Unemployed |
| 10 | Guardian | 38 | Female | Grade 5-11 | Unemployed |
| 11 | Parent | 34 | Female | Grade 5-11 | Employed |
| 12 | Parent | 33 | Female | Grade 1-4 | Unemployed |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| 13 | Parent | 29 | Female | Grade 1-4 | Unemployed |
| 14 | Parent | 36 | Female | Grade 1-4 | Unemployed |
| 15 | Guardian | 60 | Male | Never attended school | Unemployed |
| 16 | Parent | 28 | Female | Matric | Unemployed |

The total number of participants included in the study was sixteen care givers, comprised of thirteen biological parents and three guardians. During the inclusion, the age of participants was between the age of twenty-two and sixty years. Moreover, the participants between twenty and thirty years were only 2, between thirty and forty were 8, between forty and fifty were 4, and between fifty and sixty were only 2. There was variation in the educational levels of the participants, five participants reached between grades 1-4, five participants between grades 5-11, three participants reached matric and three never attended school. Most of the participants were unemployed (fourteen) and only two were employed.

The research developed and used demographic information to infer and enrich the verbatim conversation of individual participants. Connelly, (2013), and Coast, Mondain, and Rossier, (2009) studies suggest that the use of demographic data although commonly used in the qualitative study when used in conjunction with qualitative finding provide improved insight into qualitative study findings in this study, the demographic information of the participants consisted predominantly of women with 1 male as a caregiver. The academic qualification ranged from grade 4 to matric with only 3 participants although unemployed having completed matric, in this study the level of education did not predominantly suggest that participants who are educationally enlightened would be able to disclose their child HIV positive status to the child to support adherence to treatment and reduce the stress related to ongoing treatment for a chronic diagnosis.

Participants 4 & 7 although they went up to grade 5 and the others never attended school, respectively were able to disclose to the child and provide the necessary support for the child to understand the HIV diagnosis. The study findings corroborate with that of Vreeman, Gramelspacher, Gisore, Scanlon, and Nyandiko, (2013), that indicates that level of education improved the self-esteem of individual parents to disclose the HIV status of the child and relieved the stress of frequent questions on the reasons for everyday treatment from the child. The Jantarapakde, Pancharoen, Teeratakulpisarn, Mathajittiphan, Kriengsinyot, Channgam, *et al.,* (2019) suggest that improved training provided by health providers in a form of camps for children diagnosed with HIV and parents improved the ability of parents to disclose children HIV positive status.

## 4.3. RESULTS AND DISCUSSION OF FINDINGS

The results on the experiences of primary care givers regarding HIV status disclosure to children living with HIV/AIDS or on ART are outlined according to six main themes and twenty-three sub-themes in table 4.2. The findings of the study are discussed and supported by verbatim statements made by participants presented in italic format. The findings are further compared with the recommendation from South African policy guidelines, and moreover with international and national literature.

Table: 4.2 Themes and Sub-themes

| **Themes** | **Sub-themes** |
|---|---|
| **Theme 1:** Experiences of the event of HIV status disclosure to children | Pre-disclosure of HIV status to children 1.1 |
| | Child's age to disclose HIV status 1.2 |
| | The person responsible for HIV status disclosure 1.3 |
| | Caregiver's perceived self-efficacy for HIV status disclosure 1.4 |
| | Information provided during HIV disclosure 1.5 |
| | Caregiver's experience of the disclosure event 1.6 |
| | Child's response to the disclosure event 1.7 |
| **Theme 2.** Experiences of cues to disclose HIV status to children | Caregiver-related cues 2.1 |
| | Child-related cues (Questions, age, mental capacity, susceptibility to HIV and Sexual intentions) 2.2 |
| **Theme 3**. Experiences of benefits of HIV status disclosure to children | Ensure treatment continuation 2.3 |
| | Protection of future partners 3.1 |
| | Psychological benefits for the child 3.2 |
| **Theme 4**. Experiences of barriers to HIV status non-disclosure to children | Child's age and mental capacity 4.1 |
| | Psychological barriers 4.2 |
| | Social barriers 4.3 |
| **Theme 5.** Experiences of complications/threat of HIV status non-disclosure to children | Discontinuation of treatment 5.1 |
| | Susceptibility to HIV infection 5.2 |
| | Psychological complications 5.3 |
| **Theme 6.** Experiences of healthcare providers’ role in HIV status disclosure to children | Support from healthcare providers 6.1 |
| | Recommendations for support from healthcare providers 6.2 |

### Theme 1: Experiences of the event of HIV status disclosure to children

In this theme, care givers expressed that it is difficult for them to initiate the HIV disclosure process for the child. They are seven sub-themes emerged from the main theme which are pre-disclosure of HIV status to children, child's age to disclose HIV status, the person responsible for HIV status disclosure, the care giver's perceived self-efficacy for HIV status disclosure, Information provided during HIV disclosure, care giver's experience of the disclosure event and the child's response to the disclosure event. Below are the findings of each sub-themes that are explained and interpreted.

#### *Sub-theme 1.1 Pre-disclosure of HIV status to children*

The findings of the study revealed that some of the care givers have not initiated the process of disclosure of HIV status to their children. Care givers further indicated that they only tell their children to take treatment without disclosing the reason for taking treatment for the condition. However, care givers had mentioned to the child that they have a sickness without mentioning HIV. It appears that the caregivers deceive the children into thinking that they will be cured if they take treatment. The finding of the study implies that care givers are afraid or do not have knowledge on how to disclose HIV status to their children because they do not disclose everything the child needs to know about their HIV status. These findings are supported by verbatim quotes from the participants below:

***Participant 05 said**: "he just knows that he is taking treatment for sickness so that he can live like other children". (Biological Parent of an 11-year-old child)*
***Participant 07 said**: "No, I have not disclosed to him, I just give him treatment when is time". (Guardian of 10 years old child)*
***Participant 13 said:** "Nothing because the child is still young, I just tell the child to take treatment on time". (Biological Parent of 6 years old child)*
***Participant 14 said:** "she is taking treatment, but she does not know why, I didn't see a problem". (Biological Parent of 7 years old child)*

These findings are congruent with the study conducted by Mandalazi *et al,* (2014) which found that due to a lack of knowledge the care giver expressed uneasiness and apprehension with the HIV disclosure conversation. Regardless of these challenges, it is recommended that disclosure should be initiated to improve adherence, retention, and the overall well-being of the child (WHO, 2011; National Department of Health, 2016). According to Sarkar, Selvaraj *et al.,* (2018) conducted a study in India and found that caregivers hide the HIV status of children. Kiwanuka *et al.,* (2014) further indicate that care givers deceive children regarding the correct HIV and ART information. World Health organization and the South Africa HIV disclosure guideline recommended that it is imperative to give children age-appropriate accurate information regarding their illness, leading to full disclosure when the child has the reasoning and emotional maturity to understand the HIV information (National Department of Health, 2020; WHO, 2011).

Moreover, Abegaz *et al.,* (2019) conducted a study in Northwest Ethiopia, which found that there is a low prevalence of HIV disclosure, out of 449 participants, 418 were interviewed with a response rate of 93%. The prevalence of HIV-positive status disclosure to children was found to be 44%. According to Charles, Kiula, Tumbwene and Mwansisya (2019) who conducted a study in Tanzania found that common factors to low disclosure were mental maturity, specific age category and fear of HIV status being disclosed to others by children leading to stigma and discrimination. Care givers expressed a deep-seated feeling of guilt and self-blame, HIV-related stigma, and cultural sensitivity around HIV (Wariri *et al.,* 2020). Consequently, care givers cope by deception to avoid or delay disclosure until they perceive their own readiness to disclose (Kiwanuka *et al* 2014).

### *Sub-theme 1.2 Child's age to disclose HIV status*

The study findings revealed that care givers acknowledge that children should be told about their HIV status, however they indicated that they felt that disclosure should be initiated around the age of 10 years. These findings suggest that care givers do not understand the ideal age to initiate HIV disclosure to the child. Moreover, this practice will delay HIV disclosure to the child until the child is around 10 years. These findings are supported by verbatim quotes from the participants below:

***Participant 03 said****: "The child must be told, but they said we must not tell them until they are 10 years. Until the child is 10 years, we must not tell them, now the child doesn't know why he is taking treatment". (Biological Parent of a 6-year-old child)*

**Participant 04 said**: *“when the child is 11 years” (Biological Parent of 9 years old child)*
**Participant 06 said:** *“I think when he is 7 or 8 years, he will be ready, I can sit down with him and tell him”. (Biological Parent of 9 years old child)*
**Participant 10 said**: *“I started last year; the child was 10 Years old” (Guardian of 12 years old child)*

These findings are identical to a study conducted by Shallo and Tassew, (2020) which found that the mean age at disclosure was 10 years. Additionally, Okechuku *et al.,* (2018); Mweemba *et al.,* (2015); Mutumba *et al.,* (2015) state that caregivers suggested that the ideal age to disclose is between the age of 10-15 years. According to Guta *et al.,* (2020), the main reason for not disclosing HIV status to children was that the child was too young to understand the information. However, these findings are contrary to South Africa and international policy guidelines that recommend that the early HIV disclosure process should be initiated at the age of 5 years. Moreover, preparation of the disclosure process should be initiated from the age of 3 years and full disclosures are done at the age of 14 years (National Department of Health, 2020; WHO, 2011).

*Sub-theme 1.3 Person responsible for HIV status disclosure*

In this study, care givers indicated that it is their responsibility as parents to disclose HIV status to their children. They further state that they do not want their children to find out about their HIV status from someone else other than them. The researcher can conclude that care givers desire to disclose HIV status to their children. Additionally, they don’t want anyone to disclose HIV status to their children. These findings are supported by verbatim quotes from the participants below:

**Participant 03 said:** *‘Me as a parent, it must be me as a parent to disclose HIV status to my child, not anyone to tell my child, because they might not tell truth to the child”. (Biological Parent of 6 years old child)*
**Participant 05 said:** *“Me because I give birth to him, and I am the one who infected the child and is my responsibility to sit down and disclose to the child so that the child must not found out from people gossiping”. (Biological Parent of 11 years old child)*

***Participant 06 said:*** *"The mother, how can someone disclose to him. Nurses will not disclose to him, even if nurses disclose to him, the child will come to me for confirm". (Biological Parent of 9 years old child)*
***Participant 10 said:*** *"It is me as a parent because I am the parent and the child stays with me most of the time, so the child must know when to take treatment". (Guardian of 12 years old child)*

These findings are congruent with a recommendation from the national and international policy guidelines which recommended that care givers should initiate and facilitate the disclosure process. However, this should be done with assistance from healthcare providers (WHO, 2011; National Department of Health, 2016). According to Madiba (2016) caregivers are responsible for HIV disclosure to their children. The same author further states that care givers state that they desire to personally conduct the disclosure process; however, care givers reported being overwhelmed with fear of negative outcomes and revealed a lack of self-efficacy towards managing the disclosure process. These findings were echoed by Baker *et al.,* (2018) who state that care givers feel unprepared to disclose to their children due to a lack of knowledge about HIV infection, transmission, and treatment and would like guidance on how to disclose.

Contrary to these findings, Das, Detels, Javanbakht and Panda (2016) state that care givers felt that healthcare providers are the ideal people to initiate HIV disclosure and followed by the care givers themselves and unfortunately some care givers wanted their children to learn about their HIV status by him/herself.

