EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUB-DISTRICT, NORTH WEST PROVINCE, SOUTH AFRICA

By

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DECLARATION

I, **Khangale Happy Maybe Maambiwa**, hereby declare that the research titled**,** **“*Experiences of Adolescents on Antiretroviral Therapy At Rustenburg Sub-district, North West Province*”**, hasn't been previously submitted for a degree at this or another university, that it is my work in layout and execution, and that all reference fabric contained therein have been properly recognized.

Signature: **Date: 12/01/2022**

DEDICATION

This dissertation is dedicated to:

- My Father Mulimisi Moses Khangale and my mother Adziambei Rose Khangale.
- My loving supportive wife Khumbudzo Khangale.
- My siblings Phindulo, Vhutolo, Vhugalahawe, and Vhathuvhothe Khangale for their support and believing in me all through the study.

Thank you for helping me financially, mentally, and with the aid of using your time. You will continually be a blessing and a unique present from God to me, your overwhelming love to me means a lot and I will never take it for granted. May God extend your territories.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS:	Acquired Deficiency Immune Syndrome
ALHIV:	Adolescents Living with Human Immune Virus
ART:	Antiretroviral Therapy
AP:	Asia and Pacific
CCASA:	Caribbean, Central America and South America
DoH:	Department of Health
EE:	Eastern Europe
HAART:	Highly Active Antiretroviral Therapy
HIV:	Human Immunodeficiency Virus
LGBTIQ:	Lesbian, Gay, Bisexual, Transgender, Queer and Intersex
PHIV:	Perinatally HIV Infected
PMTCT:	Prevention of Mother to Child Transmission
UNAIDS:	Joint United Nations Programme on HIV and AIDS
UNICEF:	United Nations Children Emergency Fund

ABSTRACT

Background: Antiretroviral therapy is the treatment that has been implemented to combat advanced Human Immunodeficiency Virus in order to prevent the spread of Acquired Immunodeficiency Syndrome and, as a result, help in extending the lifespan of those who have been infected. In 2004, a human immunodeficiency virus (HIV) antiretroviral therapy program was initiated in South Africa.

Purpose: The purpose of the study was to explore the experiences of adolescents on antiretroviral therapy in Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome facilities in Rustenburg sub-district North West Province.

Setting: The study was conducted in two primary health care clinics at North West province in Rustenburg sub district.

Methodology: Qualitative research approach was used which is phenomenological descriptive, explorative and contextual. Non probability purposive sampling was used to select the health care facilities and adolescents were chosen using convenience sampling. In depth individual interviews were used to collect data from the participants until data saturation was reached. Collected data was analysed using Tesch's eight steps.

Results: The findings of the study reveal that HIV positive adolescents are encountering various challenges while on ART which lead to then not adhering to treatment. lack of knowledge about own disease condition by adolescents from childhood to date affects the adolescents psychologically as they try to figure out the reason of taking treatment while adolescents are not.

Recommendations: This study recommends that all adolescents living with HIV should receive ongoing counselling from health care providers so that they feel cared for and understand the need of adhering to treatment. Future research should include caregivers and health care workers for them to learn more on the experiences of the adolescents while on ART.

Conclusion: Delayed disclosure of adolescent’s HIV positive status by parents until the adolescent discover by him/herself lead to poor adherence to treatment. Furthermore, the study concludes that the adolescents on ART are not yet free to disclose and trust people with their status, this led them to not having treatment buddies.

Keywords: Adolescents, Antiretroviral therapy, Experience

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CHAPTER ONE

OVERVIEW OF THE STUDY

1. INTRODUCTION

Antiretroviral therapy is defined as the use of at least three medications from at least two classes: nucleoside and non-nucleoside reverse transcriptase inhibitors, and protease inhibitors. Antiretroviral medications have transformed the treatment of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) since 1996, substantially improving the quality of life of individuals affected and prolonging the lives of many more. The Human Immunodeficiency Virus, according to Velasco-Hernandez (2002), is the virus that causes Acute Immunodeficiency Syndrome. Acquired Immunodeficiency, on the other hand, is a combination of disorders or symptoms that eventually lead to death (Sieleunou & Souleymanou, 2009).

Antiretroviral therapy is the treatment that has been initiated to combat advanced Human Immunodeficiency Syndrome to decrease the spread of Acquired Immunodeficiency Syndrome and, in the end, to let the infected person live longer. In 2004, South Africa initiated an antiretroviral therapy program to treat the human immunodeficiency virus (HIV), (National Department of Health [NDoH], 2004).

1.1. BACKGROUND

According to the world health education (WHO) and the joint United Nations programme on HIV/AIDS (UNAIDS) 37.7 million [30.2 million–45.1 million] people globally were living with HIV in 2020. 1.5 million [1.0 million–2.0 million] people became newly infected with HIV in 2020. 28.2 million People were accessing antiretroviral therapy as of 30 June 2021. 680 000 [480 000–1.0 million] people died from AIDS-related illnesses in 2020. 79.3 million [55.9 million–110 million] people have become infected with HIV since the start of the epidemic. 36.3 million [27.2 million–47.8 million] people have died from AIDS-related illnesses since the start of the epidemic. UNAIDS (2021)

In 2020, there were 37.7 million [30.2 million–45.1 million] people living with HIV. 36.0 million [28.9 million–43.2 million] adults. 1.7 million [1.2 million–2.2 million] children (0–14 years). 53% of all people living with HIV were women and girls. 84% [67– >98%] of all people living with HIV knew their HIV status in 2020. About 6.1 million [4.9 million–7.3 million] people did not know that they were living with HIV in 2020. UNAIDS (2021)

As of 30 June 2021, 28.2 million people were accessing antiretroviral therapy, up from 7.8 million [6.9 million–7.9 million] in 2010.In 2020, 73% [56–88%] of all people living with HIV were accessing treatment.74% [57–90%] of adults aged 15 years and older living with HIV had access to treatment, as did 54% [37–69%] of children aged 0–14 years.79% [61–95%] of female adults aged 15 years and older had access to treatment; however, just 68% [52–83%] of male adults aged 15 years and older had access.85% [63– >98%] of pregnant women living with HIV had access to antiretroviral medicines to prevent transmission of HIV to their child in 2020.New HIV infections have been reduced by 52% since the peak in 1997.UNAIDS (2021)

Several major HIV outbreaks have been reported in the Caribbean, Central America, and South America (CCASA), Eastern Europe (EE), and Asia and Pacific (AP) countries, affecting all types of people, particularly in middle-income countries. In 2015, UNAIDS estimated that 74,000 adolescents aged 15–19 years in CCASA and 220,000 in AP were living with HIV and on ART, with 210,000 and 600,000 aged 15–24 years, respectively. Although the epidemic in Eastern Europe and Central Asia is smaller (an estimated 80,000 15–24-year-olds), it is the only one in the world where total incidence is rising rapidly. In addition to a perinatally HIV-infected (PHIV) population aging into adolescents and young adulthood, success in preventing mother-to-child transmission (PMTCT) has been uneven across countries in these regions, and there is an ongoing vulnerability of young people in marginalized key populations to behavioural HIV acquisition (Heather & Bailey, 2017).

Despite the fact that HIV prevention of mother-to-child transmission initiatives were dispersed in the Pacific and Asia in the late 1990s, regional coverage of ART for PMTCT was only 41% in 2015. With rates of 2% in 2016 and prenatal prevalence declining from 2.3% in 1994 to 0.6% in 2015, Thailand is the first Asian country to meet the goal of MTCT elimination. Access to ART for HIV-positive adolescents in the AP region began in the early 2000s, although funding came from a number of sources, including national budgets, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and the US President's Emergency Plan for AIDS Relief (PEPFAR). According to UNICEF, more than 400,000 children in Indonesia, Thailand, Myanmar, and Vietnam were orphans due to AIDS in 2015. The countries with the most HIV-positive adolescents include India, Indonesia, Thailand, Myanmar, and Vietnam. One of the challenges PHIV adolescents have as they transfer to adult programs in AP is that their diagnosis is not fully communicated. The World Health Organization recommends informing children between the ages of 6 and 12 years about their HIV status (Huan & Zeng, 2017).

In some sub-Saharan countries, adolescent girls are two to three times more likely to be infected with HIV than boys of the same age group. However, HIV does not only affect sub-Saharan Africa. In 2020, 18 per cent of adolescents newly infected with HIV lived outside the region. (UNAIDS,2021).

South Africa faces a critical period with children born with HIV surviving into adolescents and beyond due to the provision of highly active antiretroviral therapy (ART). Similarly, sexual transmission of HIV continues to pose a challenge as the incidence and prevalence among adolescents is increasing (UNICEF, 2016; National Department of Health [NDoH] 2015). Therefore, adolescents living with HIV are particularly a significant sub-group in the HIV and AIDS epidemic that needs to be adequately addressed.

The researcher found few studies on experiences of adolescents living with HIV/AIDS and are on ART in sub-Sahara Africa. In particular, the researcher also found few similar study conducted in South Africa. In a study conducted in South Africa by Tshuma (2015) on challenges faced by adolescents with perinatal HIV/AIDS, majority of participants revealed that they were not aware of their status prior to growing up taking medication because their caregivers didn’t disclose what it was for. The study also revealed that adolescents are facing challenges with adherence to treatment as they fail to cope with the treatment’s side effects. The study only focused on adolescents with perinatal HIV/AIDS and excluded the ones who acquired the virus horizontally.

The omission of adolescents who acquired HIV horizontally raised more questions and interest to the researcher wanting to know more on both the experiences of those who acquired HIV perinatal and horizontal, how those with perinatal HIV experienced after disclosure of their positive status and those who grew up and never thought at some stage that their status would change.

The researcher felt that it would be beneficial to conduct this study in the country to bring forth the experiences of adolescents on antiretroviral therapy since most studies focus on adults and tend to forget the adolescents.

1.2. PROBLEM STATEMENT

The researcher is a registered nurse with 12 months of community work in an HIV/AIDS facility. The researcher has noted with great concern that about 40% of adolescents aged 15-19 years who are perinatally HIV positive and on ART are not virologically suppressed, preventing them from achieving the third 90% of the 90 90 90 strategy (90% of people on ART must be virally suppressed). These adolescents are infected with opportunistic infections such as tuberculosis (TB) and candidiasis (thrush), and some are hospitalized, posing a challenge to the students by causing them to fall behind in their studies. The adolescent's emotions during their visits to the facilities to receive treatment made the researcher concerned, and made the researcher feel compelled to learn more from the adolescent as to why they did not appear to be joyful; as a result, several adolescents related their experiences while on ART. The researcher searched for information about adolescent experiences to see whether there had been any studies done on the subject. Unfortunately, data on the experiences of children aged 15 to 19 years living with perinatal HIV/AIDS was scarce, particularly in South Africa and Africa as a whole. The lack of information on the experiences that children have had while on antiretroviral therapy may be contributing to children's virological failure. In this light, the researcher is interested in learning more about the experiences of adolescent HIV/AIDS patients. This will also help researchers and other health-care providers obtain a better understanding of children's experiences and how best to help them, as this may be contributing to their virological failure.

1.3. RATIONALE OF THE STUDY

Since adolescents on ART haven't met the third 90% of the 90 90 90 strategy, which states that 90% of individuals on ART should be virologically suppressed, the researcher chose this topic for this study. A study conducted by Lee-Ann (2017) on exploration of adherence to antiretroviral treatment among adolescents revealed that I increased tablet load was also recognized as an obstacle to medication compliance, particularly among those on a second line ART regimen that mainly consists of Protease Inhibitor and Alluvia, that must be taken twelve hourly per day. The Alluvia tablet is an incredibly unpleasant pill with unpleasant side effects. This has an effect on poor treatment adherence as well.

Another study by Tshuma (2016) focused on challenges faced by adolescents with perinatal HIV/AIDS in South Africa.

Exploring adolescent experiences may aid in adolescent ART therapy adherence rates. Improving the adherence rate of adolescents on ART will result in adolescents' achieving 90% of viral suppression and decreasing the morbidity of adolescents living with HIV.

1.4. SIGNIFICANCE OF THE STUDY

The findings of the study will assist health care professionals obtain a better understanding of the challenges that adolescents face, and they will be able to run campaigns to support adolescents living with HIV/AIDS. Adolescents with HIV/AIDS may also benefit because they will receive support, care, and affection from health care providers and their families, resulting in good adherence to ART. Policymakers will benefit from the findings since they will be able to use them as a guide when making recommendations in the field of the study. The findings of the study will also benefit the community because it will allow them to learn about and understand the experiences of adolescents living with HIV, as well as the fact that they are no different than anyone else in the community and should be treated with care and love without discrimination. The families of adolescents will have a better understanding of what their children are going through and how they should treat them. They will also learn to always offer their children love.

1.5. PURPOSE

The purpose of the study was to determine the experiences of adolescents on antiretroviral therapy in Rustenburg sub-district North West.

1.5.1 OBJECTIVES

Objectives of the study were to:

- Explore experiences of adolescents on antiretroviral therapy in Rustenburg sub district North West.

- Describe the experiences of adolescents on antiretroviral therapy in Rustenburg sub district North West.

1.6. DEFINITION OF CONCEPTS

Antiretroviral therapy

Antiretroviral therapy (ART) is a drug regimen administered to HIV positive people, according to the World Health Organization (2018). A combination of at least three antiretroviral (ARV) medicines is used to suppress the virus and prevent the disease from progressing to AIDS. ART does not cure HIV, but it does keep it from multiplying and progressing to AIDS. As a result, ART is a daily medicine that must be taken for the rest of one's life, making the HIV infection chronic. In this study, ART is defined as mixture of two or more retroviral drugs.

Adolescents

Adolescence, according to the World Health Organization (2018), is a transitory period of growth and development between childhood and adulthood, with adolescents ranging in age from 10 to 19. During the journey from infancy to adulthood, adolescence is marked by unique and rapid biological and behavioral changes, as well as increasing capacities (World Health Organisation, 2018). The adolescent era can be divided into two phases: the lower band, which includes those aged 10 to 14, and the upper band, which includes those aged 15 to 19. In this study adolescents refers to those between the ages of 15-19 years living with HIV/AIDS and are on ART.

Experience

According to Kolb (2013), experience is the unity of sight and action, perception, conception, knowledge, theory and practice. It has to do with seeing into a situation or acting within it and involves both knowledge and evaluation of objects, events and situations. In this study, experience is the accumulation of knowledge and what adolescents encounter on their daily basis while living with HIV and on ART.

1.7 0RGANISATION OF THE STUDY CHAPTERS

- **Chapter 1: overview of the study**

The chapter presents the overview of the study through introduction, background, problem statement, rationale and significance of the study, purpose, objectives, , definition of concepts and chapter layout.

- **Chapter 2: Literature review**

Chapter two presents literature review around experiences of adolescents on antiretroviral therapy.

- **Chapter 3: Research methodology**

The research methodology covering research approach and design, setting, population, sampling method, pre-test, data collection, data analysis and data management of the study.

- **Chapter 4: Presentation and discussion of research findings**

Chapter four presents research findings and presentations. The research findings were supported by the relevant literature

- **Chapter 5: Limitations, recommendations and conclusion**

Chapter 5 covers the limitations, recommendations and the conclusion about experiences of adolescents on antiretroviral therapy in Rustenburg sub district in North West province.

1.7. CONCLUSION

The overview of the study was presented in this chapter. The purpose, objectives and definition of concepts on the study were outlined. The research methodology with research design, population, setting, sampling method, pre-test, data collection, data analysis and data management of the study are described in chapter.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter presented the introduction and background, problem statement, rationale of the study, significance of the study, purpose, objectives, operational definition of concepts and key terms. This chapter presents literature related to the experiences of adolescents on ART. A literature review is defined as a written document that presents a reasonably contended incident established on a comprehensive understanding of the recent state of knowledge about a topic of study Machi (2016). The literature review was conducted through perusing books and published magazine articles related to the topic and it was retrieved from various databases and search engines

According to WHO and UNAIDS, HIV among children and adolescents presents unique features that affect how diagnosis, treatment and care is provided across the age continuum of 0–19 years. Optimal antiretroviral drug regimens may require changes as children age and grow. Countries need to adapt and tailor service delivery between younger adolescents (10–14 years old) and older adolescents (15–19 years old) due to significant differences in health-seeking behaviour, number of adolescents acquiring HIV infection and health outcomes including AIDS-related causes. Further, models of care to retain children and adolescents in treatment and ensure that they have suppressed viral loads must leverage different opportunities and address various challenges over the life-course. It is a well-known fact that children and adolescents have lower reported treatment coverage, adherence to treatment and viral suppression rates than older age groups. (UNAIDS, 2020)

Globally, adolescents 10-19 years account for about 5 per cent of all people living with HIV, 11 per cent of new HIV infections and 5 per cent of all AIDS-related deaths. In 2020, about 940,000 adolescents 10-19 years, or 54 per cent of adolescents living with HIV globally, received antiretroviral treatment. Antiretroviral treatment coverage was 53 and 55 percent among adolescent girls and boys, respectively. In order to reach the 95-95-95 targets by 2025, there is an urgent need to ramp up treatment efforts among adolescents. {UNICEF, 2021)

2.2. South Africa ART programme

South Africa established a national ART program in 2004. Between 2010 and 2013, 5.6 million new patients were started on antiretroviral therapy (ART) worldwide, with South Africa accounting for the highest share (33%) of this total (UNAIDS, 2014). A 1.2 million rise in HIV prevalence was discovered in comparisons of national HIV prevalence surveys SA conducted in 2008 and 2012, which can be explained in part by the remarkable development of the ART program, which has saved many lives (Shisana et al., 2014). In 2012, the South African National HIV Prevalence, Incidence, and Behaviour Survey was conducted. More than 2 million of South Africa's estimated 6.3 million HIV-positive people were eligible for antiretroviral therapy, with 31.5% receiving treatment. According to a government publication on the Millennium Development Goals, 70.8% of men, 87.3% of women, and 56.2% of adolescents in South Africa who were eligible for ART were on treatment in 2013 (Republic of South Africa, 2013). ART was started on 86% of people over the age of 15 who were eligible. South Africa has also embraced the "90-90-90" approach, which sets 2020 HIV and antiretroviral therapy (ART) targets with the goal of eliminating HIV by 2030 (UNAIDS, 2014). According to the strategy's goals, 90% of people living with HIV will know their HIV status, 90% of those with confirmed HIV infection will receive sustained antiretroviral medication, and 90% of people on antiretroviral therapy will have viral suppression.

One of South Africa's most significant breakthroughs in the fight against AIDS has been the prevention of mother-to-child HIV transmission (PMTCT), which has lowered HIV transmission from mothers to their new-borns from around 30% to 1.8%. Thousands of babies, on the other hand, were born with HIV before effective PMTCT was developed, and are now struggling to understand what it means to be HIV positive, including taking daily medication and dealing with the stigma of having a sexually transmitted virus despite not having been sexually active (Ngubane & Lekgetho, 2016)

2.3. Challenges faced by adolescents living with HIV/AIDS

Adolescents living with HIV and AIDS face numerous challenges throughout their lives. Adolescents who have been living with HIV since birth face a variety of challenges (Mellins & Malee, 2013), including "ongoing medical treatment, hospitalizations, pain exposure, and sheltered life experiences." They also face a slew of unique issues relating to HIV's psychological impact, a highly stigmatized and transmissible illness that can make navigating adolescence tough. As a result, it's vital to look into these survivors' daily lives in order to better equip care professionals with intervention alternatives when working with adolescents who have been exposed to HIV or AIDS during pregnancy. These developmental issues are linked to a variety of behavioural patterns, including increased risky behavior, experimentation, and conformity demands, all of which can contribute to poor adherence of ART. Viral load rebound, medication resistance, morbidity, and mortality are all increased by poor adherence. HIV infection and re-infection with diverse strains of HIV are also common during adolescence. Risky sexual behavior is on the rise in South Africa, according to a nationwide household survey, as evidenced by an increase in the number of persons who had their first sexual experience before the age of 15 years (Shisana et al., 2014). According to the survey, a third of young women aged 15–19 years had sexual partners who were five or more years older. HIV infection in young women is extremely dangerous (Cowan & Pettifor, 2009).

A study conducted in Namibia revealed that adolescents living with HIV/AIDS are also most likely to be orphaned (Gentz, Romano, Martínez-Arias, & Ruiz-Casares, 2017). Congruent with other studies conducted in the Sub-Saharan African region are the findings of a qualitative study conducted in Lesotho, which found that adolescents living with HIV/AIDS express challenges of depression, financial crisis and high levels of trauma mainly due to parental loss and isolation (Ramaiya et al., 2016). Thus, these unresolved childhood experiences of trauma, sadness and shyness, as exacerbated by the absence of parental care and empathy, trouble these adolescents throughout their development years. There is need for flexible interventions and strategies that complement Highly Active Antiretroviral Therapy (HAART) that has proved to be effective in promoting quality life amongst these adolescents.

2.4. Adherence to antiretroviral therapy by adolescents

Adherence is defined as the extent to which a person's behaviour in terms of taking medications, following a diet, and executing lifestyle changes follows agreed recommendations from a healthcare provider (WHO, 2013).Adherence to a specific antiretroviral regimen is crucial for achieving and maintaining virological suppression in the patient (the absence of virus replication). There is a strong link between viral load and non-adherence. According to Maskew, Bor, Maclead, Carmona, Sherman, and Fox (2016), the National Health Laboratory Services (NHLS) database has shown a decrease in virological suppression among adolescents in the public sector since 2004. HIV-positive adolescents on antiretroviral therapy (ART) require strong and ongoing motivation to stick to their ART regimen for the rest of their lives. Ideal adherence for HIV therapy (ART) is set significantly higher than for other chronic diseases, according to Bekker, Cotton, Maarten, Meyers, Venter, and Wilson (2008), making it far more difficult to achieve.

Furthermore, low adherence and retention among the adolescent population that result in low viral suppression rates among adolescents were also attributed to the lack of adolescent-specific services in health care facilities. Most ART programmes are focused on adult and child populations (Casale et al., 2019). Adolescents generally access care either in paediatric or adult services. Furthermore, the inadequate experience and practice among healthcare workers in dealing with young HIV individuals has caused poor rates of retention among adolescents compared to other age groups (MacPherson et al., 2015).

In the Sub-Saharan African region, a systematic review found that high adherence levels were shown to positively correlate with improved quality of life to the first line regiment. (Heestermans, Browne, Aitken, Vervoort & Klipstein-Grobusch., 2016). A study conducted in Tanzania concluded that HIV patients who started ART at the beginning of the study had 87% viral load suppression at the end of the longitudinal research. The study noted that adherence to ARV medication largely improves viral suppression (Sangeda et al., 2018). In addition, research also noted that proper ARV uptake improves linkage to social support groups and outward physical health. Although there are many benefits associated with adherence to ARV medication, there are several factors that lead to poor or non-adherence to medication.

2.5. Disclosure of HIV positive status of adolescents

WHO’s guidelines recommend disclosure to adolescents of their own status but prior counselling on potential benefits and risks of disclosure should be done (World Health Organization 2019). In addition, WHO advocates that disclosure should be done progressively to accommodate cognitive skills and emotional development. Kenu et al (2018) suggest that telling adolescents about their HIV infection is a dilemma because they are often asymptomatic in the early stages of infection while they require daily medication and close monitoring.

In a study done in Nigeria by Aderemi, Razaq, Abah, Opanuga, Akanmu. (2021) it was noted that adolescent narrated how he was mistakenly disclosed to by a female doctor who assumed he knew his status because he was picking up his drugs himself and adhering. His mum and other caregivers had told him that they were just medicines he must take to keep him strong. The disclosure was so shocking for him. In his bid to get cured, he went for healing in a church. This made him stop taking his medicines which got him very sick after a while and he had to be referred to a counsellor on two different occasions to get back on track. Getting him back on track took him three years.

The study done in south Africa by Ramarumo (2018) revealed that, total disclosure remained a problem for infected children, who found it difficult to disclose their HIV positive status to anyone outside their household. Their families also pressured them to keep their status as a secret. Most youngsters kept their HIV positive status a closely guarded secret from themselves and their families. Since none of these youngsters had stopped taking their ART treatment, there were no concerns about treatment adherence. The possibility of receiving ART treatment on a daily basis for the rest of their lives weighed heavily on a handful of them. Adolescents reported that being on ART therapy had interrupted their personal lives, had a negative influence on their interactions with friends at home and at school, and had a negative impact on their academic performance.

2.6. Stigma and discrimination

Stigma is defined as an extreme devaluation of people that are living or associated with HIV/AIDS (Patankar & Pandit, 2014). HIV-related stigma and discrimination are the major obstacles to disclosure and the provision of support to adolescents living with HIV/AIDS. Worldwide, literature has documented stigma and discrimination as the major obstacles to the achievement of UNAIDS's goal of a free HIV/AIDS generation by 2030 (UNAIDS, 2018). Stigma and discrimination exacerbate the burden of HIV/AIDS by promoting a culture of secrecy, lack of knowledge and anti-social support for instance group social support where adolescents are taught about protection, which act as the major obstacles to the attainment of an HIV/AIDS free generation. Stigma and discrimination are associated with poor education. Discrimination is also unjust to adolescents living with

HIV/AIDS; for instance, seeking parental consent to access HIV/AIDS services further influences non-disclosure and discourages the seeking of social support services.

The complexity of the social environment of adolescents living HIV is vastly undervalued. Exposure to stigma has an intense effect on their experience of living with HIV (Bernays, Jarrett, Kranzer & Ferrand, 2014). For many adolescents living with HIV, navigating stigma remains a very challenging issue. The stigma related to HIV often erodes social supports that have traditionally supported families, children and adolescents in challenging circumstances and has implications for health and well-being (Cluver & Orkin, 2009 as cited in Smith-Fawzi et al, 2010)

In South Africa study done by (Rmarumo,2018) revealed that, stigma and discrimination against persons living with HIV/AIDS remains an issue in society, and children living with vertically transmitted HIV/AIDS fear being stigmatized and discriminated against if their status is revealed to others outside their family. Only a few youngsters have been subjected to bullying and discrimination at school and at home.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. INTRODUCTION

The chapter presents the research methodology used in this study of experiences of adolescents on antiretroviral therapy. The patients were interviewed in two selected primary health care facilities in the Rustenburg sub district. The chapter also covered the research design, research setting, study population, sampling method, pre-test, data collection, and analysis and data management.

3.2. STUDY APPROACH

Study approaches are research plans and procedures that cover everything from general assumptions to detailed data collection, analysis, and interpretation methodologies (Creswell, 2017). This plan necessitates a number of decisions, none of which must be made in the sequence in which they make sense to the researcher or in which they are presented here. The ultimate choice entails deciding which method should be employed to investigate a subject. Creswell is a character in the film (Creswell, 2017). Procedures of inquiry or research designs, as well as specific research methods utilized for data collection, analysis, and interpretation, are included. The nature of the study problem or issue, according to Guetterman (2015), Lewis (2015), and Creswell (2017), determines the research approach adopted. According to Creswell (2017), qualitative research is a method for analysing and comprehending the significance that individuals or groups attach to a social or human situation. Emerging questions and processes, as well as data collected in the participants' environment, data analysis inductively developed from general themes, and the researcher's interpretations of the data, are all part of the research process. Those who engage in this type of research advocate an approach to research that values an inductive approach, an emphasis on individual meaning, and the necessity of documenting a situation's complexity. As a result, the researcher has chosen a qualitative research approach in order to better understand adolescent interactions with ART.

3.3. RESEARCH DESIGN

A qualitative research approach that helps in describing the lived experiences of an individual is known as phenomenological research. The phenomenological method focuses on studying the phenomena that have impacted an individual. This approach highlights the specifics and identifies a phenomenon as perceived by an individual in a situation. It can also be used to study the commonality in the behaviours of a group of people. (Alase, 2017).

In this study phenomenological design was used because it allowed the researcher to explore the experiences of adolescents on antiretroviral therapy in their natural setting. It gave chance the researcher to record the adolescents' unique experiences. The design allowed the researcher to interact with the participants face-to-face and focus on what was going on in their lives by asking them questions and allowing them time to narrate their experiences.

It allowed participants to feel free in the presence of the researcher and allowed them to give out all information freely. This design allowed the researcher to spend enough time with the patients to get clear replies.

Data was only gathered using the phenomenological approach since it allowed participants to clarify everything they understood by asking clarifying questions.

3.3.1. Exploratory

Exploratory research design is used to gain new insights, discover new ideas, and for increasing knowledge of the phenomenon (Burns & Groove, 2014).

The exploratory qualitative research component is intended to shed light on how a phenomenon manifests itself and is particularly beneficial in revealing the true nature of a little understood phenomenon (Hunter, McCallum & Howes, 2018). In this study, an exploratory design was used to investigate the experiences of adolescents on antiretroviral therapy and make recommendations based on the findings. The use of an exploratory design demonstrates that the researcher is eager to investigate new ideas and possibilities without being guided by prior notions or premises (Creswell, 2014).

3.3.2. Descriptive

Descriptive design is concerned with gathering information from a represented sample of the population (Brink, 2016).

The purpose of the descriptive study is to give a view of circumstances while they naturally occur. It is used to develop an approach, identify faults in current policies, make judgments, or determine what others in comparable situations are doing (Burns & Grove, 2012; Polit & Beck, 2014). In this study, adolescents on ART were given the opportunity to express their full experiences while on ART through interviews. The researcher also observed the adolescents' physical expression during the interviews as another way of gathering information, and the adolescents were recorded as they shared their experiences.

3.3.3. Contextual

According to Polit and Beck (2014) and Brink (2016), the contextual design aims to investigate and provide answers to various theories on how events and processes occur. Furthermore, contextual design aims to explain and comprehend events that take place in a concrete and natural setting. The study was contextual in nature because it focused on adolescents taking antiretroviral therapy between the ages of 15 and 19 years. The study was conducted in two TB and HIV/AIDS primary health care facilities where the adolescents receive antiretroviral therapy (ART). The study was conducted in Rustenburg sub district, Bojanala platinum district in mining villages of North West province.

3.4. Research setting

The study was conducted in the Bojanala platinum District which is the largest of the four Districts of the North-West Province (Dr Kenneth Kaunda District Municipality, Dr Ruth segomotsi mopani District municipality and Ngaka Modiri Molema District Municipality). Moretele, Madibeng, Rustenburg, Kgetlengriver, and Moses Kotane are the four local municipalities that make up the Bojanala Platinum District. With a population of 40271 60, North West province contains 27 hospitals and 557 clinics. The economy of the North

West Province is built on mining, which accounts for more than half of the province's GDP and employs a quarter of its workers. The primary minerals are gold (mined in Orkney and Klerksdorp), uranium (mined in Klerksdorp), platinum (mined in Rustenburg and Brits), and diamonds (mined in Lichtenburg, Christiana, and Bloemhof). The University of North West, which has three campuses in Potchefstroom, Mafikeng, and Vanderbijlpark, is the province's only university. The study was conducted in two clinics in the Rustenburg sub-district of the Bojanala platinum district. Rustenburg is a city with significant historical and cultural significance. The Bafokeng, Bakgatla, and Botswana tribes all call it home, and each has a fascinating tribal history. There are 266 471 people in Rustenburg who are economically active (working or looking for work), with 26.4% of them being unemployed. In addition, 34.7% of the municipality's active youth (15–34 years) are unemployed.