### *Sub-theme 1.4 Caregiver's perceived self-efficacy for HIV status disclosure*

The study findings revealed that some of the care givers stated that they can initiate disclosure, however, others expressed that they are unable to initiate disclosure. These findings further conclude that care givers have a desire to initiate HIV disclosure however they don't have enough skills or knowledge to initiate HIV disclosure to the children. These findings are supported by verbatim quotes from the participants below:

***Participant 08 said:*** *"Yes, I can disclose to him". (Guardian of 10 years old child)*

***Participant 09 said:*** *“No, I do not have the knowledge or skills” (Biological Parent of 8 years old child)*
***Participant 11 said****: “I cannot disclose to the child, “eish” laughing because the child will ask me a lot of questions (laughing) and I must start from the beginning how the infection comes about”. (Biological Parent of 11 years old child)*
***Participant 15 said****: “On this one, I do not have knowledge/skills” (Guardian of 7 years old child)*

These findings are supported by Namukwaya, Paparini, Seeley and Bernays (2017) who conducted a study in Uganda which indicated that care givers have doubts as to the right timing for disclosure and how much information is meant to be shared with young children. The same authors further indicate that care givers are unable to disclose because of a perceived lack of skills on how to disclose HIV infection information to children. Similar results found in a study conducted by Madiba Sphiwe (2016) found that care givers indicated that they do not have the skills to disclose HIV status to children. The majority of the care givers lacked knowledge of the process of disclosure and had never received guidance about the disclosure process from their healthcare providers (Hayfron-Benjamin *et al.,* 2018).

Care givers who had knowledge about HIV status disclosure can disclose to HIV-infected children more than those who were not knowledgeable (Nzota, Matovu, Draper and Kiwanuka, 2015). Some of the reasons for low HIV disclosure to children is, lack of skills, knowledge, and support to care givers from healthcare providers (National department of Health, 2016).

*Sub-theme 1.5 Information provided during HIV disclosure*

The study revealed that some of the care givers who had engaged their children in HIV disclosure have explained how the child was infected with HIV. Care givers further indicate to the child that they were infected with the HIV virus, and the virus lives in their blood. Care givers explain to the child that they will take treatment for the rest of their life to remain healthy. These findings show that care givers had basic information to include during the HIV disclosure process. Below are verbatim quotes that support the study findings.

***Participant 01 said:*** *"Mhh, I told the child that it was not my intention that you are sick, it just happen as the will of GOD. And I wanted to prevent but the problem is I did not know how to prevent it, but you will remain my child and I will love you always". (Biological Parent of 18 years old child)*

***Participant 04 said:*** *"Mhh, my child I will tell my child that the mistake was done by me. I did not go for HIV test; I only knew when I went for ANC booking that am HIV positive when I was pregnant. The other time I did not know that I was HIV positive because I was never sick". (Biological Parent of 9 years old child)*

***Participant 08 said:*** *"when I started disclosing, I told him if you do not take treatment, you will get sick and you will not live long, treatment will help you. if you do not take you will get sick and even if I am not around you must take your treatment on time at 18:00. If you do not take treatment, you will always complain of chest pain is because you do not take treatment". (Biological Parent of 10 years old child)*

***Participant 09 said:*** *"The treatment you are taking is because you are HIV positive. HIV is a virus that live in your blood, I was waiting for the ideal time to tell you that the treatment you are taking is for the rest of your life. Even when I die you should take this treatment because it will boost your immune system so that you do not get sick. He knows that previous he was sick always and I told him now that you are on treatment you are no long sick as always, you live like other children". (Biological Parent of 8 years old child)*

These findings were similar to the results of the study conducted by Kiwanuka *et al*., (2014) which revealed that care givers also indicate that they reveal the source of the infection to the child, the health implications of living with HIV, and the potential to transmit the infection to others. However, the finding was contrary to the study conducted by Mafune, Lebese & Nemathaga (2017) results found that the majority of care givers unfortunately withheld specific information in disclosing an HIV-positive status to children, whereas some care givers offered an inaccurate explanation of the illness or false names of HIV diagnosis. Similar findings from study conducted by Dlamini & Matlakala (2020) found that care givers were rather deceptive about information shared during disclosure of HIV status. Same authors further state that care givers had not given any information or relatively gave only partial information without naming the disease, whilst others gave different reasons for the questions asked by the children.

*Sub-theme 1.6 Caregiver's experience of the disclosure event*

The study revealed that care givers indicated that their experience of HIV disclosure process was good. However, nevertheless care givers emphasize that it was difficulty to initiate disclosure to child. These findings conclude that the experience of care giver after disclosure was good because many care givers felt relieved and happy after they disclosed HIV status to their child. Below are verbatim quotes to support the findings.

***Participant 01 said:*** *"I felt good for disclosing to the child, because I was not going to die with the secret". (Biological Parent of 18 years old child)*
***Participant 09 said:*** *"On my side it was a relive as well because I have disclosed the secret to him, because he was always asking me why he is taking the treatment". (Biological Parent of 8 years old child)*
***Participant 10 said****: "To the child I did not see a problem and to me it was a relief because it was a pain to me, I did not know how to tell him. After disclosure, both of us we did not have a problem and I told the child that nothing will change, I did not see any problem after disclosing even I did not have a problem". (Guardian of 12 years old child)*
***Participant 15 said:*** *"I was also happy; I also give example even with other people at the clinic here and he was happy as well". (Guardian of 7 years old child)*

These findings are supported by Mukhtar-Yola and Kuczawski (2020) who conducted a study in Nigeria were out of 77 caregivers who had disclosed HIV to their children, 35 reported feeling relieved after disclosing, 9 described the process as very emotional, 7 felt it was a realistic thing to do while 8 felt it was both emotional and difficult. The same authors state that care givers reported a combination of feelings or responses such as empowering, practical, and valuable. Similar finding from a study conducted by Baker *et al.,* (2018) in Peru, care givers described that following disclosure of children's HIV status, they felt relief at not having to lie anymore. Furthermore, Sumbi, Venables, Harrison, Garcia, Iakovidi, van Cutsem and Jean Lambert (2021) indicated that care givers observed that the child were more independent and responsible for their own health, and it was also satisfying for care givers.

*Sub-theme 1.7 Child's response to the disclosure event*

The study findings revealed that after disclosure care givers indicated that children were fine and appreciated that the caregivers eventually disclose their HIV status. Care givers also indicated that children also promised that they will be able to take care of themselves. These findings concluded that children would receive HIV disclosure positively because they were happy after disclosure, and this improves self-care and accountability in children living with HIV. Below are verbatim quotes to support the findings.

***Participant 01 said****: "The child is fine because he is kind, friendly person. "The child said I thank you for telling me the truth, from now I will take care of myself". (Biological Parent of 18 years old child)*

***Participant 02 said****: "the child also did not have the problem even after I disclosed there no problem". (Biological Parent of 6 years old child)*

***Participant 09 said****: "ehh", to him at first it was difficult for the child to accept, but not that much because we started while he is young but eventually accepted. It was difficult, he even asks if he will take treatment for life, I asked him he if want to be sick like before, which one is better, and he said now is better. Now he knows time to take treatment even if I am not around. Now the child is free, now he even knows the time for treatment I can see now". (Biological Parent of 8 years old child)*

***Participant 15 said****: "the child was happy". (Guardian of 7 years old child)*

These findings are congruent with the results from the study conducted by Bulali *et al*., (2018) which revealed that HIV disclosure is associated with ART adherence and increased the odds of having good quality of life. HIV disclosure also assists children to understand HIV infection and make sense of their condition as well as the importance of adherence (Tamir et al., 2015). Odiachi (2017) states that children who know their HIV status reported that knowing their status had helped them develop better adherence to their medicines. In another study conducted in Kenya disclosure of HIV status was associated adherence and disclosed children reported more adherence than non-disclosed children (Odiachi, 2017).

Baker *et al.,* (2018) also state that care givers reported that after HIV disclosure some children were worsening in medication adherence immediately after the disclosure event, which then improved over time. Similar findings in a study conducted by Gyamfi *et al.,* (2015) found that the main benefits of HIV disclosure in children includes improved medication adherence, healthy life, and more responsible adolescent sexual behavior. Phiri and Chilemba (2015) state that after HIV disclosure care givers indicated that children expressed relief; felt it is necessary and important to know as they would not worry anymore. HIV disclosure Increased psychosocial functioning of child and family and reduces anxiety (National Department of Health, 2016).

### Theme 2: Experiences of cues to disclose HIV status to children

In this theme care givers indicate that they disclosed HIV status to the child because of their personal reasons, because they believe is the child right to know the truth about their condition. In this theme two sub-themes emerged which are care giver related cues and child related cues. findings of each sub-themes are explained and interpreted below.

#### *Sub-theme 2.1 Caregiver related cues*

The study revealed that care givers' disclosure HIV status because they wanted their children to know the truth about their condition and the child to understand the treatment they are taking. Moreover, care givers wanted their children be independent, even if they themselves are not around. These findings conclude that care givers do have their personal reasons to disclose HIV status to the child. Findings also suggest that care givers also understand that disclosure will make children more responsible for their health and able to protect others. Below are verbatim quotes supporting the findings.

***Participant 08 said****: "If I can die first and he remain, he won't know the truth about how he was infected with HIV. I must tell him while am still alive about HIV". (Biological Parent of 10 years old child)*

***Participant 10 said:*** *"But it was a must that I disclose to him, because if am not around he must not stop taking treatment. Life goes on and he is growing and if he finds out from others it will hurt him, so it was a must I tell him". (Guardian of 10 years old child)*

**Participant 12 said:** *"I wanted the child to know that when I am not around, the child should know what treatment to take. If I don't disclose the child won't know the important of taking treatment". (Biological Parent of 8 years old child)*

**Participant 15 said:** *"I left that he should know the true about his HIV status, there was no other things". (Guardian of 7 years old child)*

These findings are congruent with the results from the study conducted by Guta *et al.,* (2020) which revealed that care givers disclose HIV status to their children because of self-care, the right to know about their condition, share responsibilities, repeated questions and child thought to be matured. Same authors further state that care givers generally felt that HIV-infected children needed to know their HIV status to make sense of whatever was going on in their lives, especially in terms of their health.

Furthermore, Kiwanuka et al (2014) state that some care givers disclosed because they felt that the child has a right to know the truth. Most care givers hoped that disclosure would motivate the child to take his/her ART consistently and take more personal responsibility for his/her own care generally. Some care givers hoped disclosure could lead to mutual support for adherence in both the child and care giver. Some care givers wished the child to take deliberate actions to protect their playmates and potential sexual partners, from accidental exposure to HIV.

### *Sub-theme 2.2 Child-related cues*

The study revealed that care givers disclose HIV status of the child because they felt that the child is grown up or now, he/she will start to engage in sexual activities and the child was starting to ask questions about the treatment. Moreover, care givers were afraid that children will get information from others regarding HIV because they are being taught at school about HIV. These findings conclude that care givers disclose HIV status to children because of the pressure from the child asking questions or fear of disclosure by others. Below see verbatim quotes supporting the findings.

**Participant 01 said:** *"I saw it that anytime from now he will start having sex, because he is grown up now and I must tell him to use condom, so when I tell him to use a condom, he will ask me why I should use condom". (Biological Parent of 18 years old child)*

***Participant 10 said:*** *"He was refusing treatment and asking me lot of question, he ask me when I will be cured and stop taking treatment. I used to tell him that he is having flu, but he asked me when we will I be cured, so I disclosed to him that this is not flu but HIV. So, you should take treatment for life and on time". (Guardian of 12 years old child)*

***Participant 05 said:*** *"yes, I can see now that he is growing up now and at school, they are also teaching them about HIV". (Biological Parent of 9 years old child)*

***Participant 07 said****: "Yes, the child Is grown-up now, even when I am not around his is able to take treatment on time". (Guardian of 10 years old child)*

These findings are supported by Mweemba *et al.,* (2015) who state that care givers disclose HIV status only if the child starts to ask why they were taking medication, threats by children not to take HIV medication, desire to promote treatment self-efficacy amongst children as well as facilitating adoption of safe sexual behavior among adolescents. Madiba & Mokgatle, (2017) state that care givers disclosed for various reasons including that they believed that the child has a right to know their status, to improve child adherence to treatment, the child was asking lot of questions about medication they are taking, the child perceived to be old enough to understand information about HIV and to prevent the child from infecting others.