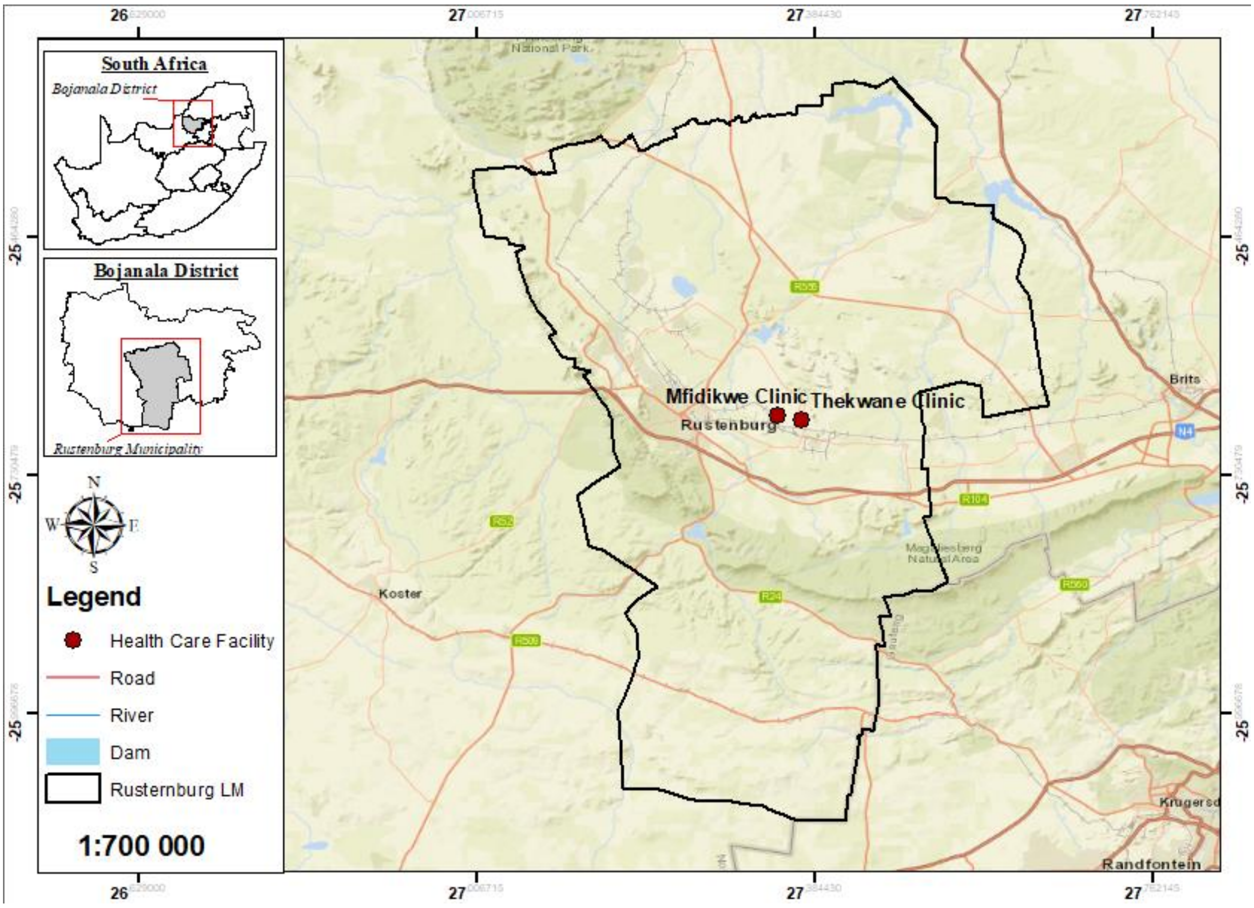

Figure 1. Bojanala district Map indicating Thekwane and Mfidikwe clinic

3.5. Study population

According to Brink (2016), population refers to the entire group or object that is of interest to the researcher or that meets the criteria that the current researchers are interested in. The study population includes adolescents living with HIV/AIDS and on ART, who have different experiences while taking ART.

Target population

The target population should meet the criteria that the researcher is interested in studying (Brink, 2017). Polit and Beck (2014) defined a target population as the entire population in which the researcher is interested and to which he or she would like to generalize the results of a study.

In this study, the target population was adolescents between the age of 15 and 19 years who are on ART.

3.6. Sampling method

The process of selecting a group of people, events, behaviors, or other items to investigate is known as sampling (Burns & Grove, 2012). A sample, according to Moule and Hek (2011), is a subset of the study population made up of participants whose data will be collected. Brink (2012) also defined sampling as the procedure by which a researcher selects a sample from a population in order to collect knowledge on phenomena that is representative of the population of interest. The health facilities and target population this study were sampled using non-probability purposive sampling. When researchers can't find the entire population, they can use the non-probability approach, which is usually more convenient and cost-effective (Brink, 2012).

3.6.1. Sampling of the health facility

The two primary health care facilities were chosen using non-probability purposive sampling. Both institutes are HIV/AIDS treatment centers that primarily serve Tswana-speaking individuals. These institutions were chosen because they both have a large number of adolescent girls and boys aged 15 to 19 years who were born with HIV/AIDS or who have been exposed to the disease after birth.

3.6.1.2. Sampling of participants

A sample is a component or proportion of a total, or a subset of a larger set, that the researcher selects for participation in a study. A sample is a group of elements or units selected from a larger group (Brink et al., 2012; Burns et al., 2012).

In this study, convenience sampling refers to a circumstance in which population elements are chosen because they are readily and easily available. Adolescents who visited the designated institutions were sampled on the day they arrived for treatment, and those who were not found during their visits were contacted by the facility's data capture to assist in locating their contacts.

3.6.2. Sample size

According to Polit and Beck (2012), sample size is the number of people in a study. There are no hard laws for sample size in qualitative research. The sample size for qualitative studies should be decided by the informational demands. As a result, data saturation, or sampling until no new information is received and redundancy is achieved, has become a guiding principle in sampling (Polit & Beck, 2012).

Twenty-five adolescents taking antiretroviral therapy in the specified health care facilities made up the study's sample.

3.6.3. Inclusion criteria

Inclusion criteria refers to the eligibility criteria that the researcher uses to decide whether or not to include the subject (Brink, 2016).

The inclusion criteria in this study were as follows:

Adolescent boys and girls between the ages of 15-19 years on antiretroviral therapy. Adolescents between the ages of 15 and 19 years were chosen because they are on ART and still experiencing virological failure, they will be able to share their experiences while on ART and others they are on ART virologically suppressed but their experiences while on ART are not being attended too.

3.7. MEASUREMENT INSTRUMENT

A research instrument is the device used to collect data in research studies (Brink, 2016). The researcher was the main instrument in conducting one-on-one semi structured interviews with the participants, who were adolescents. Adolescents were able to narrate their experiences while on ART. The researcher and the subjects were in a one-on-one situation. The one-on-one interview helps the interviewer to maintain control over the conversation while simultaneously keeping the interviewee engaged and focused on the work at hand. In addition, the strategy gave the researcher a greater understanding of the situation, allowing the researcher to ask follow-up questions on issues that came up during the interviews.

3.8. PRETEST

Pretesting entails confirming the research instrument's ability to collect data and ensuring that the instrument's instructions are clear (Brink, 2016).

Three adolescents were chosen from one of the chosen facilities and questioned prior to the start of the real data collection process to confirm that the questions were correctly phrased and that they could understand and provide useful information. When the participant was unable to follow the interview questions, the researcher rephrased the questions to make them more understandable. The pre-test assisted the researcher to identify the questions which are not suitable for the study or which need to be rephrased. Pre-test also assisted to assess the researcher’s probing skills and improve where necessary. The data that was collected during the pretesting was omitted in the findings of the study.

3.9. DATA COLLECTION

Data collection is the precise, systematic gathering of information relevant to the research purpose or specific objectives, questions, or hypothesis of the study (Burns & Grove, 2012).

The study was conducted utilizing a qualitative research technique, which means that qualitative data gathering method was used to collect information from the participants. The interview is a social relationship in which the participant and the researcher exchange information. Semi-structured interview as one of the qualitative data collection technique was utilized to acquire information from the participant (see attached Annexure A for semi-structured questions). The interviewer asked two questions followed by posing additional probes and both close-ended and open-ended question were included in the semi structured interview.

The researcher collected data from participants who were chosen based on the researcher's judgment. Adolescents who met the researcher's criteria were recruited to participate in the study while receiving antiretroviral therapy at two facilities in the Rustenburg sub-district of the North West Province. Adolescents on antiretroviral therapy between the ages of 15 and 19 years were informed about the study. The researcher scheduled appointments with all under-18-year-old adolescent guardians so that they could sign the assent consent form for their children to participate in the study. After receiving complete information regarding the research study (the benefits and risks), informed consent was obtained from participants aged 18 and 19 years. The research interview with the participants took place in their respective home as well as in the facilities. Each interview lasted for at least 30-45 minutes. To ensure privacy, interviews were conducted in private places (within the health facility's cubicles).

3.10. DATA MANAGEMENT

The information gathered about the experiences of adolescents on ART was recorded. The recorded interview between the participant and the researcher was saved and backed up on a computer system that was password protected to guarantee privacy. The data was transcribed verbatim.

3.11. DATA ANALYSIS

The process of organizing data in such a way that it provides meaning and facilitates insight into a phenomenon from multiple viewpoints in order to gain better understanding of it is known as data analysis (Creswell, 2014). Data collection and analysis occur simultaneously in qualitative research. Individual verbatim comments from tape recordings were transcribed, and those delivered in Tswana were translated into English. Each transcription was examined separately before being discussed with the supervisors, as well as the final arrangement of the themes, divisions, and subcategories. Tesch's open coding method was used to analyze the data in this study. According to Tesch (Creswell, 2014), the following steps follow:

Step one: Get a sense of the whole:

The researcher listened to the interview recording multiple times, transcribing and double-checking for any missing information. The researcher read the transcripts numerous times to ensure that they made sense for all the interviews, and also highlighted similar themes from different transcripts.

Step two: The researcher selected the most intriguing document and read it several times, attempting to comprehend it. The researcher jotted down his thoughts on a piece of paper.

Step three: A list of all the themes was prepared once the researcher completed the assignment for a number of subjects. Similar themes were grouped together to make columns. The themes were divided into columns and categorized as significant topics, unique topics, and leftovers to make the process easier. To make the process easier, several colored pens were utilized.

Step four: Returning to the data, the researcher abbreviates the themes as codes and assigns a code to the corresponding text segments. The researcher then sought to build a preliminary scheme in order to see whether any new categories or codes emerged.

Step five: The researcher attempted to identify the most descriptive terminology for the issues before categorizing them into themes and sub-themes. By grouping themes that are related to one another and drawing lines between the categories to indicate interrelationships, the researcher attempted to reduce the overall number of categories.

Step six: The abbreviation for each category and code was finalized, and they were sorted alphabetically. This is done after going over the codes numerous times to ensure that all of them have been noted.

Step seven: A preliminary study was performed on data material that belonged to each other. Based on the grouping list, this makes it easy for the researcher to come up with themes and sub-themes.

Step eight: The researcher records existing data to ensure that no data is missing.

3.12. MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is a technique for ensuring data quality or rigor in qualitative research that is based on the model developed by Lincoln and Guba in 1985. As stated by Lincoln & Guba (1985) and Krefting (1991), researchers acquire many techniques to ensure data trustworthiness. The models focus on the following criteria: credibility, dependability, confirmability, and transferability.

3.12.1. Credibility

In qualitative research projects, trustworthiness of findings is regarded as credibility. Participants perceive the stated research findings as their own experiences, demonstrating credibility (Polit & Beck, 2014). To ensure credibility, the researcher employed the following measures:

- **Prolonged engagement**

Polit & Beck (2012) define prolonged engagement as sacrificing more time during data collection to ensure in-depth understanding of the situation under study.

In this study, the researcher spent time with the adolescents to build trust. The researcher also met with the adolescents in the facility setting. The researcher introduced himself to the participants and explained the aims of the research, after which they were requested for permission to return and conduct the real interview with the participants when they were ready. The interviews were conducted until the data saturation was reached.

- **Member checking**

Member checking entails the researcher giving study participants comments on evolving perceptions and obtaining their realities (Polit & Beck, 2012).

In this study, purposeful probing was used for member checking throughout the interview. The researcher's findings were discussed with the participants. Following data processing, the researcher returned to the participants to conduct final member checks to ensure that what was transcribed accurately reflected what they meant.

3.12.2. Dependability

The dependability requirement is the consistency of findings. According to Lincoln and Guba (1985), there’s no reliability without validity (and thus no dependability without credibility). As a result, proving the former is sufficient to show the latter's existence. In this study, the same principle was applied.

To ensure trustworthiness, the researcher detailed the study's methodology, allowing the reader to assess the amount to which good research practices were followed (Shelton 2004). For the purpose of conducting an audit trail, all interview materials, transcriptions, documents, findings, interpretations, and suggestions were retained, and any other relevant material was made available and accessible to the supervisor and any other researcher.

3.12.3. Transferability

Transferability is a method of establishing rigor in qualitative research without sacrificing relevance. Rigor assists the researcher in preventing errors (Polit & Beck, 2014). The researcher offered a detailed description of the research methods, participants' backgrounds, and the research context in order for someone considering a transfer to determine whether or not it is conceivable. Therefore, the researcher recorded information on the audio tape with the purpose of keeping the data for people who might need it in order to permit judgment.

3.12.4. Conformability

Conformability in qualitative research, is the extent to which the findings can be judged as accurate based on the data collected, and not simply the subjective views or interpretation of the researchers (Rees, 2016).

Tape recordings were retained in this investigation to allow for an appropriate trail and to see if the conclusion, interpretation, and recommendation could be traced back to their sources. Conformability was ensured by using the tape-recorder during interviews with the participants to assist with transcription and minimize bias. The researcher tried not to be judgmental by preventing the use of the word “Why” throughout the interview.

3.13. ETHICAL CONSIDERATIONS

Research ethics are more important when conducting a study irrespective of which research approach was utilized when conducting the study. In this section, the permission to conduct the study, the principle for respect for persons (Informed consent, confidentiality, anonymity and voluntary) ethics was utilized and taken into consideration to avoid errors that hinder the research process. The research presented to different committees starting from the department of Advanced Nursing and to the School of Higher Degrees Committee. The research was approved by the following committees: Executive School Higher Degree committee, University Higher Degree Committee, and Rec.

3.13.1. Permission to conduct the study

The researcher sought permission from the following bodies to continue the study: The Research Ethics Committee at the University of Venda. The research was presented to the School of Health Sciences' Higher Degrees Committee, Ethics committee at the North-West Department of Health Research, Department of Health, Rustenburg Sub-District and operational managers of primary health care facilities. Participants have given their permission.

3.13.2. Informed consent

Informed consent gives the participants the power to choose what shall or shall not happen to them (Grinnell & Unrau, 2010).

Information was given to participants regarding benefits of the study, purpose of the study, and how data was collected. Assent form was signed by participants under the age of 18 years and those of age 18 and above were given an informed consent.

- **Privacy**

The right to privacy refers to an individual's ability to select when, how much, and under what conditions personal information was shared with, or withheld from, others. Attitudes, beliefs, behaviors, opinions, and records are all part of this data (Burns & Grove, 2012).

The right to privacy of participants was honored by conducting individual interviews in a quite cubicle. Participants were not pushed to reveal the information they didn’t want to talk about. In addition, participants were also informed that no untested data would be used against them, and their names would not be revealed.

- **The right of self determination**

The right to self-determination is based on the ethical principle of respect for persons and it indicates that humans can control their own destiny (Burns & Grove, 2012).

The participants were allowed to decide if they want to participate in the study or not. They also had the right to withdraw from the study at the time they felt they can’t continue with the study.

- **Confidentiality**

Confidentiality refers to an agreement about how data (records), field notes, digital recordings of interviews, transcripts, and other similar items will be handled in the research to ensure privacy (Boijie, 2010).

The researcher chose assured confidentiality as the study's goal in order for participants to feel free and open while taking part. The participants were advised by the researcher that no personal information would be associated to the data obtained.

- **Anonymity**

According to Bless et al., (2006), the assurance that the identity of research participants would remain secret is known as anonymity. The researcher did not reveal the participants' identities for the purposes of the study.

3.14. DISSEMINATION OF RESULTS

The results of the study will be made available to the University of Venda library. The study findings will be published in accredited journals. The study findings were also made available and presented through research seminars, national and international conferences. Meetings with the community were held reporting to them the findings of the study. The stakeholders such as DoH also received the findings of the study where a copy was submitted to them.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF THE RESEARCH FINDINGS

4.1. INTRODUCTION

The methodology and research design that led the study were described in the previous chapter, which included an explanation of the study site, population and sampling, research technique and design, data gathering method employed, and data analysis. This chapter summarizes and analyses the findings of individual semi-structured in-depth interviews performed with teenagers on antiretroviral medication in the Rustenburg sub-district of the North West province. The researcher posed two semi-structured questions, which are as follows: When did you start using ART? What has been your experience with ART? The researcher then asked probing questions in response to the two questions.

There were four main themes and sub-themes that arose. Direct quotes from the transcripts are used to discuss and support each subject and sub-theme. In the discussion of themes and sub-themes, quotes from participants have been italicized. The participants were all adolescents on antiretroviral therapy in the Rustenburg sub-district. Literature is presented to support the findings.

TABLE 4.1: BIOGRAPHICAL INFORMATION OF PARTICIPANTS

Participant	Age	Gender	Number of years on treatment	Level of education	Perinatal acquired HIV or Horizontal
Participant 1	17	M	15+	Grade 12	Perinatal
Participant 2	18	M	2+	Grade 12	Horizontal
Participant 3	19	F	2	Tertiary	Horizontal
Participant 4	17	F	1	Grade 11	Horizontal
Participant 5	18	F	16+	Grade 12	Perinatal
Participant 6	18	F	2+	Grade 11	Perinatal
Participant 7	19	M	16+	Tertiary	Perinatal
Participant 8	18	F	17+	Grade 12	Perinatal

Participant 9	17	F	1	Grade 11	Horizontal
Participant 10	18	M	10+	Grade 12	Perinatal
Participant 11	17	F	15+	Grade 11	Perinatal
Participant 12	19	M	1	Tertiary	Horizontal
Participant 13	19	M	2+	Grade 12	Horizontal
Participant 14	18	M	17+	Grade 11	Perinatal
Participant 15	17	F	16+	Grade 11	Perinatal
Participant 16	19	M	1	Tertiary	Horizontal
Participant 17	17	F	15+	Grade 10	Perinatal
Participant 18	18	F	6 months	Grade 12	Horizontal
Participant 19	19	F	17+	Grade 12	Perinatal
Participant 20	19	M	3	Tertiary	Horizontal
Participant 21	18	F	4 months	Grade 12	Horizontal
Participant 22	17	F	16+	Grade 10	Perinatal
Participant 23	19	F	1	Grade 12	Horizontal
Participant 24	19	F	2	Tertiary	Perinatal
Participant 25	18	M	12	Grade 12	Perinatal

4.2. PRESENTATION OF FINDINGS

During data analysis, five themes and sub-themes emerged and they are presented in table one below.

TABLE 4.2: THEMES AND SUB-THEMES REFLECTING THE EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUB-DISTRICT IN NORTH-WEST PROVINCE

Themes	**Sub-themes**
1. Description of the experiences of adolescents living with HIV to adulthood	1.1. Paradoxical experiences of being diagnosed HIV+ and being on antiretroviral treatment explained 1.2. Explanation why the disclosure of HIV+ status to sexual partner is a difficult process to experience 1.3. Different types of problems including side effects together with signs and symptoms experienced caused by being HIV+ and ARTs

	1.4. Experiences related to adherence versus lack of adherence to ARTs during first few months of initiation explained 1.5. Existence versus lack of treatment buddies and consequences thereof explained 1.6. Explanation of lack versus the existence of counselling and support experienced from different people
2. Challenges experienced from childhood to adolescence period	2.1. Poor understanding of the disease condition and lack of adherence to ARTs resulting from lack of disclosure by parents 2.2. Feelings of fear, despair and fear of stigma and discrimination experienced 2.3. Challenges experienced related to sexual relationships and engaging in activities that might endanger their physical health explained 2.4. Disclosure versus lack of disclosure of HIV+ status and how it was transmitted to them by parents viewed as a challenge 2.5. Explanation of paradoxical challenges experienced
3. Knowledge related to HIV+ status and related factors	3.1. Lack versus existence of knowledge related to the disease condition from childhood to date explained 3.2. Lack versus existence of knowledge related to the importance of adherence to treatment and its future implications described 3.3. Lack versus existence of knowledge related to the initial diagnosis, side effects, signs and symptoms explained 3.4. Lack of knowledge related to the HIV+ status and how it was transmitted (parents blamed) 3.5. Disclosure of HIV positive status viewed as important

4. Suggestions made to promote quality of life by adolescents on ARTs	4.1. A request for communities to be educated on HIV which may lead to support provided to adolescents 4.2. Request for initiation of health education programmes that will assist in enhancing knowledge related to the disease 4.3. Revision of treatment schedule to be considered

4.2.1 Theme 1: Description of the experiences of adolescents living with HIV to adulthood

This theme is divided into six subthemes which describes the experiences of adolescents living with HIV to adulthood.

4.2.1.1 Sub-theme 1.1: Paradoxical experience of being diagnosed HIV+ and being on antiretroviral therapy

The study revealed that adolescents have different paradoxical experiences of being diagnosed HIV+ and being on antiretroviral therapy. In this study, this is supported by one of the participants, participant 4 who said:

“*(taking a breath) Well, I was angry and disappointed at the same time, and I felt like it was the end of my life. I had a lot of questions in my head, wondering how and when I contracted the virus, and denial was creeping in.”.*

Participant number 3 said: *“I was shocked and disappointed at myself thinking that it is the end of my future”.*

According to Mburu, Hodgson, Kalibala, Haamusjompa, Cataldo, Lowenthal, and Ross (2014), disclosure had diverse consequences on adolescence. The children reported that they felt frightened, upset, and blamed themselves after learning they were HIV positive. This is further supported by participant 3 who indicated that:

“*(looking down) When the test results came back positive for HIV, I knew it was the result of something I could have avoided if I had used a condom while having sex, but I didn't, and I had to accept that I would have to take HIV treatment for the rest of my life.”.*

According to Vreeman, Gramelspacher, Gisore, Scanlon and Nyandiko (2013), learning about one's HIV+ status was a creational and essential milestone in children's life. Children experience sadness and grief, as well as anxiety and fear about the implications of their diagnosis in the future.

The feeling of death was common to some participants who felt disappointed after being diagnosed HIV+ and saw no meaning in living. This is supported by the following quote from participant 20: "*I was disappointed, angry and I wished I could just die*".

According to a study conducted in Zimbabwe by Mavhu, Berwick, Chirawu, Makamba, Copas, Dirawo, Willis, Araya, Abas, Corbett, and Mungofa (2013), children had difficulties accepting their HIV positive status and feelings of despair, hopelessness, and impending death were common among these infected children. It was difficult for participants to accept being diagnosed with HIV infection. This is reinforced by Abubakar et al., (2016), who discovered that when children learned they were HIV positive, they accepted their status. However, a few people said they were in anguish, crying and having suicidal thoughts.

In this study, participants experienced different challenges following the initial diagnosis of HIV leaving most participants with the feeling of no hope in life after the initial diagnosis. The researcher notes that thorough continuous counselling is of importance to all adolescents diagnosed with HIV so that they may not see HIV as the end of their life. Counselling will give adolescents hope in life and promote adherence to treatment.

4.2.1.2 Sub-theme 1.2: Explanation why the disclosure of HIV+ status to a sexual partner is a difficult process to experience.

The findings of this study revealed that disclosing of HIV status by adolescents to their sexual partners is a difficult process to experience because their partners hardly accept the situation. According to Fair & Albright (2012), disclosing ones HIV status to a sexual partner often results in negative outcomes such as rejection and stigma. This is supported by the following quotes from participants:

The following quote from participant 9 supports the statement "*The partner I had while I tested not only refused to acknowledge but also refused to test, blaming me for spreading the virus, which is not true because I was fine until I had a sexual relationship with him".*

Participant 2 further indicated that *“(looking up) Since starting ART, I've had a variety of experiences. The first was when my partner was a member of the LGBT community, and they began to disown me, claiming that I knew my status for a long time and didn't tell them, and that I was on a mission to spread the infection to them”.*

Participant 6 said *“I was also afraid of disclosing my status to my partner because he would not accept it, and it would be the end for both of us, especially because he would think I knew my status all along and was trying to infect him with the virus”.*

The study's findings are similar to those of Doat, Elham, and Hosein (2020), who found that the majority of adolescents in some type of relationship had not reported their HIV status to their partners. When questioned why they kept it a secret, they said they were afraid of losing their relationships if they revealed their status. They would rather live with remorse than tell their partners about their HIV status.

In other research done in Sub-Saharan Africa, teenagers found it difficult to disclose their HIV status to partners because they fear rejection and loss of respect if their status is revealed (Siu et al. 2012). The findings contradict those of Hogwood et al., (2012), who discovered that teenagers were more likely to divulge their HIV diagnosis in specific situations, such as in a romantic relationship, while getting married, having a kid, or starting a career. A comparable study on the barriers, attitudes, and effects of HIV disclosure by PLHIV in Zambia found that most teenagers do not disclose their HIV status to their sexual partners for fear of rejection (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014).

In this study, adolescents experienced difficulties to disclose their HIV status to their sexual partners. The fear of rejection by sexual partners following disclosure of HIV**+** status was also viewed as a challenge by the participants. The researcher notes with great concern that couple testing should be emphasised in order to educate both partners prior to testing, this will reduce the blame that the partners make towards each other. The partner who tests first HIV+ without the other end up being blamed by the other partner that he or she knew all along about the status and was in a mission of spreading the infection of which no one knows about ones HIV+ status until they test.

4.2.1.3. Sub-theme 1.3: Different types of problems including side effects together with signs and symptoms experienced caused by being HIV+ and ARTs

The findings of the study revealed that adolescents encountered different problems caused by HIV+ status and using ARTs. This includes problems such as side effects, different signs and symptoms which compels one to test, social secrets kept by parents about HIV+ status and psychological problems. It is supported by the participants who indicated the following:

Participant 24 said *"After testing, I went home and notified my mother, only to discover that she is HIV positive and on treatment, and that she knew I was positive since birth. She also stated that she skipped treatment during her pregnancy, which resulted in her giving birth to a positive baby. That made me even more frustrated and angry at her for not seeking help".*

Participant 5 indicated "*Yes, it was difficult because I never suspected that I could be taking treatment for HIV, and as a child, I had to be furious that I wasn't told and that I was forced to take treatment that I didn't know was for".*

Children develop sentiments of uncertainty and hostility against their parents (Asiimwe-Kateera, Kestelyn, Vyankandondera, Pool, Ruhirimbura, Kanazuke, Reiss, Geelen, van de Wijgert, and Boer, 2013) because they don't understand why they have HIV and their peers don't, some children may try to punish their parents.

Participant 6 emphasized that he grew up not knowing about his status since his mother kept it a secret*. "After a period of pressuring her, she finally confessed. She had been on treatment for years and informed me that she was not taking her medication consistently while she was pregnant, which resulted in her giving birth to a positive baby, which was me, and she never forced me to take treatment, instead kept quiet and waited for me to find out on my own".*

Physical side effects such as nausea, dizziness, rashes, insomnia and difficulty to sleep, weakness, and other symptoms affect the participants' relationship with their bodies. Similarly, treatment tiredness, dose frequency, pill burden, and ART treatment side effects have all been identified as reasons for poor adherence among HIV-positive adolescents (Chandwani et al. 2012). All of the participants said it was difficult to take their medication in a public setting, thus they had to withdraw from social circumstances in order to take their prescription. All of the participants were open about their thoughts on defaulting their ART.

In the study, participants revealed that their HIV status was kept as a secret from them by their parents even though they were taking treatment. The researcher notes that it is important for parents to be educated more on early disclosure of HIV+ status. Disclosure of HIV+ status by parents will promote both adherence and trust to parents by their adolescents.

4.2.1.4. Sub-theme 1.4: Experiences related to adherence versus lack of adherence to ARTs during the first few months of initiation

The adolescents in the study revealed different experiences related to adherence during their first months of initiation of ARTs. The feeling of disappointment and the thought of thinking that one must take treatment became an emotional stressing situation to many participants. Adherence during the first months was challenging as they had to adjust to side effects and the everyday routine of taking ARTs. This is supported by the participants who indicated that:

Participant 22 said *"I feel weak and disappointed in myself since I am not following protocol and am missing my treatment dosages".*

Participant 23 said *"I do not feel ok, my body gets weak, and I end up disappointing myself".*

Participant 3 explained *"Yes, I've missed a couple of days of treatment. It usually happens when I'm visiting relatives who I haven't informed about my status, so I leave the treatment behind for fear of them asking additional questions about what the treatment is for. I also miss treatment when I go out of town and return late, and I study when I want to study for a couple of hours so that I don't fall asleep and miss my treatment dose,"*

Participant 9 said *"Yes, I have missed treatment on a few of occasions, particularly in the early days when there was a lot of bickering at home and no sign of being supported, which made me to lose hope and believe it would be better if I died. I also miss treatment if I haven't had enough sleep or if I am not at home".*

Participant 13 said *"I miss my treatment when I am in denial; I only take it when I feel like it, and I miss treatment when I am not at home visiting other family members or when I am still playing outside".*

Kim, Mazenga, Yu, Ahmed, Paul, Kazembe, and Abrams (2017) found that self-reported adherence was poor in nearly half (45%) of all children in Malawi, that children had previously missed ART, and that the most common reported barriers to adherence were forgetting (90%), traveling away from home (14%), and being preoccupied with other activities (14%). Three people (27%) said that being on ART treatment has disrupted their personal lives. ART treatment had an impact on their interactions with friends at home and at school, and it made life tough for them at times (Abrams, Kim, Mazenga, Yu, Ahmed, Paul, Kazembe, and Kim, Mazenga, 2017).

These findings echo those of Michaud et al., (2016), who discovered that adherence to ART treatment frequently deteriorates for a variety of reasons, including forgetting, stigma, body image issues, and a desire to be normal (Hazra et al., 2016). While they recognized the value of ART in their lives, two individuals (18%) in this study reported weariness and apathy with adherence to the treatment regimen. They also admitted that ART therapy interfered with their lifestyles at times. They have, nonetheless, never stopped taking them.

In this study, adhering to treatment during the first month of starting treatment was revealed as challenging by participants as they had to deal with side effects and adjusting to the change of their normal lives which they had no disturbance of making sure that in a particular time they must make sure they are home. The researcher notes that health care providers should further educate adolescents on the side effects of treatment, this should be done continuously in every visit so that they feel supported and relieved from the thought of defaulting due to side effects.

4.2.1.5 Sub-theme 1.5: Existence versus lack of treatment buddies and consequences

The buddy system of support and care for HIV/AIDS patients on antiretroviral therapy was created to help people, particularly in the first few months after starting medication. People who are having trouble sticking to their treatment can also benefit from the program. Patients' treatment friends specifically support them in sticking to their treatment schedules and reminding them to attend 72 medical appointments (Zyderduin, 2004). Anyone can be a treatment buddy in South Africa; a buddy might be a friend, a family member, a neighbour, a relative, a community health care worker, or a co-worker (May & West, 2000). The patient is offered the option of selecting his or her own therapy companion. Buddies can be HIV positive or negative, much like in the Boston buddy program.