Similar finding from the study conducted by Shallo & Tassew (2020) found that care givers disclosed because they believe that a child who knows his/her status will take treatment as prescribed by the physician, and the child will be responsible for their health. Same authors further state that some care givers also mentioned that they disclosed because of the pressure from the child repeatedly asked them why she/he is taking the drug.

### Theme 3: Experiences of benefits of HIV status disclosure to children

In this theme care givers indicate that HIV disclosure improves treatment adherence and quality of life. Three sub-themes emerge from the theme which are to ensure treatment continuation, protection of future partner and psychological benefits for the child. See below discussion and interpretation of the sub-themes.

These findings are relevant with what South Africa HIV disclosure guideline recommends, that disclosure reduces mortality and morbidity, it Increases psychosocial functioning of child and better adherence to medication, it Improves attitudes and quality of life. Children fare better within social and educational contexts; children develop responsibility for their own health and proactive health seeking behavior (South Africa, 2016).

*Sub-theme 3.1 Ensure treatment continuation.*

The study findings revealed that care givers state that HIV disclosure improves children's understanding about their condition, important of treatment and adherence. These findings implies that care givers know the benefits of HIV disclosure in improving treatment adherence. Below are verbatim quotes supporting the findings.

***Participant 09 said:*** *"My understanding Is that I must disclose to him about his or her condition. So that when I die the child must know that the treatment should be taken for life". (Biological Parent of 8 years old child)*

***Participant 11 said:*** *"the child should know why he or she is taking treatment so that the child will understand the important of taking treatment". (Guardian of 11 years old child)*

***Participant 13 said:*** *"The child should be told that when you are HIV positive, and it can kill you if you don't take treatment". (Biological Parent of 6 years old child)*

***Participant 16 said:*** *"so that the child can be able to take treatment by herself, even when I am giving her treatment, she should not ask me lot of question. The child should know that she is taking treatment because she is HIV positive". (Biological Parent of 11 years old child)*

These findings are supported by Mukhtar-Yola and Kuczawski (2020) who state that most of the care givers reported improved medication adherence. Amankwah-Poku, Klutsey and Asante (2021) also indicate that disclosure resulted in improved psychological wellbeing in children living with HIV who had their status disclosed to them. Disclosure also clarifies the need for medication to remain healthy. The disclosure also clears tensions and the curiosity that these children have about their condition. More evidence from the study conducted by Das *et al*., (2016); Sariah *et al.,* (2016); Namasopo-Oleja *et al.,* 2015) state that a common benefit of HIV disclosure was that knowledge about the disease motivate a child to maintain their own health, and many care givers felt that HIV disclosure would improve their health-seeking behaviours and motivate them to take their medications regularly.

Children who know their HIV status have higher self-esteem than children who are unaware of their status (American academy of peadiatric, 1999). Cantrell *et al.,* (2013) also state that HIV disclosure improves self-esteem, does not negatively affect the child's quality of life, and promotes independent medication practices. Below see verbatim quotes supporting the findings.

*Sub-theme 3.2 Protection of future partners*

The study found that caregivers disclose HIV status to the child because they fear that the child might infect future sexual partners with HIV. These findings implies that caregivers know about HIV transmission and the benefits of HIV disclosure in preventing HIV infection in children living with HIV. See below Verbatim quotes supporting the findings.

***Participant 01 said:*** *"He will meet with a girl outside and the girl may not have HIV and he may infect her with HIV". (Biological Parent of 18 years old child)*

***Participant 02 said:*** *"The important is that the child must know the truth that he is sick, so that the child can protect him or herself". (Biological Parent of 6 years old child)*

***Participant 04 said:*** *"The child must know that there is illness and if you do not use condom, you can get infected with HIV and so that she must not infect other, so that the child can protect other". (Biological Parent of 9 years old child)*

***Participant 06 said****: "when he is grown up, the important of telling him is for him to know his condition. he must know how to live his life and he must not do certain things, even when he starts dating, he must know how to protect himself and not to go around doing wrong things because he is on treatment. So, he must know how to protect himself and others when he meets other people". (Biological Parent of 9 years old child)*

These findings are congruent with the results from a study conducted by Sariah *et al* (2016) who state that HIV disclosure improves safe sexual practices to prevent secondary transmission in children. Children grow older into adolescents, the knowledge about their HIV disease will enable them to make safe and healthy life choices about relationships, sex, and reproduction (UNESCO, 2011; Hayfron-Benjamin *et al.,* 2018). Disclosure empowered the child with vital information leading to better self-care and decision making around health (South Africa, 2016).

*Sub-theme 3.3 Psychological benefits for the child*

The study revealed that care givers disclosed HIV status to the child because they want to motivate the child to be more responsible with their health and treatment. These findings conclude that care givers understand the benefits of HIV disclosure in improving child accountability and responsibility in their care and treatment compliance. See the verbatim quotes supporting the findings below.

***Participant 07 said:*** *"The child must grow-up know the truth about his condition, because he will ask me why he was taking treatment but not knowing he is HIV. He will see how to take care of himself as life goes". (Guardian of 10 years old child)*

***Participant 10 said:*** *"To disclose HIV to the child, is for the child to know the he or she is living with HIV. I don't want the child to find out from other people, I want the child to grow knowing that he or she is HIV positive, and he or she will live with HIV for the rest of the life". (Guardian 12 years old child)*

***Participant 14 said****: "It is important because you have to take care of yourself in life". (Biological Parent of 7 years old child)*

These findings are supported by results from the study conducted by Amankwah-Poku *et al.,* (2021) who state that disclosure improves medication adherence and psychological wellbeing. Another study also shows that disclosure significantly reduces anxiety than non-disclosed children (Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington & Mellins, 2011). A study by Odiachi A (2017) found that most of the children felt that disclosure was a positive event for them and their family, however 90% of the children preferred disclosure and 10% did not. This is because some of disclosed children experiences depression and other psychological stress. After disclosure emotions ranged from sadness immediately after disclosure to normalcy by most children after 6 months of disclosure. However, contrary to other studies Vreeman *et al.,* (2010) state that HIV disclosure in children is not associated with treatment adherence as reported in other studies.

**Theme 4: experiences of barriers to HIV status non-disclosure to children**

In this theme care givers indicate that they did not disclose because they felt that HIV disclosure will cause psychological stress to the child. Three sub-themes emerged from this theme which are child's age and mental capacity, psychological and social barriers. The findings from three sub-themes are discussed and interpreted below.

*Sub-theme 4.1 Child's age and mental capacity*

The study revealed that care givers do not disclose HIV status to the children because they felt that the child is still young and mentally incapable of understanding the HIV information. These findings conclude that care givers do not understand the cognitive development of the child hence they delay initiating HIV disclosure to the child. See below verbatim quotes supporting the findings.

***Participant 01 said****: "I think he was still young; at 18 year I think he is responsible enough". (Biological Parent of 18 years old child)*

***Participant 05 said:*** *"for the child to understand that he is HIV, the child is still young he will not understand, but he will know as he grows". (Biological Parent of 11 years old child)*

***Participant 09 said:*** *"The first thing was age; the child was young to understand and sometimes he will tell other people about his status. Because the child is still young". (Biological Parent of 8 years old child)*

***Participant 10 said:*** *"I thought the child will not understand, now that his 10 years I think he can understand what HIV is, so I thought the child was still young for me, even nurse told me at the clinic that I must disclose to the child". (Guardian of 12 years old child)*

These findings are congruent with the findings from the study conducted by Domek (2010) who state that many care givers did not disclose because they share the desire to ‘protect’ children from harmful information that might lead to negative psychological consequences. Moreover, a study conducted in China found that care givers who did not disclosed HIV to their children, because care givers believe that children were too young to understand HIV information (Zhou, Zhang, Li & Kaljee, 2013).

A study conducted in Ghana by Gyamfi *et al.,* (2017) found that the main barriers to disclosure included age of child. Mukhtar-Yola, M and Kuczawski, M (2020) state that most common reasons care givers identified as barriers to disclosure were the fear that the child may inform others and being too young. According to Alemu, Berhanu and Emishaw, (2013); Madiba and Mokgatle (2017); Gyamfi *et al.,* (2017); Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal and Ross (2014) state that various studies conducted on the barriers of HIV disclosure find that the age of the child has an influence on HIV disclosure, also care givers indicated that the child would not understand the consequences of HIV diagnosis.

*Sub-theme 4.2 Psychological barriers*

The study revealed that care givers did not disclose HIV to the children because they are attempting to protect the child emotionally, they think the child will be stressed by the information. Moreover, the care givers felt the child will not accept the disclosure and this will eventually hurt the child psychologically. These findings conclude that care givers believe that HIV disclosure will bring more psychological harm than good to the child. See below Verbatim quotes to support the findings.

***Participant 07 said****: “eish” I think I will stress him too much. I do not want him to think too much like he was before. If I am cooking, give him food and give him treatment then life will continue”. (Guardian of 10 years old child)*

***Participant 09 said:*** *“It became as stress think how the child will accept this information and the child will ask why me no other children. The child will be asking question like why I am taking treatment but other children not on treatment. The child will feel pressure if he will be able to take treatment. Yes, that was the stress”. (Biological Parent of 8 years old child)*

**Participant 10 said:** *"I was thinking maybe he will not accept it and it will hurt the child, I was afraid to disclose because the child will ask me many questions, on how he was infected". (Guardian of 12 years old child)*

**Participant 11 said:** *"Myself when I think of disclosing to the child, I feel like I will be causing pressure and tension to the child. I think the child will ask lot of question that I must explain how the infection came about. So, I think it will be difficult for the child". (Biological Parent of 11 years old child)*

These findings are congruent with the findings from the study conducted by Zhou *et al*., (2013) who state that care givers don't disclosure because they fear of being stigmatized, and fear of increased psychological burden to children. Doat *et al.,* (2019) state that due to perceived psychological implications of HIV disclosure to the child, care givers are not disclosing child's HIV status. They believe they are protecting the child from psychological harm and negative reactions.

Gyamfi *et al.,* 2017 also indicated care givers felt that the child's emotional and psychological wellbeing will be affected after disclosing HIV status. Care givers explained that their reluctance was based on their anxiety about the unknown potential psychological outcomes of HIV disclosure to children. Namukwaya *et al.,* (2017) further state that caregivers reported that they are worried that disclosure might result in children retreating from social and educational engagements and interactions. They feared it would deprive them of their happiness and of the opportunity to live what the caregivers considered to constitute "a normal life."

### *Sub-theme 4.3 Social barriers*

The study revealed that care givers don't disclose because they fear that the child will disclose to other people and people will tease them and the child about their HIV status. These findings imply that care givers do not disclose HIV status to the child with the fear that the child will disclose it to others.  See the verbatim quotes supporting the findings.

**Participant 02 said:** *"if I tell my child and my child tell others in public and in case I fight with my neighbor, they will tease me about my HIV status. So, I won't feel good about that". (Biological Parent of 6 years old child)*

***Participant 06 said:*** *"what comes to my mind is that the child is still young when the child will be playing will be telling other child that I have HIV and I am taking treatment in front of other children. Those children will be talking about this at their homes. So other children will be teasing my child that he or she is sick. So, I just told him to take treatment you will be cured". (Biological Parent of 9 years old child)*

***Participant 09 said:*** *"the child will also tell other people" (Biological Parent of 8 years old child)*

***Participant 16 said:*** *"I am afraid the child won't be free to play with other children, or she may feel that she is not loved or there is problem she is not the same as other children". (Biological Parent of 11 years old child)*

Phiri and Chilemba (2015); Murnane *et al.,* (2017) state that care givers do not disclose HIV status to their children for fear of the child spreading the news, which might lead to stigmatization. Gyamfi *et al.,* (2017) also state that barriers to HIV disclosure include perceived causes of HIV stigma attached to HIV, child's inability to keep HIV status to self and fear of psychological harm to child. Mukhtar-Yola, M and Kuczawski, M (2020) also indicated that many care givers do not disclose because they fear that the child will inform others about their HIV status.