In this study, participants revealed that their family members especially the parents are their treatment buddies while other participants had no treatment buddies.

The following quotes were the responses by three of the participants who had treatment buddies supporting them.

Participant 7 indicated: *“I'm now debating whether or not to disclose to some of my family and friends; it's difficult for me to do so because I'm terrified of losing people I care about if I do. I'm also having trouble keeping clinic appointments; I'd rather have my mother collect treatment for me so that my friends don't question me”.*

Participant 6 said *“My sister is the only one who gives me hope and who made sure that I finished my TB treatment, despite the fact that it was difficult at times because I was still in denial and angry, but she made sure that she was there every day while I was on treatment and that I took the proper doses”.*

Participant 3 said *“Yes, my mother does assist me with taking treatment and she does collect the treatment on my behalf while I am at school”.*

The study also revealed that some participants had no treatment buddies since they preferred keeping their status as a secret than disclosing to people who instead won’t be supporting but spreading the news of their status all over. This is supported by the following participant quote:

Participant 24 said *“I don't have any since I'm not ready to trust others with my personal information. I'm worried that they'll spread the news regarding my condition because many of my family members are unaware that I'm undergoing treatment”.*

Participants with no treatment buddies experienced different consequences such as missing clinic appointments and missing the treatment dose. This is supported by the following three participant’s quotes:

Participant 4 said *“I struggled to get used to going to the clinic every month because I was always worried that my neighbors would see me and spread the word that I was on treatment since that's what people do when they hear you're on it”.*

Participant 18 said *“Yes, I've skipped treatments in the past because I wanted to study, and I couldn't drink medication since it would put me to sleep. I also miss my treatment, and I become irritated when I remember what occurred to me previously”.*

Participant 5 explained *“Coming to the clinic every now and then was now a worry to me since some of my friends are staying near the clinic which would make them suspicious”.*

Family members were also a regular source of support, according to Mburu et al (2014), especially when it came to adherence to therapy. They verbally reminded the children to take their ARV therapy and supported them when they were having side effects. According to the study participants, family members frequently accompanied participants to clinics to refill their ART and assist them with new ARV treatment routines. This assistance was beneficial to them. Furthermore, participants stated that family support was not restricted to HIV/AIDS; the family also assisted them with safety concerns and provided emotional support and direction.

In this study, participants regard their parents as their treatment buddies while others still do not have treatment buddies. The researcher notes that participants are not yet free to disclose and trust people with their status, this led to them not having treatment buddies. Health education on the importance of treatment buddies should be emphasised to the adolescents.

4.2.1.6 Sub-theme 1.6: Explanation of lack versus existence of counselling and support experienced from different people

The participants revealed lack versus existence of counselling and support from different people. In the study, some participants positively revealed their parents as the ones giving them more support and counselling to be able to cope with acceptance and take treatment well. This is supported by the following quote from participant 21 who explained support and counselling from the parents *“When I told my parents about my HIV status, they were furious and disappointed in me, but they eventually came around and supported me, making sure that they explained HIV to me every day and that I should get treatment.* The other participants revealed the lack of support from the parents due to parents having the feeling of disappointment with their children since they were not expecting that their children might be HIV positive.

Participant 3 said *"Firstly, since I began treatment, I have received less love from my parents, as I had disappointed them by failing to do what they had advised me to do as a child, namely, use condoms to avoid not only conception but also STIs".*

Participant 6 revealed *"I was faced with a lack of family support, particularly from my mother, who provided me with less support despite the fact that she is also undergoing treatment, and I had no energy to undergo treatment because my mother does not receive treatment on a daily basis, which caused me to lose hope".*

The study conducted by Hazra et al., (2016) highlighted the relevance of a supportive family in enabling HIV-positive children and adolescents to manage with the disease (Hazra et al., 2016; Li et al. 2016; Petersen et al. 2016). The researcher notes that even though parents are disappointed with their children becoming HIV+, they end up supporting them and their support improves adherence to treatment by adolescents. Adolescents with no support are prone to defaulting treatment. It is important for families to be educated on importance of giving support to the children living with HIV.

4.2.2. Theme 2: Challenges experienced from childhood to adolescence period

The theme is divided into five sub-themes that describe the challenges experienced from childhood to adolescence period.

4.2.2.1 Sub-theme 2.1. Poor understanding of the disease condition and lack of adherence to ARTs result from lack of disclosure by parents.

The lack of disclosure by parents has led to the poor understanding of the disease condition and lack of adherence by the adolescents in the study. Delayed disclosure, alcohol use, difficulty identifying with HIV negative peers, anxiety about sexual relationships and future planning, low self-esteem, and feelings of hopelessness, according to Zanoni (2013), are psychosocial factors associated with poor adherence and non-adherence among children living with HIV/ADS.

Participant 18 said *"I couldn't take my treatment because I didn't understand why, and the treatment I was taking was so hot that I couldn't stomach swallowing it, so I didn't take it every day. On days when I pretended to take the treatment but didn't, I would act as if I did".*

Participant 6 said *"I also miss my treatment, especially when I recall that my mother never cared to inform me of my status".*

Participant 8 explained *"Looking down), I was at school when nurses came in and asked if anyone was receiving treatment for which they had no idea what it was for. They presented the bottles and urged us to go home and ask what the treatment was for".*

Participant 10 said *"Yes, I have missed several treatment doses, especially before I knew it was ART, when I used to spit off the treatment in the toilet, and I have also missed additional treatment doses when I was still struggling with denial".*

Participant 11 said *"I was fine at the time since I didn't know much about HIV until I used my phone to Google for more information. That's when I became frustrated, and I didn't take my treatment as seriously as I should have".*

Participant 17 explained *"I didn't go through much as an adolescent, but as I approached the age of 15 years, I began to wonder why I was taking treatment while other children my age were not. This caused me to stop taking treatment the way I was supposed to. On some days, I would take treatment and act as if I had consumed it by throwing it down the toilet, leading my mother to believe that I had drunk when I hadn't".*

The majority of the children in this study were unaware of the disease's nature. However, all of the youngsters who took part in Mutwa et al., (2017) study were vertically infected with HIV and faced disclosure issues. Even after they started taking ARTs, the children's HIV + status was kept disguised, and they had no idea what the medicine was for. Non-disclosure of HIV status to HIV-infected children and adolescents, according to Dlamini., (2017), is a known impediment to them adhering to ART.

In this study, participants grow up and transited to adolescence without knowing what the treatment they are using is for. The lack of knowledge regarding why they are on treatment for led to difficulty in adhering to treatment by adolescence. The researcher notes that disclosing HIV to the adolescents at an early age promotes adherence. Parents should be thoroughly educated on the process of HIV disclosure and also counsellors together with health care providers should assist in process of disclosure.

4.2.2.2 Sub-theme 2.2: Feelings of fear, despair and fear of stigma and discrimination experienced

The study revealed that participants experienced the feelings of fear, despair and fear of stigma and discrimination.

Fear is a negative emotional state that people experience when they are in danger, when something horrible has happened, or when they are afraid of something. Anxiety is defined as a great want or concern to do something or for something to happen, as well as a sensation of worry, uneasiness, or unease about something with a uncertain consequence (Sperry, 2012). Fear, according to Taylor (2010), is a form of anxiety that causes a person to remain coiled in a specific position. HIV/AIDS is often associated with a great deal of fear, making PLWHA fearful of taking risks in life or socializing with others. Fear can exacerbate depressive symptoms and contribute to feelings of helplessness, frustration, and overwhelm (UNAIDS, 2010).

Fear and anxiety may also be triggered by apprehension about how others may react if they are diagnosed with HIV. Children living with HIV/AIDS may also be fearful of informing others about their HIV status, such as friends and family members (Jahangir, 2013). Fear of stigma and discrimination made it difficult for children to openly discuss their HIV positive status in other care situations such as the family and school (Mupambireyi, Bernays, Bwakura-Dangerembizi, and Cowan, 2014). According to Zanoni (2013), children living with HIV/AIDS are especially concerned about the prospect of a drug shortage, as well as the difficulty of finding future marriage partners who will accept their HIV status.

For most HIV-positive youngsters, living in terror is a way of life. Children are scared of being discovered to have HIV (Ross & Deverell, 2015), and fear of rejection is always bigger than fear of dying. According to Zanoni (2017), perinatal HIV is associated with mental health concerns, as well as frequent disruption of social and academic activities due to clinic visits or hospitalization, which can lead to anxiety and sadness.

Participant 25 said *“(Looking down) it was not easy, I cried and felt hopeless and angry”.*

Participant 9 said *“(taking a breath) Well, I was angry and disappointed at the same time, feeling as if it was the end of my life. I had a lot of questions in my head, wondering how and when I contracted the virus, and denial was creeping in”.*

Participant 4 explained *“I feel better as each day goes by and I'm gaining strength and overcoming denial, despite the fact that life has changed, and I'm afraid of how people will react if they find out about my status”.*

Children living with HIV/AIDS were identified as facing substantial problems such as stigma and discrimination. According to Dorrell, Earl, and Reveley (2016), HIV/AIDS stigma impacts everyone afflicted and affected by the disease, and victims are stigmatized, lonely, and isolated with no way out. It has an impact on the disease's progression since it impairs or causes non-adherence to treatment (Martinez et al., 2012).

The presence of stigma also affects a person's psychological and emotional well-being, as it is associated with less social support from family and friends (Mburu et al. 2014).

The findings of this study concur with those of Mavhu et al. (2010), who found that, while stigma and discrimination against HIV positive people were diminishing, they remained prevalent in Harare. It was also stated that if one's HIV + status becomes known to one's peers, stigma is particularly common in the school setting.

Participant 3 said *"Well, I had to live in fear that if my schoolmates found out, it would be the end of me. It makes it tough for me to talk about my problems with other people".*

Participant 7 said *"I'm also having trouble attending medical appointments; I'd rather have my mother collect the treatment for me so that my friends don't interrogate me".*

Despite the fact that HIV/AIDS is now widely known, people living with the disease and their families continue to endure stigma and prejudice in society. According to Campbell, Skovdal, Mupambeyi, and Greyson (2015), children and adolescents living with HIV/AIDS are more likely to be stigmatized by peers, family, and community members. Participants in South Africa said they were chased out of their homes, asked to use different utensils, and had their rooms restricted (Cloete, Strebel, Simbayi, van Wyk, Henda, and Nqeketo, 2016). As a result, stigma and discrimination constitute a huge barrier to an individual's ability to live a normal life.

In this study, participants experienced the fear of what other people will say about them if they could find out about their HIV status. Adolescents face difficulty to honour the clinic due to the fear that their friends in the community will notice them going to the clinic and be suspicious. The researcher notes with great concern that the fear of stigma and discrimination is still high in the communities. It is important for communities to be thoroughly educated on HIV to stop stigma and discrimination amongst the community.

4.2.2.3. Sub-theme 2.3: Challenges experienced related to sexual relationships and engaging in activities that might endanger their physical health explained

In the study, participants reported being in sexual relationships and engaging in activities that might endanger their physical health. The participants in the study had disclosed their

HIV+ status to their partners although the process of disclosing their status was mostly accompanied by the challenge of fear of rejection by their sexual partners. The loss of sexual partners after the disclosure was common amongst participants who were in sexual relationships. It is supported by the following quotes from participants in the study:

Participant 13 said *“Since starting treatment, I've gone through a lot of changes. I lost my girlfriend because she had lost faith in me, believing that I was trying to get her sick by sleeping around”.*

In the study, participants also received blame from their sexual partners that they knew their status and it was their mission to transmit the virus.

Participant 2 said *“(looking up) Since starting ART, I've had a variety of experiences. The first was when my partner was a member of the LGBT community, and they began to disown me, claiming that I had known my status for a long time and didn't tell them as I was on a mission to transmit the infection to them”.*

Participant 18 explained *“Being on treatment led me to lose my boyfriend because I was reluctant to tell him about my status, and when he found out, I had visited him and it was time for treatment, the alarm was blaring with the reminder 'treatment time,' he wanted to know what the treatment was for. I had to be honest and tell him the truth, which enraged him and made him upset, accusing me of wanting to make him sick all along. He then decided to stop our relationship”.*

This conclusion supports previous research by Fair & Albright (2012) that revealing ones HIV status to a sexual partner generally leads to negative consequences such as rejection and stigma. According to research conducted in Sub-Saharan Africa, teenagers find it difficult to disclose their HIV status to partners because they fear rejection and loss of respect if their status is revealed (Siu et al., 2012; Birungi et al., 2014). The findings contradict those of Hogwood et al. (2016), who discovered that teenagers were more likely to divulge their HIV diagnosis in specific situations, such as in a romantic relationship, while getting married, having a kid, or starting a career. A comparable study on HIV disclosure barriers, attitudes, and outcomes was undertaken in Zambia.

In this study, participants faced challenges in their sexual relationship, this includes losing one’s sexual partner after disclosing the HIV+ status. Sexual partners lose trust to their partners saying they were not faithful to them which is the reason why they ended up being HIV+. The researcher notes that counselling should be done and emphasise the outcomes of disclosing how disclosing ones status to a sexual partner can have a negative and a positive impact hence one should be ready for any response.

4.2.2.4 Sub-theme 2.4 Disclosure versus lack of disclosure of HIV+ status and how it was transmitted to them by parents viewed as a challenge

Disclosure of HIV+ status to adolescents in the study was considered as a challenge because some participants did not know they were HIV+ and had to discover it for themselves either at the clinic while receiving treatment or at school. Participants claimed that their parents had lied to them about their condition rather than being truthful and explaining why they needed to take treatment every day. The following quotes from the participants back this up.:

Participant 5 said *"Yes, it was difficult because I had no idea it could be HIV treatment and as a child, I had to be angry that I was not told and that I was constantly forced to take treatment that I had no idea what it was for until my mother told me that I had a flu condition and that if I didn't take treatment, I would keep coughing. (Crying)".*

According to Gachanga et al., (2014), disclosure is a parental decision and a child's right. The parent must decide and be prepared to completely disclose the child's HIV status. HIV-positive youngsters are objected to their parents lying about their sickness because it damaged their confidence.

One of the interviewees in Hill's Guardian piece (2012) said that he discovered his ailment by accident when he was a teenager and that he had always been taking medication disguised as sweets. The study's findings revealed that some parents and guardians of adolescents with prenatal HIV and AIDS are afraid to disclose their status. Instead, they make comparisons and contrasts between the treatment and other illnesses. Despite attending clinics every three months for medication, Woollett (2017) discovered that between 25% and 90% of HIV-positive school-aged children are unaware of their own status.

Participant 5 further emphasised *"When it came to the days following disclosure, I had a hard time accepting it and recalling all the previous days when my own mother would lie and say the treatment was for flu (weeping), which hurt me a lot. Since finding out, I've been concerned about what others would think if they learn of my status".*

Participant 6 said *"Yes, she did after a lot of coercion. She had been on treatment for years and informed me when she was pregnant that she wasn't following her treatment* *properly, which resulted in her giving birth to a positive baby, which was me, and she never forced me to take treatment because she kept quiet and waited for me to find out on my own".*

Participant 10 said *"Yes, she did inform me that I was born HIV-negative, but that I tested positive for HIV/AIDS within six months of breastfeeding. It was difficult for me to comprehend the process of becoming pregnant while breastfeeding".*

Participant 11 explained *"I've lost trust in my mother, despite the fact that I was positive and unaware all along, and this has caused me to lose trust and have resentment toward her, which I don't tell her about, but it's getting better every day as I accept it".*

Caregivers have also acknowledged being hesitant to tell their children about their HIV status because they are afraid of social rejection and isolation, a parental sense of guilt, and a fear that the children will not be able to keep the news to themselves and will be furious at them (Kenu et al 2014:2; Kiwanuka et al., 2014).

Participant 1 said *"(Looking up) I felt resentment at my mother because she never told me when I was younger, and I began to fear how society would view me. My mother told me when I was 15 years old at home that she was diagnosed with HIV as she was about to give birth in her last month, which resulted in her giving birth to an HIV-positive child, and I was the child".*

The most common route for HIV transmission is from mother to child, with 90% of children infected this way (UNAIDS 2014). As a result, the parent is guilty of infecting an innocent child, making disclosure difficult. Furthermore, parents are concerned that when their children learn of their illness, they will become depressed and lose their will to life. HIV infection, however, may impair many of the social support networks that children rely on for optimum development, in addition to the direct consequences on their neurocognitive and psychosocial functioning (Kennedy et al., 2016).

In this study, it is revealed that participants were taking treatment without their HIV positive status being disclosed to them. The study further revealed that some participants discovered that they are HIV positive on their own while visiting health care facilities and while in school. The researcher notes with great concern that all pregnant women who are HIV positive need to adhere to treatment and it needs to be emphasised to prevent mother to child transmission.

4.2.2.5 Sub-theme 2.5: Explanation of paradoxical challenges experienced

The findings of the study revealed that adolescents encounter different challenges living with HIV. Challenges including the side effects of ART, acceptance of their own status and the treatment from their family. The challenge of taking treatment disturbed the adolescent’s life. The adolescents in the study revealed how their life is revolving around treatment in such a manner that when its treatment time, everything else has to stop, no matter what it is.

This is supported by the following quotes from four participants who revealed the challenges they encounter:

Participant 19 said *“Okay, I used to study more before starting treatment, but now that I'm on treatment, I can't study for more hours because I'm dizzy and sleepy, and I also don't enjoy playing with my friends because I'll be called home when it's time to take treatment, which may make them suspicious as to why I have to be home at the same time”.*

Participant 24 said *“The dizziness I have after treatment causes me to fall asleep early, and I am unable to complete all of my school work”.*

Participant 6 said *“Yes, I have missed my treatment sometimes because sometimes I want to study, and I can’t drink medication as it will make me sleep”.*

Participant 5 explained *“I couldn't take my treatment because I didn't understand why, and the treatment I was taking was so hot that I couldn't stomach swallowing it, so I didn't take it every day before disclosure. I pretended to take the treatment on some days even though I wasn't”.*

According to Boopa (2016), adolescents faced a variety of problems, including medication-related factors such as pill size, pill number, pill taste, side effects, and treatment tiredness, all of which contributed to poor adherence. They reported that some pills were too large to take, and that several pills tasted unpleasant and smelled bad. Participants said they stopped using their medication because of negative effects like nausea. They claimed that taking medication would make them feel queasy every day, so they decided not to take it.

The challenge of not knowing one’s HIV positive status but being on treatment was also revealed in the study and it is supported by the following quote from the participant:

Participant 8 said *"So, when I got home (sobbing), I sought answers from my grandma about why she was receiving treatment. My grandmother sat me down and informed me that I was born HIV + because my mother was not receiving treatment at the time she was pregnant with me, resulting in me being born positive".*

Marukutira (2016) discovered that teenagers who had lost their parents were the most non-adherent to ART in Botswana. These adolescents displayed signs of mourning and despair, which led to them failing to take their prescriptions.

Participant 9 said *"I've had a variety of experiences, such as being labelled as the one who doesn't listen but is stubborn because I was already sleeping around at a young age and ended up being HIV positive; this made me feel unwelcome at home and put pressure on me to do things for myself because I no longer have the support I had before becoming HIV positive".*

A study conducted by Zanoni, Sibaya, Cairns, Lammert and Haberer (2017:3) reported that support and care tailored specifically for adolescents with HIV yielded positive and beneficial outcomes.

In this study, participants revealed the negative effect that being on treatment brings to their educational life. The feeling of dizziness after taking treatment was common amongst the participants which led to participants being confused as to how they have to take their treatment and not get any disturbances in their studies. The researcher notes that adolescents should be thoroughly educated on the initial diagnosis to choose the time which will be conducive for their studies. This implies to parents of children growing up with HIV, they should choose time that won't have a negative impact tomorrow.

4.2.3 Theme 3: Knowledge related to HIV+ status and related factors

The theme is divided into five sub-themes which describe the knowledge related to HIV+ status and related factors.

4.2.3.1 Sub-theme 3.1: Lack versus the existence of knowledge related to the disease condition from childhood to date explained

Participants in the study revealed a lack of understanding of their disease condition, explaining that they only learned about it after visiting a health care facility because they were sick, and it was then that they discovered they were HIV+. Others have been taking treatment without realizing it was ARTs, which was only revealed to them when they went for collection. This is supported by the following quotes from the participants:

The participant said, *“I came because I was losing weight and having non-stop discharges, so they decided to test me in the clinic, and the results came back positive”.*

Participant 3 said *“I was really sick, and my sister drove me to the facility to consult, where I was diagnosed with HIV/AIDS and pulmonary tuberculosis a day after HIV diagnosis”.*

Participant 1 said *“(Looking down angry) I found out a few months ago when I went to get my prescription with my mother, and she took me to the counselling room with her, where I was told everything (crying)”.*

Participant 20 said *“I was sick and came to the clinic and tested positive for HIV”.*

The above quotes are supported by the study done by Ramarumo (2018) which revealed that the majority of the individuals had been ill for a long time and had been hospitalized several times both before and after receiving their ART treatment. Some of the children's schooling was negatively affected as a result of their illness, since they were forced to repeat classes. They failed because they were sick most of the time and were unable to attend school on a regular basis, and studying was difficult due to their illness.

In this study, participants had no knowledge about their HIV status until they developed opportunistic infection symptoms which led them to visit the clinics where they were diagnosed HIV+. The researcher notes that it is important for communities to be educated on the importance of continuous HIV testing. Communities should be educated on the signs and symptoms of HIV&AIDS together with opportunistic infections.

4.2.3.2 Sub-theme 3.2: Lack versus the existence of knowledge related to the importance of adherence to treatment and its future implications described.

The study revealed that all participants have knowledge of the importance of treatment adherence. This is supported by the following quotes from the participants:

Participant 20 said *“Yes, I can see the benefits because I am no longer sick as I used to be when I began treatment”.*

Participant 22 said *“Yes, I see the benefits because when I'm on treatment, people don't realize I'm sick because my body is healthy”.*

Participant 17 said *“Yes, I see the benefits because treatment has made me stronger”.*

Another participant explained *“Yes, there are benefits; for example, you don't get sick as much when you're on treatment (looking down); but there are times where there are no benefits because I sleep and don't finish my school work”.*

Participant 3 said *"Yes, there are benefits since the treatment makes you stronger and no one can tell you have HIV".*

Participant 19 said *"Yes, I recognize the benefits of treatment, and I have benefited from it. Without treatment, I would not have reached my current age".*

Participant 7 said *"Yes, there are additional benefits to receiving treatment, such as being protected from becoming ill and making it difficult for others to notice that you are HIV positive".*

Participant 6 said *"Yes, I see more benefits because I was really sick and ended up with TB when I wasn't taking treatment, and I've seen the benefits of taking treatment after starting treatment".*

Participant 8 said *"I see the benefits, but I have my doubts because I am receiving treatment and instead of studying, I am sleeping, therefore I am not benefiting".*

The participants have embraced the treatment's importance in their lives, and it appears that it is their reason for living. They have put their faith in receiving treatment because it keeps them healthy.

The findings are similar to those of a study conducted by Ramarumo, (2018), which found that an individual's experiences determine adherence and non-adherence. A study conducted by Ramarumo (2018) revealed that their parents, caregivers, and health-care providers influenced their treatment adherence by instilling a fear of dying in them. Four of the participants (36%) recognize the value of ART treatment in their lives, which pushes them to live. They believe that if they follow their ART treatment plan, they will be healthier and live longer. Therefore, the researcher observed from this study that adherence to treatment was viewed as important by majority of participants who believed if it wasn't for treatment they wouldn't be living. In the study, only one participant was perplexed by the importance of treatment, and how treatment was viewed as significant when he did not complete his school work, which was supposed to help him construct a future. It is critical to emphasize the importance of health education on side effects.

4.2.3.3 Sub-them 3.3: Lack versus existence of knowledge related to the initial diagnosis, side effects together with signs and symptoms explained

The study revealed that participants have lack of knowledge related to the initial diagnosis of HIV. The side effects together with signs and symptoms after the initial diagnosis were explained by different participants who emphasized the difficulty to roll out their daily routines after taking treatment. This is supported by the following quotes from the participants:

Participant 7 said *“I was struggling to cope with the side effects after taking treatment since I couldn't do anything but sleep, especially school work, which I couldn't do after taking treatment, but now that the school day has changed, I only have trouble waking up and feeling sleepy in the mornings”.*

Participant 6 said *“I've also failed in school since I've been unwell and missed school days, and on other days I don't have the energy to study after taking treatment”.*

Participant 24 said *“As for me, I've noticed that being positive might make you feel different from other children, particularly in the months following disclosure. The dizziness I have after treatment forces me to go to bed early, sometimes I don't manage to do all my school work”.*

According to Mburu, Ram, Oxenham, Haamujompa, Lorpenda, and Ferguson (2014a), children living with HIV infection in Zambia reported going through changes following learning of their HIV positive status, including enduring the obstacles associated with being infected with HIV/AIDS. After being diagnosed with a life-threatening illness, these children were able to survive. Some of the children, on the other hand, recounted feeling despair after learning of their HIV positive diagnosis, which came after a long time of illness. Disclosure was both alarming and disempowering for these children. Caregivers' extended revelation of their HIV-positive status was influenced by mistrust, worries of stigma and discrimination, and secrecy (Willis et al., 2014).

In this study, participants had difficulties with to coping with the side effects during the first month of diagnosis. Therefore, the researcher observed that support for the adolescents during their first month on treatment is important in order for them to endure the side effects and regain hope after being diagnosed with a lifelong condition.

4.2.3.4 Sub-theme 3.4: Lack of knowledge related to the HIV+ status and how it was transmitted (parents blamed)

The participants in the study explained the lack of knowledge related to the HIV+ status. Adolescents took treatment without the knowledge of their status which lead to them putting more blame on their parents after disclosure of their status and how HIV was transmitted to them. Participants who were infected through mother to child transmission believed that their mother would have taken treatment to prevent mother to child transmission.

Participant 6 said *"Yes, she did after a bit of coercion. She had been on treatment for years and informed me when she was pregnant that she wasn't taking her treatment properly, which resulted in her giving birth to a positive baby, which was me, and she was never forced to take treatment; instead, she remained silent and waited for me to find out on my own".*

Participant 10 said, *"Yes, she did inform me that I was born HIV-negative, but that I tested positive for HIV/AIDS within six months of breastfeeding. It made it difficult for me to comprehend the process of becoming positive while breastfeeding".*

Participant 22 said *"My mother told me when I was 15 years old that she was diagnosed HIV as she was about to give birth in her last month, which caused her to give birth to an HIV positive child, of which I am the child".*

A study conducted by Jena (2014) affirmed this finding in her study where participants displayed some anger and blaming attitude towards their biological parents for infecting them with the virus. This is also consistent with the findings by Joshi, Mithilesh, Venkatnarayan, Dalal and Mathai (2017) and Person and Newman (2012), who reported that children born with HIV who survive into adolescence are at risk of developing psychological disturbances because of long-term HIV and its related stressors, together with the long-term effects of medications.

Participants with perinatal HIV were dissatisfied in how they contracted the virus once their parents' HIV positive status was revealed in this study, and they blamed their parents for not doing more to prevent them from contracting the virus. The researcher expresses great worry that both parents and their children should receive comprehensive counselling, as well as the importance of PMTCT.

4.2.3.5 Sub-theme 3.5: Disclosure of HIV positive status viewed as important

Participants in the study thought it was crucial to disclose their HIV positive status because it affects adherence. Knowing why you need to take treatment motivates you more than not knowing. Participants in the study shared their experiences before and after disclosure, emphasizing the importance of disclosure. This is supported by the following quotes from the participants:

Participant 5 said *“Yes, it was difficult because I had no idea it could be HIV treatment, and as a child, I had to be furious that I was not told and that I was constantly forced to take treatment that I had no idea what it was for”.*

Participant 5 said *“I couldn't take my treatment before disclosure because I didn't understand why, and the treatment I was taking was so hot I couldn't stand swallowing it, so I didn't take it every day. Some days I pretended to take it when I didn't, and after disclosure I was able to take treatment knowing exactly what it was for”.*

Furthermore, when adolescents are aware of their HIV status, they are better able to comprehend the importance of hospital visits and drug regimens, allowing them to make meaning of their life (Midtbo et al., 2016).

Another participant said *“I had support from my sister, who was able to sit with me and show me love by correcting me and telling me that no matter what had occurred, I should not lose hope and that there is still life even if you have HIV”.*

For a variety of reasons, it is critical to inform children with PHIV about their HIV status. The fact that they have been diagnosed with HIV has become significant, and it is now part of their complete HIV care. According to research, children who are told about their HIV infection are more likely to grasp it and stick to their antiretroviral therapy (ART), (Madiba & Mokgatle, 2016; Campbell et al., 2015. According to Arage et al., (2014), disclosed children are four times more likely than non-disclosed children to adhere to ART. As a result, in both developing and developed countries, non-disclosure to children with PHIV and adolescents has been highlighted as a barrier to adherence to ART (Biressaw et al., 2015). Norms, taboos, and beliefs about talking about sex, lack of family guidance by HCWs to disclose the HIV status to their children, and lack of family guidance by HCWs must all play a role in breaking the taboos and norms of caregivers to talk about sexuality and disclose to their children in order to facilitate adherence to ART. To make an informed decision to take medication, adolescents must first comprehend the consequences of non-adherence to their health and well-being. The findings of this study are similar to those of Madiba (2016), who discovered that disclosing HIV improves knowledge and understanding of the condition while also lowering risky behaviors. Unprotected sexual intercourse and unintentionally infecting the partner are two risky activities that adolescents engage in. When people are informed of their HIV status, they can take steps to protect their health and reduce the risk of infecting others (Jemmott et al., 2019).

4.3.4. Theme 4: Suggestions made to promote quality of life by adolescents on ARTs

The theme is divided into three sub-themes which describe the suggestions made to promote quality of life by adolescents on ARTs.

4.3.4.1. Sub-theme 4.1: A request for communities to be educated on HIV may lead to support provided to adolescents.

Participants in the study showed how their communities react to adolescents living with HIV, prompting them to propose that communities be informed on the virus, which could lead to support for adolescents. Adolescents will be more likely to adhere to treatment if the community is taught about HIV. They will be free of the fear of being stigmatized by the community.

According to the findings of Lawan et al., (2015), children reported being avoided by friends and colleagues in intimate relationships and during social activities such as football, parties, or other community gatherings, while others dropped out of school due to discrimination. Participant 2 said *“Well, society still requires more HIV education, as well as guidance on how to deal with persons who have been diagnosed as HIV positive. They still need to learn that individuals who are positive are entitled to the same love as those who are negative. For example, in my case, my partner still sees me as an HIV positive person on a mission to spread the infection, which is not the case, and they have discriminate against me because of my status.”.*

According to Williams (2015), community-based HIV/AIDS interventions have a significant impact on the epidemic's transmission. By interacting with communities, the focus is increasingly on influencing policies, social structures, social norms, and cultural practices that surround individual risk behaviors. Many of these initiatives emphasize the importance of incorporating and empowering people through participatory methods.

The researcher believes that more HIV education should be provided to communities in order to increase support for HIV-positive people. Educating the public will aid in the fight against stigma and discrimination against HIV-positive people.