### Theme 5: Experiences of complications/threat of HIV status non-disclosure to children

This theme finding of the study revealed that care givers indicated that non-disclosure of HIV status will result in children refusing treatment, which will lead them to get sick and increase the risk of HIV transmission to others. Three sub-themes emerged from the main theme which are discontinuation of treatment, susceptibility to HIV infection and psychological complications. Findings from the sub-themes are explained and interpreted below.

#### *Sub-theme 5.1 Discontinuation of treatment*

Care givers state that non-disclosure will lead to poor treatment adherence. Care givers further indicate HIV status in children will improve treatment adherence. These findings conclude that care givers know the complication of not disclosing HIV status in treatment compliance. See verbatim quotes below to support the findings.

***Participant 01 said:*** *"Complications are there because the child will not accept taking treatment for his life without knowing the reasons for taking treatment". (Biological Parent of 18 years old child)*

***Participant 03 said:*** *"There is lot of complication, if he is not taking treatment, he will be always sick". (Biological Parent of 6 years old child)*

***Participant 05 said****: "Is the treatment he is taking, he will start asking questions about the treatment, he will start saying I am taking treatment that I do not know why I am taking them. Hence when he takes treatment, I told him that the treatment is for HIV so that he will be cured the sickness". (Biological Parent of 11 years old child)*

***Participant 09 said****: "The complication will be, if the child does not know the true, he or she won't be able to adjust when his grown up. It will cause a problem, now I can control so it can happen that in future when a said take treatment he will refuse. He will default treatment and start getting sick and he will be taking treatment to knowing so he will be asking himself lot of questions without answers". (Biological Parent of 8 years old child)*

These findings are supported by Odiachi A (2017) who conducted a qualitative study in South Africa which included 25 adolescents and their care givers reported good treatment adherence after HIV disclosure and as such adherence would help them live longer. van Elsland *et al*., (2019) also state that non-disclosure of HIV status to the child can lead to a delay in access to treatment, non-adherence, and consequent treatment failure. Additionally, Bulali *et al.,* (2018) state that ART adherence was 4.5 times higher among children with HIV status disclosure, compared to those who had no disclosure.

Madiba and Diko, (2020) indicated that delayed HIV disclosure contributes to children's refusing to take their medication and hence poor health outcomes. South African disclosure guidelines state that non-disclosure can lead to delays in clinical treatment, increased opportunistic infections, poor prognosis, and non-adherence (National Department of Health, 2016).

*Sub-theme 5.2 Susceptibility to HIV infection*

The study revealed that care givers indicated that if you don’t disclose HIV status to child, the child will not adhere to treatment and eventually will get sick. These findings implies that care givers understand that HIV disclosure improves adherence and health of the child living with HIV.

South African Disclosure guidelines state that non-disclosure will increase non-adherence to treatment and ultimately risk for opportunistic infections increases leading to symptomatic disclosure (National Department of Health, 2016). See below verbatim quotes to support the findings.

***Participant 02 said:*** *“Because the child will not be taking treatment and viral load will increase and start to be sick”. (Biological Parent of a 6-year-old child)*

***Participant 04 said:*** *“The child may get sick because we as black people we like to consult at traditional healer, while me as the mother knowing that my child is HIV positive and was infected from the parent. But I will say my child has been witched but knowing the real reason”. (Biological Parent of 9 years old child)*

***Participant 08 said:*** *“ehh”, there will be a problem. If I do not disclose to him some time I won’t be around, and he won’t know what kind of sick he has. He will just say I am sick, so I must tell him until 21 years so that he knows the true”. (Biological Parent of 10 years old child)*

***Participant 12 said:*** *“Yes, it is important for the child know, because if you do not disclose the child will die. If I had hidden the child, she or he would have died by now”. (Biological Parent of 8 years old child)*

These findings are congruent with the results from a study conducted by Mukhtar-Yola, M and Kuczawski, M (2020) who state that non-disclosure will lead to poor life outcomes and self-protection. Van Elsland *et al*., (2019) also further state that non-disclosure of HIV status to the child can lead to a delay in access to treatment, non-adherence, and consequent treatment failure. Non-disclosure is linked to poor treatment adherence, which would lead to treatment failure, increased viral load, increased risk of early disease progression or dramatic changes in the clinical course of HIV infection, and consequently decreased survival time of these children (National department of Health, 2016; WHO, 2011).

*Sub-theme 5.3 Psychological complications*

Care givers indicate that if they don’t disclose the child will be angry with them and that the child will be asking them why she/he is taking treatment. These finding imply that care givers understand the psychological implication for not disclosing HIV status to the child.

***Participant 06 said:*** *“Mhh”, there will be a problem, he may be angry and even to hate me. Because why I did not disclose his HIV status to him. He will also be angry that he is taking treatment, but my mother did tell me anything, why I am taking treatment. This will cause a problem to the child”. (Biological Parent of 9 years old child)*

***Participant 10 said****: “If he finds out from other people it will hurt him, he will ask me why I did not disclose to him as a parent and while I am living with him, I did not want him to find out from other people. So, I wanted to disclose to him myself”. (Guardian of 12 years old child)*

***Participant 13 said:*** *“It is not good not to disclose, the child will ask why he or she is taking treatment. The child is not feeling any pain but not knowing why he or she is taking treatment”. (Biological Parent of 6 years old child)*

***Participant 15 said:*** *“iesh”, that will be a serious problem because the child will grow without knowing why he is taking treatment. If other people tell him, it will affect him psychologically and he will start thinking my family is hiding this illness form me which mean it a bad illness”. (Guardian of 7 years old child)*

These findings are congruent with results from Hayfron-Benjamin *et al.,* 2018; Van Elsland *et al* 2018 who state that care givers acknowledge that not disclosing HIV to children will lead to non-adherent on ART and potentially transmitting HIV to their sexual partners through unprotected sex. Delaying disclosure contributes to children’s refusing to take their medication in future, leads to the accidental disclosure of HIV, give rise to anger and resentment towards the care giver, increase the risk of secondary transmitting of HIV, and poor health outcomes (Madiba & Diko, 2020; National department of Health, 2016). South Africa HIV disclosure guideline state that with non-HIV-disclosure children psychologically fare poorly (National Department of

Health, 2016). Failure of full disclosure by early teenage years can lead to emotional difficulties (National Department of Health, 2020).

### Theme 6: Experiences of healthcare providers' role in HIV status disclosure to children

The study revealed that some of the care givers state that they were not educated or trained in how to do HIV disclosure to the children. Care givers further indicated that they need assistance from healthcare provider to advise them on how to do HIV disclosure.

According to Baker *et al.,* 2018; Domek, 2010; Mandalazi *et al.,* 2014) care giver does not know how to initiate the disclosure process, care givers often struggle with the issues of when and how to begin the disclosure process. Moreover, South Africa HIV disclosure guidelines state that healthcare provider misses the opportunity to educate care givers about the significant of disclosure and the disclosure process, because they don't have access to policies or guidelines to assist them in the disclosure process (National Department of Health, 2016).

*Sub-theme 6.1 Support from healthcare providers*

The study found that care givers state that they were not trained on how to initiate HIV disclosure, however care givers indicated that healthcare provider did advise them to disclose HIV status to their children. These findings conclude that care givers do not have capacity to disclose HIV status to the child, however they knew that they have to disclose HIV to the child. See below verbatim quotes to support the findings.

***Participant 02 said****: "Yes, they said when the child is about 5 years, i must disclose to him about his or her HIV status so that he must know". (Biological Parent of 6 years old child)*

***Participant 05 said:*** *"eish" No, I have not received any training/support". (Biological Parent of 11 years old child)*

***Participant 08 said:*** *"Yes, the nurse who tested the child have told me to disclose to the child about HIV. The nurse advised me to use me as an example because I am on*

*ART as well and support the child. So that the child can understand and know that HIV is real" (Biological Parent of 10 years old child)*

**Participant 14 said***: "No, they have not educated me" (Biological Parent of 7 years old child)*

These findings are supported by Madiba (2016) who conducted at study which revealed that care givers lack disclosure skills but believed they were primarily responsible for disclosure to children.  Kiwanuka *et al*., (2014) state that care givers desired to personally conduct the disclosure; however, most revealed a lack of self-efficacy towards managing the disclosure process. Consequently, most cope by deception to avoid or delay disclosure until they perceive their own readiness to disclose. Hayfron-Benjamin *et al*., (2018) further state that majority of the care givers lacked knowledge on the process of HIV disclosure and majority also had never received guidance about the disclosure process from their healthcare providers.

*Sub-theme 6.2 Recommendations of support from healthcare provider*

The study revealed that care givers felt that they don't know how to disclose, and they state that they need assistance from healthcare provider. Some caregivers even indicated that nurses should conduct disclosure because they have more knowledge on how to disclose. These findings conclude that caregivers do not have knowledge on how to disclose HIV status to the child and feel that health providers should conduct HIV disclosure to the child. See below verbatim quotes to support the findings.

**Participants 01 said***: "Nurses must disclose to the child about his or her HIV status, because most of the time they are the once who are educating children about HIV in support group". (Biological Parent of 18 years old child)*

**Participant 06 said:** *"Yes, I do not know how to explain it, but I will need help on guidance on how to disclose to my child, maybe It will be better". (Biological Parent of 9 years old child)*

**Participant 09 said:** *"the health department should assist us because they know more than us. I can tell him, but more information is with nurses". (Biological Parent of 9 years old child)*

***Participant 16 said:** "I don't know, I will need assist maybe from nurses or social worker". (Biological Parent of 11 years old child)*

These findings are supported by a study conducted in sub-Saharan Africa by Modiba and Diko (2020) found that care givers delay HIV disclosure because of lacking disclosure skills or knowledge of how to disclose. Hence care givers feel unprepared even to answer some of the questions from children. This has been identified as major barriers to the early initiation of HIV disclosure to children. Due to lack of knowledge, care giver expressed uneasiness and apprehension with the disclosure conversation, whether they had already told their child that he or she had HIV (Mandalazi, Bandawe, Umar, 2014).

In a study conducted in Botswana and South Africa by Modiba (2016) found that care givers reported lack of HIV knowledge, lack of communication skills on HIV, lack of skills on how to conduct HIV disclosure and disclosure skills. Care givers believed they were primarily responsible for HIV disclosure to children and required support from healthcare providers during the disclosure process.

Elizabeth Glaser Peadiatric AIDS Foundation state that healthcare providers should support caregivers' on how to disclose an HIV diagnosis, and they should respect the family's timing and expectations (Elizabeth Glaser Peadiatric AIDS Foundation, 2018; South Africa, 2016).

## 4.4 SUMMARY

This chapter discussed the results and interpretation. The demographic profile of the participants was described, and themes and sub-themes that emerged from the data were discussed and supported by the existing literature. The next chapter will focus on the integration of research results and theoretical framework.

# CHAPTER 5

# INTEGRATION OF RESEARCH RESULT AND THEORETICAL FRAMEWORK

## 5.1 INTRODUCTION

Study findings were discussed in chapter 5 in association with National and International literature regarding the experiences of the care givers on HIV disclosure in children living with HIV in the Mopani District. The following chapter focused on the application of a theoretical framework relative to the study findings.

## 5.2 HEALTH BELIEF MODEL

The theory is a systematic, abstract explanation of some aspects of reality. Theories and conceptual models are the main tools used by researchers to consolidate findings into a wider conceptual context (Polit & Beck, 2017). Health Belief Model suggests that people's beliefs about health problems, perceived benefits of action and barriers to action, and self-efficacy explain the engagement (or lack of engagement) in health-promoting behaviour. A stimulus, or cue to action, must also be present to trigger the health-promoting behaviour (Strecher *et al,* 1997). The researcher used HBM in the study to guide the structure of the data collection tool and research findings. The study findings were discussed and integrated with Health Belief Model. The model is comprised of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy (Strecher *et al*., 1997). The researcher integrated study findings with the HBM framework is discussed below.

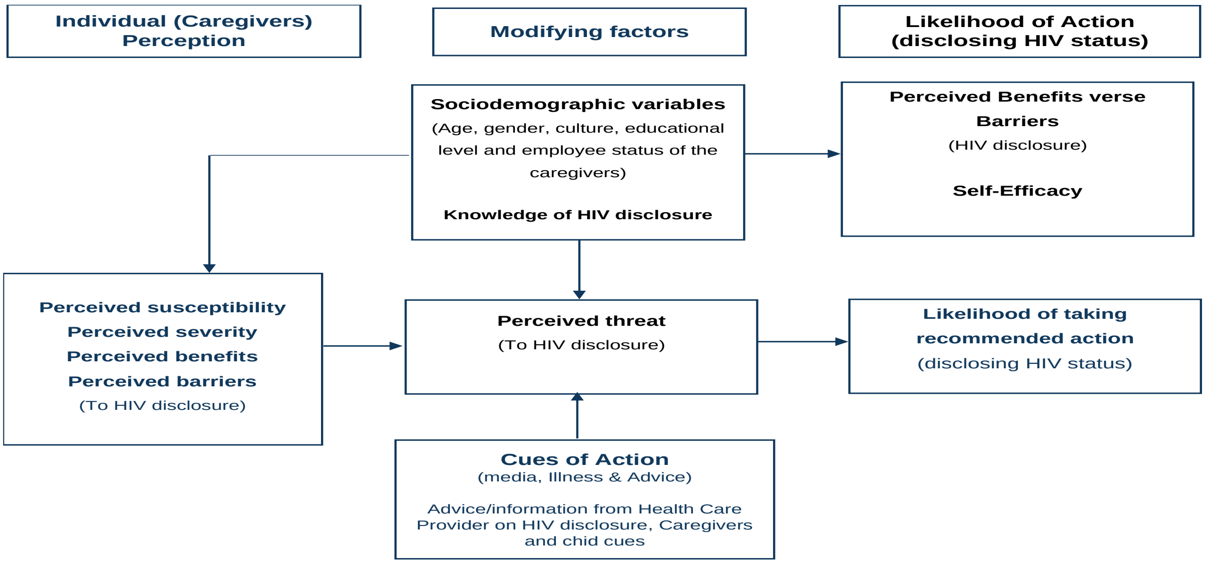


*Figure 5.1 HBM diagram, Adapted from Stretcher, Champion & Rosenstock (1997)*

### 5.2.1 Perceived threat (susceptibility and severity)

Refers to an individual perception on how the outcome will be severe if the condition will occur (Joseph, 2018). The finding in this study revealed that care givers expressed that non-disclosure of HIV status to children can result in children refusing treatment, which will lead them to be more vulnerable to illness and increase the risk of HIV transmission to others. South Africa National HIV/TB Consolidated Guideline state that failure of disclosing HIV status in the early teenage years can lead to poor adherence, emotional difficulties, poor school performance and HIV transmission if sexually active (National department of Health, 2020).

In this study, the researcher concluded that care givers know the risk and complications of non-HIV disclosure in children. Care givers state that non-disclosure will lead to poor treatment adherence and eventually the child will get sick. Furthermore, care givers indicate that if they do not disclose the child will be angry with them, why they withheld the information from them.

### 5.2.2 Perceived benefits

This refers to an individual perception on the important of engaging in good health behaviour to reduce risk of the disease (Onoruoiza, Musa, Umar, & Kunle, 2015). In this study, findings reflect that care giver recognised that HIV disclosure improves treatment adherence and quality of life. Care givers further highlight that disclosure also assist the child to protect him/herself and others from HIV infection and it motivates the child to take responsibility for their own health. Das *et al*., (2016); Sariah *et al*, (2016); Namasopo-Oleja *et al*., (2015) also state that care giver indicated that a common benefit of HIV disclosure was that knowledge about the disease motivate a child to maintain their own health, and many caregivers felt that HIV disclosure would improve their health-seeking behaviours and motivate them to take their medications regularly.

In this study, the researcher concluded that care givers are knowledgeable about the benefits of HIV disclosure in children. Care givers state that HIV disclosure improves child understanding of their condition, and the importance of treatment and adherence. Care givers state that the importance of disclosing HIV status to the child is to motivate the child to be more responsible with their health and treatment.

### 5.2.3 Perceived barriers

This refers to a person's feelings on the obstacles to performing a recommended health action (Onoruoiza *et al*., 2015). In this study, findings suggested that care givers are not disclosing HIV status to the child because they felt that HIV disclosure will cause psychological stress to the child. Care givers also felt the child is still young and immature to understand HIV information and they fear that the child might disclose their HIV status to others. These findings are congruent with the finding from a study conducted by Wariri *et al*., (2020) who state that care givers avoid disclosure because they think the child will accidentally disclose their diagnosis to other people and expected negative consequences related to a stigma may delay or prevent disclosure.

In this study, the researcher concluded that care givers are not disclosing HIV status to their children because they felt that the child is still young and mentally incapable to understand the HIV information. They indicated that they are trying to protect the child emotionally, they think the child will be stressed by the information. They also fear that child will disclose to other people and people will tease them and the child about our HIV status.

### 5.2.4 Cue to action

This is the internal and external stimulus needed to trigger the decision-making process to accept an indorsed health action (Glanz, Rimer & Viswanath, 2015). The study findings from some of the care givers who have disclosed indicate that they disclosed HIV status to the child because of their personal reasons, because they believe is the child’s right to know the truth about their condition and moreover because it will relieve them from the pressure of keeping a secret. Care givers also indicate that they disclose because children were asking many questions about their conditions and treatment. Madiba and Mokgatle, (2017) state that care givers disclosed for various reasons including that they believed that the child has a right to know their status, to improve child adherence to treatment, the child was asking a lot of questions about the medication they are taking.

In this study, the researcher concluded that care givers disclose HIV status to the child because personally, they want to feel free from keeping the secret and believed that it Is the right of the child to know the truth. Moreover, they also state that they disclose because the child was asking questions about the treatment they are taking.

### 5.2.5 Self-efficacy

This refers to the level of a person's confidence in his or her ability to successfully perform a behaviour. Self-efficacy is a construct in many behavioural theories as it directly relates to whether a person performs the desired behaviour (Strecher *et al.,* 1997). In this study, findings suggested that caregivers can initiate disclosure, however, others expressed that they are unable to initiate disclosure because they are not educated or trained on how to do HIV disclosure to children. Madiba Sphiwe (2016) found that caregivers indicated that they do not have the skills to disclose HIV status to children. Most of the care givers lacked knowledge of the process of disclosure and had never received guidance about the disclosure process from their healthcare providers (Hayfron-Benjamin *et al.,* 2018).

In this study, the researcher concluded that some care givers have knowledge on how to disclose HIV status to the child, however, some indicated that they do not have the necessary skills or ability to disclose HIV status to the child. Care givers further indicated that they need assistance from health providers to advise them on how to do HIV disclosure in children.

## 5.3 SUMMARY

This chapter presents the findings of the study on the care giver’s experience in disclosing positive HIV status to children diagnosed with the infection and on antiretroviral treatment in the Mopani district, Limpopo province. The discussion of the findings was arranged into Themes and Sub-themes. Care givers expressed that it is important to disclose HIV status to the child, however they indicated that due to lack of knowledge and skills it is difficult to initiate and handle the HIV disclosure process. Child-related barriers like age and mental maturity to understand and maintain confidentiality were among other factors for non-disclosure. However, regardless of these barriers’ care givers acknowledge the complication of non-disclosure so they indicated that they need support and to be capacitated on how to manage the HIV disclosure process.  Summary, limitations, and recommendations will be discussed in chapter 5.

# CHAPTER 6

# SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

## 6.1. INTRODUCTION

In Chapter 5 study findings on the experiences of care givers on HIV disclosure were discussed and integrated with the theoretical framework. This is the final chapter of the research study that presents the summary, recommendations, the contribution of the study, limitations, and a conclusion of the study. The recommendations are based on the conclusion of the Themes.

## 6.2 SUMMARY OF THE STUDY

### 6.2.1 Restatement of research purpose

- The purpose of the study was to determine and explore the experiences of HIV status disclosure to children living with HIV/AIDS among primary care givers in Mopani District Limpopo Province, South Africa.

The purpose of the study was achieved by exploring and describing the experience of care givers regarding the disclosure of HIV in children. A detailed data analysis was done on 6 themes and 21 sub-themes identified through exploring data collected and a description of the experience of caregivers on HIV disclosure was done.

### 6.2.2 Restatement of research questions

The study research question was:

- What are the experiences of primary care givers on HIV status disclosure to children with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa?

The research question was answered through face-to-face data collection, analysing, and describing the experience of care givers regarding HIV disclosure in children. During data, collection care givers were encouraged to feel free and to elaborate more on their answers.

### 6.2.3 Restatement of research objectives

The objectives of this study were to:

- To explore experiences, fears, and threats, care givers meet related to HIV status disclosure to children living with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa.
- To describe experiences, fears, and threats among care givers on HIV status disclosure to children living with HIV and on ART at selected clinics in Mopani District Limpopo Province, South Africa.

The researcher developed specific questions and probing questions that further explore the experience of care givers on HIV disclosure. Member checking was done during and at the end of the interview to get more descriptions and explore any information missed.

### 6.2.4 Research Methodology

Qualitative, explorative, and descriptive design was utilised to respond to the objectives of this study. Therefore, to explore the experience of care givers on HIV disclosure the researcher used explorative design in this study. Thus, to describe the experience of care givers on HIV disclosure the researcher used descriptive research which assists the researcher to obtain accurate information from participants. Ethical considerations were observed, and the study was conducted in the greater Tzaneen subdistrict in 4 selected facilities. Non-probability sampling was used, and data were collected through a face-to-face interview. The researcher interviewed the participants by the 16th participant data saturation was reached. Therefore, to enhance the trustworthiness in research, the researcher used four criteria for trustworthiness which include credibility, dependability, transferability, and confirmability. The ethical consideration for participants was maintained through respect for persons, beneficence, justice, fair treatment, privacy, anonymity, confidentiality and being protected from harm or discomfort. Informed consent was obtained after explaining the benefits and rationale of the study. Interviews were recorded and records were safely stored, thematic analysis was done.

## 6.3 SUMMARY OF THE RESEARCH FINDINGS AND RECOMMENDATIONS BASED ON IDENTIFIED THEMES

### Theme 1: Experiences of event of HIV status disclosure to children

The findings of the study indicated that care givers have trouble initiating the HIV disclosure process to the child. This was evident because some of the care givers expressed that they do not have the knowledge and skills to initiate the disclosure process for children living with HIV. They indicated that they felt the child is too young to understand HIV information and they are afraid of how the child will react to the information. Care givers further state that they don’t know exactly what to tell the child during the process of disclosure, so they only tell their children to take treatment without disclosing their HIV status. However, they indicated that as parents they are responsible to initiate the HIV disclosure process.

### Recommendation based on Theme 1

The researcher recommends that healthcare providers should provide continuous support and education to caregivers on the HIV disclosure process from the day of HIV diagnosis. The education should emphasise the age at which disclosure should be initiated and what information to include in each developmental stage of the child. These educational sessions should be conducted and documented during each facility visit on the clinical stationery as a portfolio of evidence and to review if the child went through the necessary stages of the disclosure process.