4.3.4.2. Sub-theme 4.2: Request for initiation of health education programmes that will assist in enhancing knowledge related to the disease

Due to their lack of understanding of the disease, participants expressed a desire to start health education programs to help them have a better understanding of the disease. The importance of adherence and disclosure of one's HIV+ status programs, as well as health education about sexual reproductive health (SRH), the various modes of transmission, and the value of adherence and disclosure of one's HIV+ status. This is supported by the following quotes from the participants:

Participant 24 said *"(looking down), It was normal, although I was surprised that my partner tested negative while I tested positive, leaving me with unanswered questions such as how did I test positive while using a condom?".*

Participant 18 said *"I was receiving treatment without knowing what it was for until I discovered it was ART, which was excruciating because my mother would even lie and say I had flue".*

Participant 8 said *"I had a lot of questions about how I became HIV positive, and I couldn't obtain all of the answers because my mother passed away.".*

The findings of the study are similar to those of Tshuma (2016), who discovered that while most adolescents have been HIV-positive since birth, they have little knowledge of the epidemic that has become a part of their life. According to the findings, there is a pervasive lack of critical HIV/AIDS education. The majority of the participants had very rudimentary knowledge of HIV/AIDS, such as how it spreads and that it is a lifetime condition. They have information obtained from the limited knowledge they gained in school. The initiation of health education programs will eventually increase adolescent knowledge of the disease and improve disease transmission prevention among adolescents.

4.3.4.2. Sub-theme 4.3 Revision of treatment schedule to be considered

The study participants' responses revealed a sense of disappointment when it came to appointments for receiving treatment at the facility. The collecting schedule for each month was unfavourable to the participants, who requested that it be changed. Due to a lack of transportation money, adolescents may find it difficult to attend regular monthly sessions to receive their doses, significantly impacting adherence to ART (Agwu & Fairlie, 2013). This is supported by the participants who indicated that:

Participant 5 said *“Coming to the clinic every now and then was becoming a source of concern for me, since some of my friends who live near the clinic would be suspicious”.*

Participant 25 said *“Taking ART has taught me that the treatment is continually changing, and I have to visit the clinic once a month, which is exhausting, and the treatment is not always available.”.*

Adolescents' adherence to ART has also been found to be hindered by structural constraints in health care facilities. Adherence to ART is hindered by clinic appointments that conflict with school schedules and clinics that are not user friendly for adolescents (Bygrave et al., 2012; Denison et al., 2015).

Participant 6 said *“I am unable to attend the clinic due to a scheduling conflict. I'm always worried that people would find out about my status, particularly my classmates, because I don't go to school on some days because I have to get medication which leads to me missing tests”.*

Participant 13 said *“I'm afraid to go to the doctor now because others, including my school friends, will find out that I'm HIV positive”.*

Participant 15 said *“I've had the fear of going to the clinic because I'm afraid my friends would think I'm always going to the clinic, which makes me feel confined while I'm with them”.*

In addition, in some studies, the treatment schedule has been identified as an obstacle to optimal adherence to ART in adolescents (Agwu and Fairlie, 2013; Mutwa et al., 2016; Nabukeera-Barungi et al., 2015).

The majority of these adolescents were in school, and data suggested that they had trouble adhering to their school timetable and keeping their clinic appointments. The data also suggested that a clash between the scheduled clinic appointments and school activities was one of the reasons the adolescents missed their clinic appointments. The biggest issue for the adolescents was a clash between scheduled clinic appointments and class tests or examinations; they claimed that the decision they made resulted in them missing appointments and not receiving their ART on time (Unaswi, 2017).

Participants in this study showed that they are not comfortable coming to the clinic every month because they are afraid that people will be suspicious if they do so. As a result, the researcher expressed great concern that clinics should set some time aside suitable for adolescents to attend without being concerned about other people. Adolescents will gain confidence and be able to keep all of their visits if they are given at least two months of treatment.

4.4. Conclusion

In this chapter, the research findings have been presented and supported with relevant literature. The researcher provided biographical information of the participants in order to give the reader a background about the participants in the study. The researcher proceeded to describe the themes which emerged during the process of data analysis which was done using Tesch’s open coding method, which included transcribing and interpreting the data as well as regrouping major themes into sub-themes. The themes were explained using direct quotes from the participants. The following chapter will focus on limitations, recommendations and conclusion.

CHAPTER FIVE

LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1. INTRODUCTION

The study's findings were discussed in the previous chapter. The study's limitations, recommendations, and conclusion are presented in this chapter, which focused on the experiences of adolescents on antiretroviral therapy in the Rustenburg sub-district in South Africa's northwest province. The experiences of adolescents on ART were explored and described using an exploratory, descriptive, and contextual design. This study collected data through in-depth individual interviews until data saturation was reached. The study population consisted of 25 adolescents aged 15 -19 years on antiretroviral therapy. Four major themes emerged: Description of the experiences of adolescents living with HIV to adulthood, challenges experienced from childhood to adolescence period, knowledge related to HIV+ status and related factors and suggestions made to promote quality of life by adolescents on ARTs.

5.2. LIMITATIONS

The researcher faced different challenges in the study during data collection. Since the adolescents are still afraid to discuss their HIV status, it was difficult for the researcher to ask the participants many questions. Since it was difficult to locate the adolescents for clinic appointments, the researcher had to reschedule their appointments, and most adolescents requested that their parents collect their treatment for them. Adolescents between the ages of 15 and 16 years were not informed of their HIV positive status, making it difficult to conduct an interview with them.

5.3. RECOMMENDATIONS

5.3.1. Nursing practice

- The nursing staff should do continuous counselling promoting early disclosure to parents raising children with perinatal acquired HIV.
- HIV campaigns should also be conducted in communities to educate the public about HIV, reducing stigma directed at people on ART.
- Adolescent clinic appointments should be reviewed and completed in a way that does not interfere with their education or school time.
- All adolescents living with HIV should receive ongoing counselling from health care providers so that they feel cared for and understand the need of adhering to treatment.

5.3.2. Education and training

- The Department of Education should place a greater emphasis on HIV education in schools so that there is no HIV stigma in schools since students are unaware of the virus.
- To prevent the spread of HIV, school-based HIV prevention campaigns should be implemented.
- Teachers should be taught about HIV and how to deal with situations involving HIV-positive students.

5.3.3. Parents

- Parents and guardians of HIV-positive adolescents should be taught more on the significance of disclosing their HIV+ status to their children rather than lying about it.

5.3.4. Future researchers

- Future researchers should look into the factors that contribute to parents delaying disclosure to their children.
- To generalize the findings, researchers must broaden the study on adolescent experiences on ART to include a big sample and a large geographic area.
- Future researchers should investigate HIV knowledge in HIV-negative adolescents in order to aid them in preventing HIV transmission due to a lack of understanding about the disease.

- Future research should include caregivers and health care providers to learn about their experiences as they care for adolescents on ART.

5.4. SUMMARY

The purpose of the study was to determine the experiences of adolescents on antiretroviral therapy in Rustenburg sub-district North West. In order to attain this purpose the following objectives were formulated:

- Explore experiences of adolescents on antiretroviral therapy in Rustenburg sub-district North West.
- Describe the experience of adolescents on antiretroviral therapy in Rustenburg sub-district North West.

A phenomenological, descriptive, explorative and contextual research design was used to explore and describe the experiences of adolescents on antiretroviral therapy. Non probability purposive sampling was used to select the health care facilities and adolescents were chosen using convenience sampling. In depth individual interviews were used to collect data from the participants until data saturation was reached. Collected data was analysed using Tesch's eight steps. An independent coder analysed verbatim transcripts of the data

Theme 1: Description of the experiences of adolescents living with HIV to adulthood

- The findings of the study revealed that the adolescents encounter the feeling of no hope after finding out about their HIV positive status
- Adolescents fear of rejection by their sexual partners lead the not to disclose their HIV positive status to their partners.
- The study revealed that adolescents are taking ART without the knowledge what it was for, this is because their parents lie to them and not disclose to them what it was really for.
- Adhering to treatment in the first months of being diagnosed is a challenge since adolescents take time to adjust to side effects and new routine of making sure that treatment time find them at home.

Theme 2: Challenges experienced from childhood to adolescence period

- The findings of the study revealed that, participants grow up and transited to adolescence without knowing what the treatment they are using is for. The lack of knowledge regarding why they are on treatment for led to difficulty in adhering to treatment by adolescence.
- The study further revealed that some participants discovered that they are HIV positive on their own while visiting health care facilities and while in school.
- Adolescents educational studies get disturbed as adolescents fail to tolerate treatment side effects at diagnosis

Theme 3: Knowledge related to HIV+ status and related factors

- Participants with perinatal HIV were dissatisfied in how they contracted the virus once their parents' HIV positive status was revealed in this study, and they blamed their parents for not doing more to prevent them from contracting the virus.
- Support for the adolescents during their first month on treatment is important in order for them to endure the side effects and regain hope after being diagnosed with a lifelong condition.

Theme 4: Suggestions made to promote quality of life by adolescents on ARTs

- Educating the public will aid in the fight against stigma and discrimination against HIV-positive people.
- The study revealed that adolescents are not comfortable with attending clinic every months and they prefer at least ones in 3months.

5.5. CONCLUSION

The research study explored and described the experiences of adolescents on antiretroviral therapy at Rustenburg Sub-district in North West province. The study's findings revealed that HIV-positive adolescents on antiretroviral therapy (ART) face a variety of challenges in their lives. Adolescents who contracted HIV perinatally and those who contracted HIV vertically throughout their adolescent years face similar challenges. Adolescents with perinatal HIV had to struggle with receiving treatment without understanding why they were receiving it, as well as being told by their parents that they were receiving treatment for certain illnesses such as the flu. Those with vertical acquired HIV faced the challenges of rejection by their sexual partners as they were being blamed that they were on a mission of transmitting the virus. Early HIV+ status disclosure to adolescents with perinatal acquired HIV is more important than ever, and communities should be regularly informed about HIV to prevent stigmatization of those on ARTs.

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ANNEXURES

ANNEXURE A

Semi structured interview

1. When did you start taking ART?
2. What are your experiences while on ART?

ANNEXURE B

RESEARCH ETHICS COMMITTEE

UNIVEN Informed Consent **Appendix B**

LETTER OF INFORMATION

Title of the Research Study : Experiences of adolescents on antiretroviral therapy at

Rustenburg Sub district North West Province

Principal Investigator/s/ researcher : (*Khangale Maambiwa, BCURP*)

Co-Investigator/s/supervisor/s : (*Dr Raliphaswa Ndidzulafhi, Lecturer*

Brief Introduction and Purpose of the Study: The pandemic of the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is one of the most important contemporary sexual health issues impacting humanity today. Children who are living with HIV and AIDS encounter a variety of obstacles as they grow up. According to Mellins and Malee (2013), teenagers who have been living with HIV since birth face numerous challenges, including "ongoing medical treatment, hospitalizations, pain exposure, and sheltered life experiences." They also face a slew of special challenges relating to HIV's psychological impact, a highly stigmatized and transmissible illness that can make adolescence tough to navigate. As a result, it is critical to investigate the daily experiences of these survivors in order to better equip service providers with intervention options when working with adolescents with disabilities.

Outline of the Procedures: Once the approval has been granted to conduct the study, the project will be explained to the participants and relevant managers. An appointment will be made with the participants when they visit the facility. The study objectives, aims and benefits of the study will be explained to participants to gain rapport and the study will only be conducted to participants who are willing to participate. Researcher will use an in-depth individual interview to collect data. It will be one-to-one interview between the researcher and the participants. The interviews will be conducted in the private quiet place, and it will be at the participant's convenient time. The interview will last for 30-45 minutes per participant. The researcher will go back to the field for more data if there is still some information that is useful or has been omitted.

Risks or Discomforts to the Participant: No Risk

Benefits:

The findings will be presented to the Department of Health in North West Province and in other workshops, national and international conferences. Findings will be published in the peer review accredited journals for possible publication.

Reason/s why the Participant May Be Withdrawn from the Study: Participants may withdraw from the study anytime with no penalties.

Remuneration: No remuneration

Costs of the Study: None

Confidentiality: In this study, the researcher will not share information gathered at the research field with anyone outside research team, such as friends, close family members or any unauthorized persons. When reporting the data collected, the researcher will not use names or participants identities, coding and pseudonyms will be used.

Research-related Injury: There will be no compensation in the study.

Persons to Contact in the Event of Any Problems or Queries:

(Dr Raliphaswa N.S) Please contact the researcher (0791013244), my supervisor (0822627809.) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

General:

Potential participants must be assured that participation is voluntary and the approximate number of participants to be included should be disclosed. A copy of the information letter should be issued to participants. The information letter and consent form must be translated and provided in the primary spoken language of the research population

CONSENT

Statement of Agreement to Participate in the Research Study:

- I, ……………………………………………….hereby confirm that I have been informed by the researcher, ***Khangale Maambiwa***, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number:
- I have also received, read and understood the above written information (*Participant Letter of Information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant Date Time Signature

I, …………………….. …………… ………… ……………………..

Khangale Maambiwa herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher

……………………… Date………………. Signature…………………

Full Name of Witness (If applicable)

……………………… Date ………………. Signature…………………..

Full Name of Legal Guardian (If applicable)

………………… Date……………… Signature……………………

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counselling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant’s file and not thrown away, and copies thereof must be issued to the participant.

References:

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes* http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at: http://www.nhrec.org.za/?page_id=14

ANNEXURE C

Letter to the Department of Health North West

Private bag x2068

Mmabatho

2735

01 June 2020

Dear sir/madam

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I Khangale Happy Maybe Maambiwa, student no 15001968, a registered student in the Department of Advanced Nursing Science; School of Health Sciences, University of Venda, hereby request permission to conduct research. The topic of the study is: ***EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUBDISTRICT NORTH WEST PROVINCE.***

The purpose of the study is to describe the experiences of adolescents on antiretroviral therapy. I assure you that there will be no disturbance in the facilities when conducting research. A complete anonymity and confidentiality of every response is guaranteed to all the respondents. No names will be required. No rewards will be given to participants as a result of participating in research. For more information, feel free to contact me at 0791013244 or email: maambiwak@gmail.com

I hope that my request will be taken into consideration.

Yours faithfully

____

Khangale HMM

ANNEXURE D

Rustenburg sub-district

Private bag X82055
Rustenburg
0300

01 June 2020

Dear sir/madam

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I Khangale Happy Maybe Maambiwa, student no: **15001968,** a registered student in the Department of Advanced Nursing Science; School of Health Sciences, University of Venda hereby request permission to conduct research in your sub district. The topic of the study is: ***EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUBDISTRICT NORTH WEST PROVINCE.***

The purpose of the study is to describe the experiences of adolescents on antiretroviral therapy. I assure you that there will be no disturbance in the facilities when conducting research. A complete anonymity and confidentiality of every response is guaranteed to all the respondents. No names will be required. No rewards will be given to participants as a result of participating in research. For more information, feel free to contact me at 0791013244 or email: maambiwak@gmail.com

I hope that my request will be taken into consideration.

Yours faithfully

____

Khangale HMM

ANNEXURE E

Letter to Thekwane Clinic

Private bag X 82055

Rustenburg

0300

01 June 2020

Dear sir/madam

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I Khangale Happy Maybe Maambiwa, student no: **15001968**, a registered student in the Department of Advanced Nursing Science; School of Health Sciences, University of Venda hereby request permission to conduct research in your sub district. The topic of the study is: ***EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUBDISTRICT NORTH WEST PROVINCE.***

The purpose of the study is to describe the experiences of adolescents on antiretroviral therapy. I assure you that there will be no disturbance in the facilities when conducting research. A complete anonymity and confidentiality of every response is guaranteed to all the respondents. No names will be required. No rewards will be given to participants as a result of participating in research. For more information feel free to contact me at 0791013244 or email: maambiwak@gmail.com

I hope that my request will be taken into consideration.