### Theme 2: Experiences of cues to disclose HIV status to children

The findings of this study revealed that care givers disclosed HIV status to the child because of their various and individual reasons. They believe it is the right of the child to know the truth about their condition and the treatment they are taking. Additionally, caregivers state that the disclosure can relieve them from the pressure of keeping a secret. Care givers also indicate that they disclose because children were asking many questions about their conditions and treatment.

### Recommendations based on Theme 2

The researcher recommends that care givers should be encouraged and supported to initiate the disclosure process at any early or recommended age from 5 years. This will allow the child to grow-up knowing the truth about their condition, less pressure of keeping a secret for care givers and the child will not be asking many questions. The healthcare provider needs to review and check if the process is initiated from a preparatory phase at age 3 years.

### Theme 3: Experiences of the benefits of HIV status disclosure to children

The study revealed that care givers acknowledge that HIV disclosure improve child understanding about their condition, importance of treatment, adherence, and quality of life. Care givers further highlight that disclosure also assist the child to protect themselves and others from HIV infection and it motivates the child to take responsibility for their health.

### Recommendations based on Theme 3

The researcher recommends that the healthcare provider can continue counselling the care giver on the importance of HIV disclosure in children. Healthcare facilities should also provide health education and information materials for care givers to read in local languages on the HIV disclosure process and benefits.

### Theme 4: Experiences of barriers to HIV status non-disclosure to children

The findings of the study indicate that care givers who did not disclose it because they felt that HIV disclosure will cause psychological stress to the child. Care givers also felt the child is still young and immature to understand HIV information and they fear that the child might disclose their HIV status to others and people will tease them and the child about their HIV status.

### Recommendations based on Theme 4

The researcher recommends that care givers should be educated about the cognitive development of the child so that they will understand what information to disclose in each developmental stage. The care givers should be encouraged and supported during HIV disclosure so the child will receive the information positively. More psychological support should be provided to the child and care givers and confidential education to the child as well. Resuscitation and strengthening the implementation of HIV Support group or Integrated Access to Care and Treatment (I-ACT) strategy. This can improve access to HIV information, support people living with HIV and create a platform to discuss HIV disclosure.

### Theme 5: Experiences of complications of HIV status non-disclosure to children

The findings of the study show that care givers state that non-disclosure of HIV status can result in children refusing treatment, which will lead them to get sick and increases the risk of HIV transmission to others. Care givers further indicate that if they do not disclose the child will be angry with them, why they did not tell them the truth. They also fear that the child will be asking them why they are taking treatment. Moreover, they fear if the child receives HIV information from others the child will be angry with them.

### Recommendations based on Theme 5

The researcher recommends that healthcare providers assist care givers to utilise all the opportunities to initiate HIV disclosure to children. Care givers should be encouraged to initiate early HIV disclosure because delayed HIV disclosure will make it more complicated at a later age for the child. The healthcare providers should refer to psychologists for special or complicated cases during or after HIV disclosure.

### Theme 6: Experiences of healthcare providers’ role in HIV status disclosure to children

The findings of the study show that care givers did not receive any training or education from healthcare providers on how to initiate HIV disclosure. However, care givers indicated that healthcare providers did advise them to disclose HIV status to their children. Care givers also felt that they do not know how to disclose, and they state that they need assistance from the healthcare providers. Therefore, some care givers even indicated that healthcare providers should conduct HIV disclosure because they have more knowledge on how to disclose it.

### Recommendations based on Theme 6

The researcher recommends that healthcare providers should educate care givers on the HIV disclosure process. Healthcare providers should continue advising care givers to disclose but should also give more education and support on the HIV disclosure process. The Department of health needs to assess the capacity of the healthcare system in supporting care givers with the HIV disclosure process. The knowledge and skills of healthcare providers should be capacitated so that they can better support care givers.

## 6.4. CONCLUSION OF THE RESEARCH FINDINGS

The care giver’s experience suggested that HIV disclosure is a difficult process to initiate and is aggravated by a lack of skills and support from healthcare providers on how to disclose HIV to children. However, they acknowledge the importance of HIV disclosure and the complication of non-HIV disclosure. To improve disclosure and overcome barriers to HIV disclosure care givers state that they need more support from healthcare providers. Care givers state that they do not disclose because they think that the child is still young to understand HIV diagnoses and the child might disclose to others. More support from a healthcare provider is required to guide care givers to initiate the HIV disclosure process at an ideal age.

## 6.5 RECOMMENDATION OF THE STUDY

### Recommendations for nursing research

- The researcher recommends that the same study be conducted in the same context, on the experience of children living with HIV regarding the HIV disclosure process.
- The researcher recommends a study on the prevalence of HIV disclosure to perinatal infected children in Limpopo.

### Recommendations for nursing education

- To respond to patient changing dynamics and guidelines there is a need to train and mentor healthcare providers on new development regarding HIV disclosure process in children to improve nurse’s practices.

## 6.6 LIMITATIONS OF THE STUDY

- Due to financial constraints the study was only conducted in 3 facilities in the Mopani district with the Greater Tzaneen subdistrict. So, the results cannot be generalized to other areas.
- The study was conducted during the Covid-19 pandemic. This means that patients should spend less time in the facilities and participants were wearing musk, so it means that the researcher could not read the facial expressions**.**

## 6.7 SUMMARY

This is the last chapter of the research project. Qualitative, explorative, and descriptive design was utilised to respond to the objectives of this study. The study orientation was done in chapter 1, literature was discussed in chapter 2, the research methodology was outlined in chapter 3 after the implementation results were discussed and integrated with the theoretical framework in chapter 4 and the summary, recommendations, limitations, and conclusion of the study was discussed in chapter.

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## **APPENDIX A** Ethical Clearance Certificate (University of Limpopo)

**University of Limpopo**
**Faculty of Health Sciences**
**Executive Dean**
**Private Bag X1106, Sovenga, 0727, South Africa**
**Tel: (015) 268 2149, Fax: (015) 268 2685, Email:tebogo.mothiba@ul.ac.za**

**DATE: 11 NOVEMBER 2020**

| | |
|---|---|
| **NAME OF STUDENT:** | **MUDITAMBI NN** |
| **STUDENT NUMBER:** | **202057275** |
| **DEPARTMENT:** | **MNURS** |
| **SCHOOL:** | **HEALTH CARE SCIENCES** |
| **QUALIFICATION:** | **MNURS** |

Dear Student

**FACULTY APPROVAL OF PROPOSAL (PROPOSAL NO. FHDC2020/7)**

I have pleasure in informing you that your MNURS proposal served at the Faculty Higher Degrees Meeting on the 03 NOVEMBER 2020 and your title was approved as follows:

Approved Title: “Disclosure of Positive Human Immunodeficiency Virus Status to children diagnosed with the Infection and on antiretroviral treatment: Experiences of primary caregivers at selected clinics in Mopani District, Limpopo Province”

**Note the following:**

| **Ethical Clearance** | **Tick One** |
|---|---|
| Requires no ethical clearance<br>Proceed with the study | |
| Requires ethical clearance (TREC) (apply online)<br>Proceed with the study only after receipt of ethical clearance certificate | √ |

Yours faithfully

**Prof T.M Mothiba**

**Chairperson**

**CC: Supervisor: Dr P.M Mamogobo**
**Co-Supervisor : Mrs T.E Mutshatshi**

Finding solutions for Africa

**APPENDIX B** Letter to Provincial office, Limpopo Department of Health

## Letter to the Provincial Office, Limpopo Department of Health

Muditambi Nathaniel
Cell number: 078 118 4247
Email: *muthundinne@gmail.com*

P.O BOX 4415
Thohoyandou
0950

The Director

Research ethic committee

Limpopo Provincial Department of Health

18 College street

Polokwane 0699

Dear Sir/Madam

**Application for conducting research in Limpopo, Mopani District**

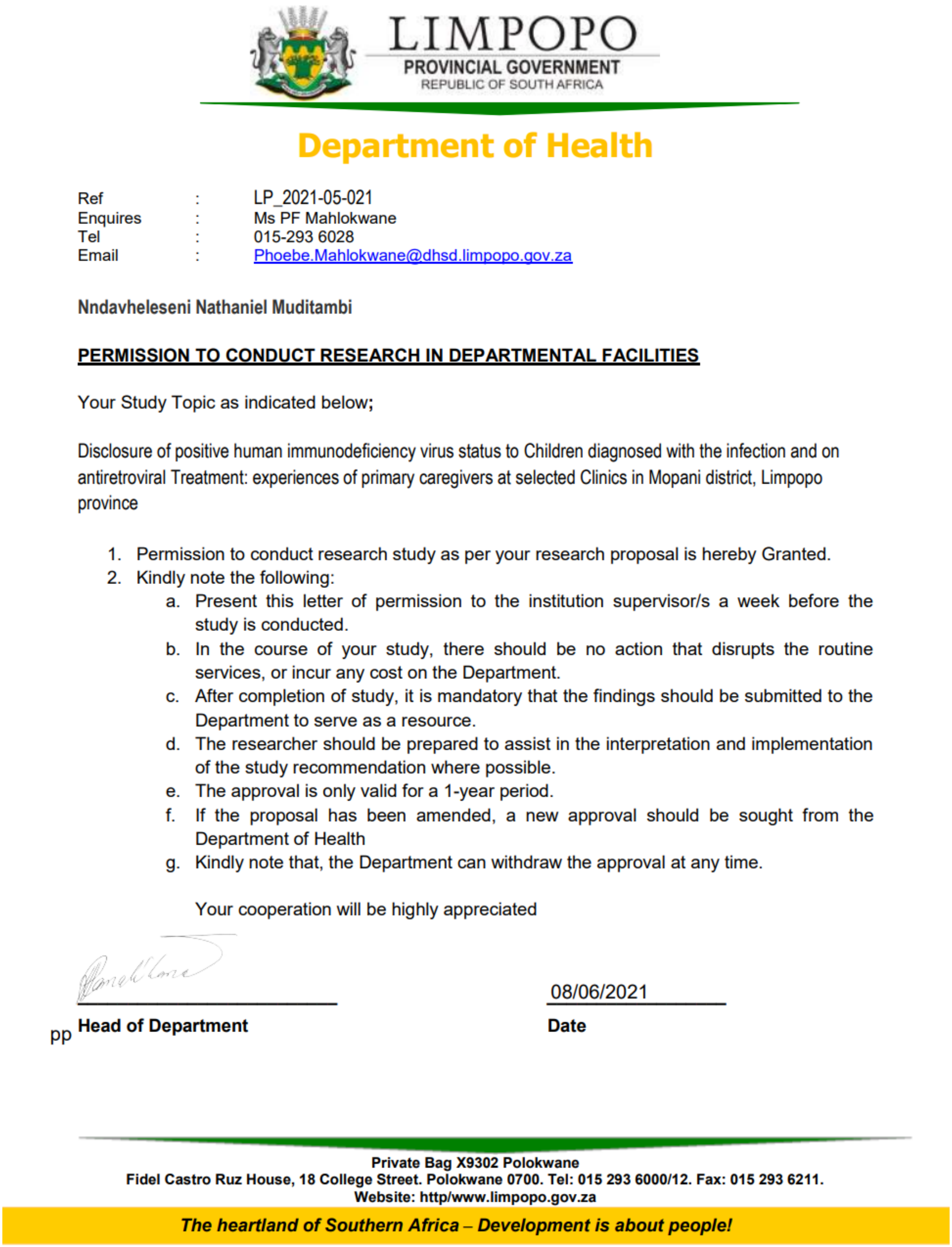
I request permission to conduct research in the above-mentioned area. I am a student who is furthering his studies in Master of Nursing Science at University of Limpopo. The purpose of the study is to determine and explore experiences of HIV disclosure to infected children among Primary caregivers in Mopani District Limpopo Province, South Africa. I request to conduct interview to primary caregivers who have accompanied their children or adolescent to collect treatment in Primary Healthcare Facilities in Mopani District.

Enclosed find research proposal, consent form, interview guide and the approval letter from university of Limpopo.

Yours sincerely

Muditambi NN (student)

**APPENDIX C** Permission to conduct Research in departmental facility



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**Department of Health**

Ref : LP_2021-05-021
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Phoebe.Mahlokwane@dhsd.limpopo.gov.za

**Nndavheleseni Nathaniel Muditambi**

**PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES**

Your Study Topic as indicated below;

Disclosure of positive human immunodeficiency virus status to Children diagnosed with the infection and on antiretroviral Treatment: experiences of primary caregivers at selected Clinics in Mopani district, 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 institution supervisor/s a week before the study is conducted.
   b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
   c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   e. The approval is only valid for a 1-year period.
   f. If the proposal has been amended, a new approval should be sought from the Department of Health
   g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

pp **Head of Department**

08/06/2021
**Date**

**APPENDIX D** Letter to Mopani District Office, Department of Health

## Letter to the Mopani District Office, Department of Health

Muditambi Nathaniel
Cell number: 078 118 4247
Email: **muthundinne@gmail.com**

P.O BOX 4415
Thohoyandou
0950

The Director
Research ethic committee
Limpopo Provincial Department of Health
18 College street
Polokwane 0699

Dear Sir/Madam

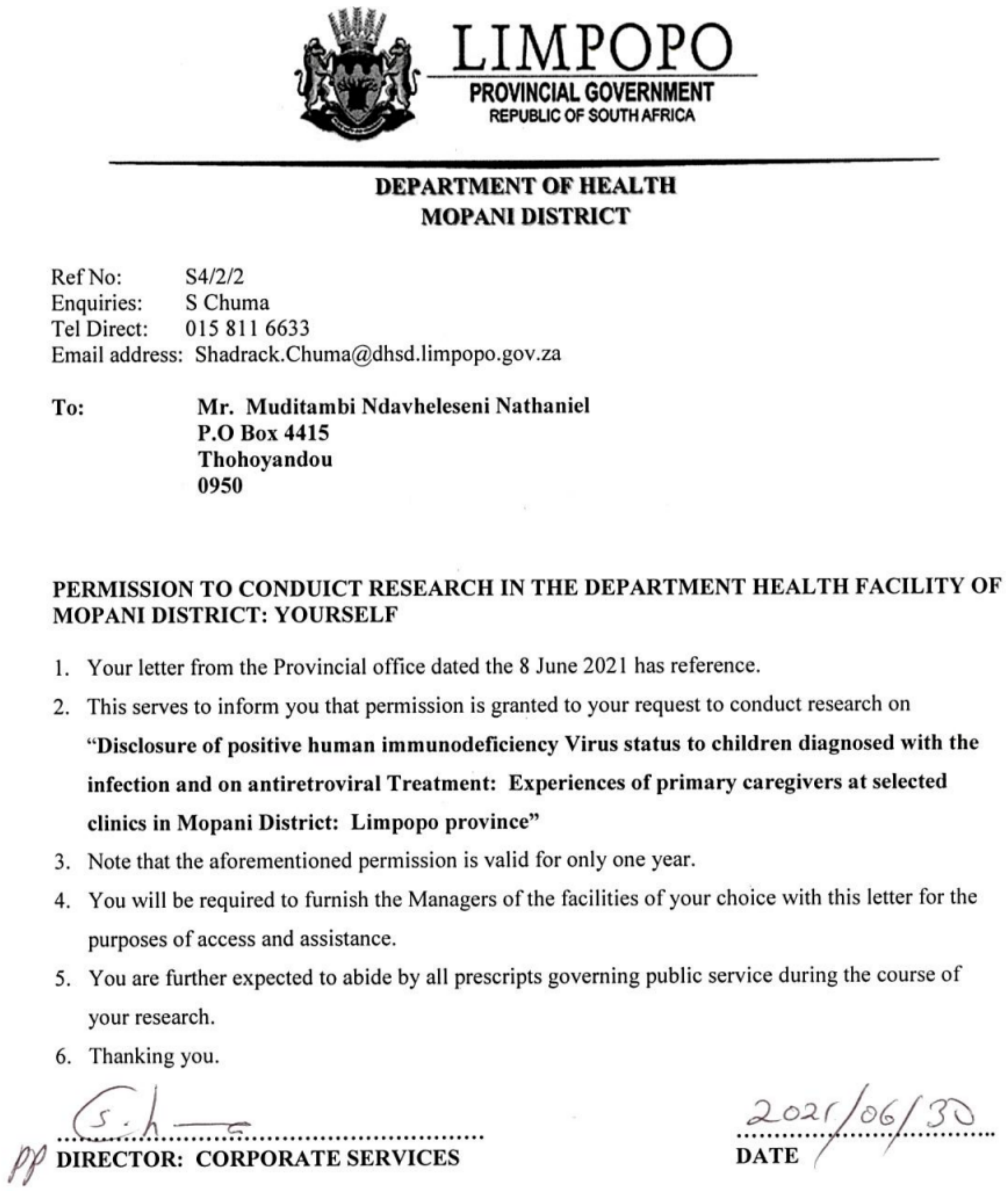
**Application for conducting research in Mopani District, PHC facilities**

I request permission to conduct research in the above-mentioned area. I am a student who is furthering his studies in Master of Nursing Science at University of Limpopo. The purpose of the study is to determine and explore experiences of HIV disclosure to infected children among Primary caregivers in Mopani District Limpopo Province, South Africa. I request to conduct interview to primary caregivers who have accompanied their children or adolescent to collect treatment in Primary Healthcare Facilities in Mopani District.

Enclosed find research proposal, consent form, interview guide and the approval letter from university of Limpopo.

Yours sincerely
Muditambi NN (student)

**APPENDIX E** Permission to conduct research in Department health facility of Mopani District



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH**
**MOPANI DISTRICT**

Ref No: S4/2/2
Enquiries: S Chuma
Tel Direct: 015 811 6633
Email address: Shadrack.Chuma@dhsd.limpopo.gov.za

**To:** **Mr. Muditambi Ndavheleseni Nathaniel**
**P.O Box 4415**
**Thohoyandou**
**0950**

**PERMISSION TO CONDUICT RESEARCH IN THE DEPARTMENT HEALTH FACILITY OF MOPANI DISTRICT: YOURSELF**

1. Your letter from the Provincial office dated the 8 June 2021 has reference.
2. This serves to inform you that permission is granted to your request to conduct research on **"Disclosure of positive human immunodeficiency Virus status to children diagnosed with the infection and on antiretroviral Treatment: Experiences of primary caregivers at selected clinics in Mopani District: Limpopo province"**
3. Note that the aforementioned permission is valid for only one year.
4. You will be required to furnish the Managers of the facilities of your choice with this letter for the purposes of access and assistance.
5. You are further expected to abide by all prescripts governing public service during the course of your research.
6. Thanking you.

pp **DIRECTOR: CORPORATE SERVICES**

2021/06/30
**DATE**

**APPENDIX F** Study Information sheet

- INFORMATION SHEET

**Name of the study:** Disclosure of human immunodeficiency virus status to infected children: experience of primary caregiver in mopani district Limpopo province

Researcher: Muditambi Nathaniel
Contact: 078 118 4247
Email: *muthundinne@gmail.com*

The purpose of the study is to determine and explore experiences and perception of HIV disclosure to children living HIV/AIDS among primary caregivers in Mopani District Limpopo Province, South Africa. The reasons for this study are that there is high number of children living with HIV and taking ART and unfortunately, they are not aware of their HIV positive status. Primary caregivers' delays to initiate the progress on disclosure of HIV. The delays in HIV positive status disclosure are likely to lead to a delay in access to treatment and/or to address problems related to adherence to treatment.

During the study participants can withdraw their participation at any time without any reprisal. The participants will be treated fairly; even if the participants refused to participate, they will receive the same care and respect as those who participated. All the participants will be identified by the study number for anonymity so that no information will be traced back to the participants. The researcher will ensure confidentiality and anonymity at all levels of the study by avoiding use of names of participants and unique identifiers will be used.

By participating the findings may provide information of significance to health service provision by ensuring that health education is strengthen towards capacitating primary caregiver on HIV disclosure process. Hence assisting children living with HIV to know their status and live healthy and happier after.

Feel free to ask any question regarding the study and your participation.

- Thank you for your participation

**APPENDIX G** Consent form

## **Consent form**

**Name of the study:** Disclosure of human immunodeficiency virus status to infected children: experience of primary caregiver in mopani district Limpopo province

Researcher: Muditambi Nathaniel
Contact: 078 118 4247
Email: muthundinne@gmail.com

I have read the information on the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I know that this study has been approved by Turfloop Research Ethics Committee (TREC), Limpopo Department of Health and Pietersburg Hospital Ethics Committee. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study

…………………………………………………
Signature of the participants

| | | |
|---|---|---|
| ……………………………… | ……………………….. | …………………… |
| Place | Date | witness |

Statement by the Researcher

•I provided written information regarding this Study

•I agree to answer any future questions concerning the Study as best as I am able.

•I will adhere to the approved protocol.

| | | | |
|---|---|---|---|
| .............................. | ....................…… | ……………. | ……………… |
| Name of Researcher | Signature | Date | Place |

**APPENDIX H** Interview Guide/Questionnaire

## INTERVIEW GUIDE

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## DISCLOSURE OF POSITIVE HUMAN IMMUNODEFICIENCY VIRUS STATUS TO CHILDREN DIAGNOSED WITH THE INFECTION AND ON ANTIRETROVIRAL TREATMENT: EXPERIENCES OF PRIMARY CAREGIVERS AT SELECTED CLINICS IN MOPANI DISTRICT, LIMPOPO PROVINCE

### SECTION A

### Biographic data

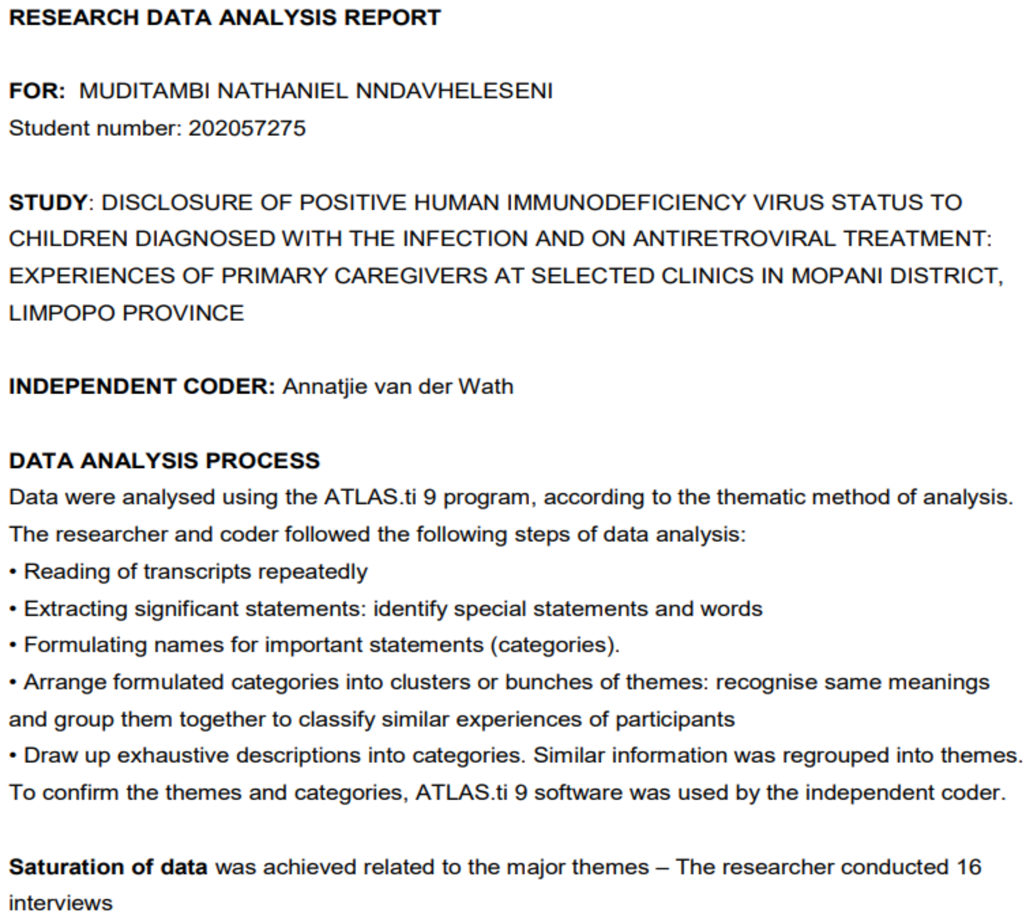
**INSTRUCTION: Tick in the appropriate block**

| | | |
|---|---|---|
| Gender | Females | |
| | Males | |
| Level od education | Matric and above | |
| | Grade 5 – 11 | |
| | Grade 1 to 4 | |
| | Never attended school | |
| Employment | Employed | |
| | Unemployed | |
| Relationship to the child | Parent | |
| | Guardian | |
| | Foster<br>Other(specify) | |

## Section B

| **Topic area** | **Questions** | **Probe** |
|---|---|---|
| Experiance of HIV status disclosure | What do you understand about HIV disclosure?<br>How would you describe the event of telling your child that she or he is HIV positive? | - Have you already disclosed to your child that he /she is HIV positive?At which age did you initiate HIV disclose to your child<br>- Do you mind indicating issues that you had to consider when you are disclosing? |
| Importance/benefits of HIV status disclosure | Do you think it is important to disclose HIV status to the child living with HIV? | - What do you think are the benefits of disclosing HIV status to the child living with HIV?<br>- What do you think are the complication for non-disclosure of HIV positive status to the child living with HIV? |
| Skills of HV status disclosure | Do you think you have capacity to do HIV disclosure? | - Have you ever received any support/training regarding how to do HIV disclose to the child?<br>Tell me how to go about initiating HIV disclosure process? |
| Barriers to HIV status disclosure | Tell me things or issues that made you not disclosed to the child about his/her HIV status? | - What do you fear most about HIV disclosure?<br>- Do you think your child is ready for closure? And why?<br>- What do think can be done to assist you with HIV disclosure of child living with HIV? |

## **APPENDIX I** Independent coder certificate



**RESEARCH DATA ANALYSIS REPORT**

**FOR:** MUDITAMBI NATHANIEL NNDAVHELESENI
Student number: 202057275

**STUDY**: DISCLOSURE OF POSITIVE HUMAN IMMUNODEFICIENCY VIRUS STATUS TO CHILDREN DIAGNOSED WITH THE INFECTION AND ON ANTIRETROVIRAL TREATMENT: EXPERIENCES OF PRIMARY CAREGIVERS AT SELECTED CLINICS IN MOPANI DISTRICT, LIMPOPO PROVINCE

**INDEPENDENT CODER:** Annatjie van der Wath

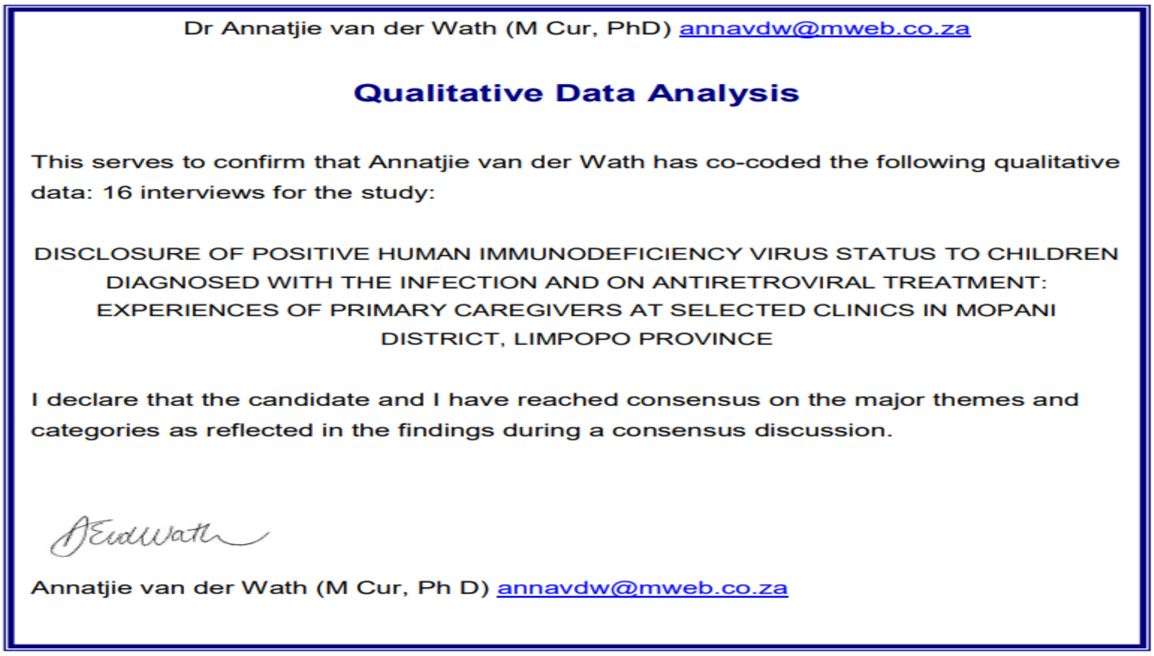
**DATA ANALYSIS PROCESS**

Data were analysed using the ATLAS.ti 9 program, according to the thematic method of analysis. The researcher and coder followed the following steps of data analysis:

- Reading of transcripts repeatedly
- Extracting significant statements: identify special statements and words
- Formulating names for important statements (categories).
- Arrange formulated categories into clusters or bunches of themes: recognise same meanings and group them together to classify similar experiences of participants
- Draw up exhaustive descriptions into categories. Similar information was regrouped into themes.

To confirm the themes and categories, ATLAS.ti 9 software was used by the independent coder.

**Saturation of data** was achieved related to the major themes – The researcher conducted 16 interviews



Dr Annatjie van der Wath (M Cur, PhD) annavdw@mweb.co.za

### Qualitative Data Analysis

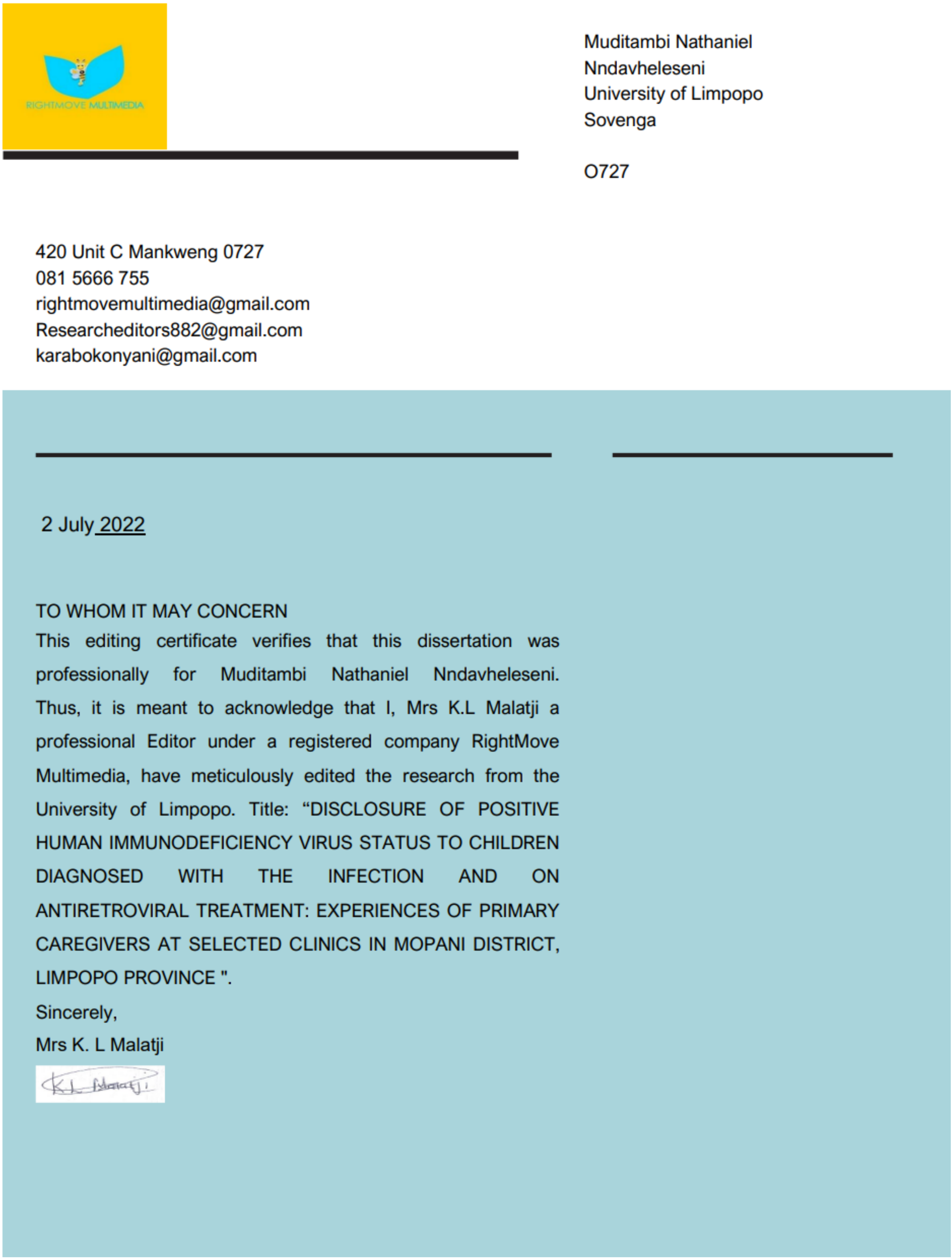
This serves to confirm that Annatjie van der Wath has co-coded the following qualitative data: 16 interviews for the study:

DISCLOSURE OF POSITIVE HUMAN IMMUNODEFICIENCY VIRUS STATUS TO CHILDREN DIAGNOSED WITH THE INFECTION AND ON ANTIRETROVIRAL TREATMENT: EXPERIENCES OF PRIMARY CAREGIVERS AT SELECTED CLINICS IN MOPANI DISTRICT, LIMPOPO PROVINCE

I declare that the candidate and I have reached consensus on the major themes and categories as reflected in the findings during a consensus discussion.

Annatjie van der Wath (M Cur, Ph D) annavdw@mweb.co.za

# **APPENDIX H** Language and Technical Editing Certificate



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2 July 2022

TO WHOM IT MAY CONCERN

This editing certificate verifies that this dissertation was professionally for Muditambi Nathaniel Nndavheleseni. Thus, it is meant to acknowledge that I, Mrs K.L Malatji a professional Editor under a registered company RightMove Multimedia, have meticulously edited the research from the University of Limpopo. Title: “DISCLOSURE OF POSITIVE HUMAN IMMUNODEFICIENCY VIRUS STATUS TO CHILDREN DIAGNOSED WITH THE INFECTION AND ON ANTIRETROVIRAL TREATMENT: EXPERIENCES OF PRIMARY CAREGIVERS AT SELECTED CLINICS IN MOPANI DISTRICT, LIMPOPO PROVINCE ".

Sincerely,

Mrs K. L Malatji

K.L Malatji