Yours faithfully

____

Khangale HMM

ANNEXURE F

Letter to Mfidikwe Clinic

Private bag X82055

Rustenburg

0300

01 June 2020

Dear sir/madam

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I Khangale Happy Maybe Maambiwa, student no: **15001968**, a registered student in the Department of Advanced Nursing Science; School of Health Sciences, University of Venda hereby request permission to conduct research in your sub district. The topic of the study is: ***EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUBDISTRICT NORTH WEST PROVINCE.***

The purpose of the study is to describe the experiences of adolescents on antiretroviral therapy. I assure you that there will be no disturbance in the facilities when conducting research. A complete anonymity and confidentiality of every response is guaranteed to all the respondents. No names will be required. No rewards will be given to participants as a result of participating in research. For more information, feel free to contact me at 0791013244 or email: maambiwak@gmail.com

I hope that my request will be taken into consideration.

Yours faithfully

____

Khangale HMM

ANNEXURE G

TRANSCRIPT

Participant No 6

AGE: 18 years

GENDER: Female

KEY: P – Participant

I – Interviewer

In the health care facility, the participant enters the cubicle accompanied by sister

I – Good morning how are you?

P – I am fine thanks and you?

I – I am doing well?

P – Ok

I – How can I help you today?

P – I received a message yesterday from my sister that I am wanted today in the clinic

I – Yes, I am the one who called earlier this week with regard to the study that I am doing of which I would love you to be part of the study which is about **EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTENBURG SUBDITRICT IN NORTH WEST PROVINCE**. The target group is all adolescents between the ages of 15 – 19 years on ART.

P – Ok no problem.

I – The interview will not take time and feel free to say anything that you want to say.

P – Ok

I – I have a consent form which I would love you to read and sign for me showing that you were not forced to participate in the study.

P – (Reading the consent form). I am done and I have also signed

I – Thank you, remember the interview will also be recorded for assistance while transcribing the data for report purpose.

P – It's fine

I – We will be starting with our interview, when did you start taking your treatment ART?

P – I started to take my treatment in January 2019

I – How did you know that you are taking ART?

P – I was very sick having lost more of my body weight which made my sister to bring me to the facility to consult and I was diagnosed with HIV&AIDS and also Pulmonary TB a day after HIV diagnosis.

I – How was your reaction and how did you feel?

P – I was very sad and surprised I never thought I could be taking treatment for HIV, and this was just a few weeks after learning about HIV at school, I cried thinking and asking myself questions why me? How come could I be HIV positive how?

I – What did your parents say?

P – My mother was quite about it until I realized that she is also taking treatment which I don't know what it is for, I had to dig trying to know from her what the treatment she is taking is for.

I – Did she manage to tell you?

P – Yes, she did after a while of forcing her. She has been taking treatment for all the past years and by the time she was pregnant, she told me that she was not taking her treatment well which led to her giving birth to a positive baby and that was me and never made me to take treatment but kept quiet and waited for me to find out by my own.

I – That was hard

P – It was really hard for me especially after hearing that she knew about my status all along and never took an option of making sure I take treatment (crying), have I been taking treatment since birth I wouldn't have been the way I am.

I – I am sorry for that, what other experiences did you face while taking ART?

P – I faced the challenge of poor support within the family especially my mother, I had less support from her although she is also taking treatment and I had no energy to take treatment since my mother does not take her treatment every day, that made me lose hope.

My sister is the only one giving hope who also made sure that I complete my TB treatment although I was difficult at times because I was still in denial and in anger.

I – other experiences?

P – I had an experience of failing at school because I would be sick, missing school days and while I had no energy to study after taking treatment but only on some days.

I am not free with coming to the clinic I always feel like people will find out about my status especially my school mates. That's all with regards to my experiences.

I – Owk, do you know the treatment you are taking?

P – No I don't know them.

I – Alright, you must make sure you know the treatment that you are taking so they can be able to assist you if you happen to be at a place where they do not have your history.

P - Ok

I – What time do you take your treatment?

P – I take my treatment at 20h00

I– Ok do you take your treatment every day?

P – Yes

I – Have you ever missed your treatment and why?

P – Yes, I have missed my treatment at times because I wanted to study, and I can't drink medication as it will make me sleep. I also miss my treatment mostly when I remember what happened to me previously, so I tend to get angry.

I – Who helps you when you are not well?

P – My sister does help me

I – How do you feel when you don't take treatment?

P – I don't feel well I regret, and my body gets weak and when I take treatment again, I experience more side effects.

I – Do you see any benefits of taking treatment?

P- Yes, I see more benefits because the time I was not taking treatment I was very sick and ended up having TB which made me realize the benefits of taking treatment after I had started taking treatment.

I – Alright, we are coming to the end of our interview Do you have anything that you want to add?

P – What I can say is that being in denial and failing to accept my situation led me to lose control of my life and ended up falling pregnant that made me to learn that no matter what situation I must not allow to do things I will regret because trying to get stress of by sleeping around never helped but paid off by giving me pregnancy which instead of focusing at school am focusing on it.

I – Thanks for sharing that will truly assist even other adolescents who might find themselves in the same situation.

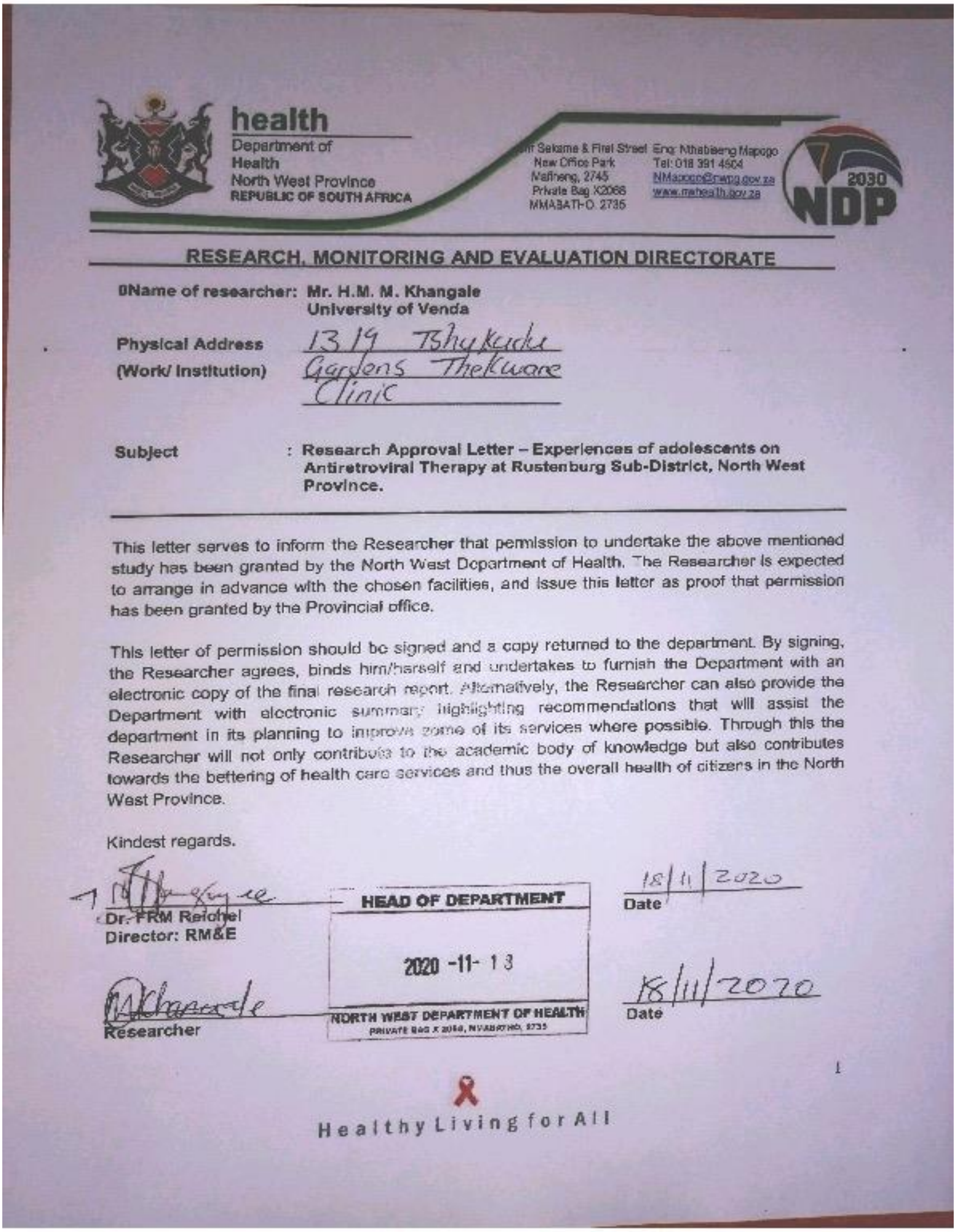
P – Yes

I – Thank you very much for your time

(Participant departing the cubicle)

THE END

ANNEXURE H: RESEARCH APPROVAL LETTER



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

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

Enq: Nthabiseng Mapogo
Tel: 018 391 4504
NMapogo@nwpg.gov.za
www.nwhealth.gov.za

2030 NDP

RESEARCH, MONITORING AND EVALUATION DIRECTORATE

0Name of researcher: **Mr. H.M. M. Khangale**
University of Venda

Physical Address (Work/ Institution) 13 19 Tshukudu Gardens Thekwane Clinic

Subject : **Research Approval Letter – Experiences of adolescents on Antiretroviral Therapy at Rustenburg Sub-District, North West Province.**

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher is expected to arrange in advance with the chosen facilities, and issue this letter as proof that permission has been granted by the Provincial office.

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

Kindest regards.

Dr. FRM Reichel
Director: RM&E

HEAD OF DEPARTMENT
2020 -11- 13
NORTH WEST DEPARTMENT OF HEALTH
PRIVATE BAG X 2068, MMABATHO, 2735

18/11/2020
Date

Khangale
Researcher

18/11/2020
Date

1

Healthy Living for All

ANNEXURE I: CODING CERTIFICATE

Qualitative data analysis

MASTER OF NURSING SCIENCE

OF

KHANGALE HAPPY MAYBE MAAMBIWA

THIS IS TO CERTIFY THAT:

Professor Tebogo M. Mothiba has co-coded the following qualitative data:

Unstructured one-to-one interviews

For the study:

EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AT RUSTERNBURG SUBDISTRICT IN NORTH-WEST PROVINCE

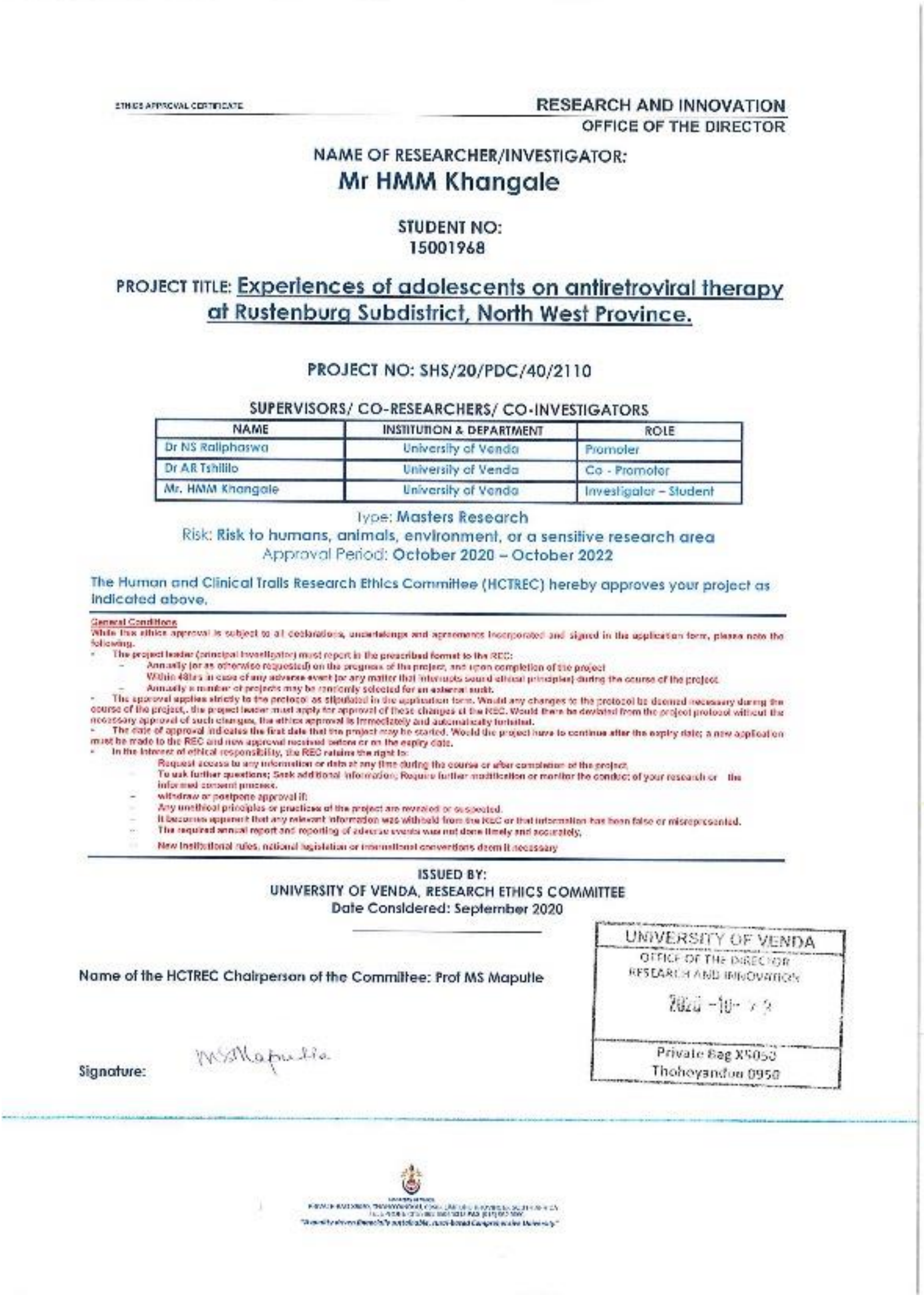
I declare that the candidate and I have reached consensus on the major themes reflected by the data. I further declare that adequate data saturation was achieved as evidenced by repeating themes.

Prof TM Mothiba

SEPTEMBER 2021

TM Mothiba (PhD)

ANNEXURE J: HCTREC ETHICS CERTIFICATE



ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mr HMM Khangale

STUDENT NO:
15001968

PROJECT TITLE: Experiences of adolescents on antiretroviral therapy at Rustenburg Subdistrict, North West Province.

PROJECT NO: SHS/20/PDC/40/2110

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr NS Raliphaswa	University of Venda	Promoter
Dr AR Tshililo	University of Venda	Co - Promoter
Mr. HMM Khangale	University of Venda	Investigator – Student

Type: **Masters Research**
Risk: **Risk to humans, animals, environment, or a sensitive research area**
Approval Period: **October 2020 – October 2022**

The Human and Clinical Trails Research Ethics Committee (HCTREC) hereby approves your project as indicated above.

General Conditions

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following.

- The project leader (principal investigator) must report in the prescribed format to the REC:
  - Annually (or as otherwise requested) on the progress of the project, and upon completion of the project
  - Within 48hrs in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
  - Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project,. the project leader must apply for approval of these changes at the REC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date; a new application must be made to the REC and new approval received before or on the expiry date.
- In the interest of ethical responsibility, the REC retains the right to:
  - Request access to any information or data at any time during the course or after completion of the project.
  - To ask further questions; Seek additional information; Require further modification or monitor the conduct of your research or the informed consent process.
  - withdraw or postpone approval if:
  - Any unethical principles or practices of the project are revealed or suspected.
  - It becomes apparent that any relevant information was withheld from the REC or that information has been false or misrepresented.
  - The required annual report and reporting of adverse events was not done timely and accurately.
  - New institutional rules, national legislation or international conventions deem it necessary

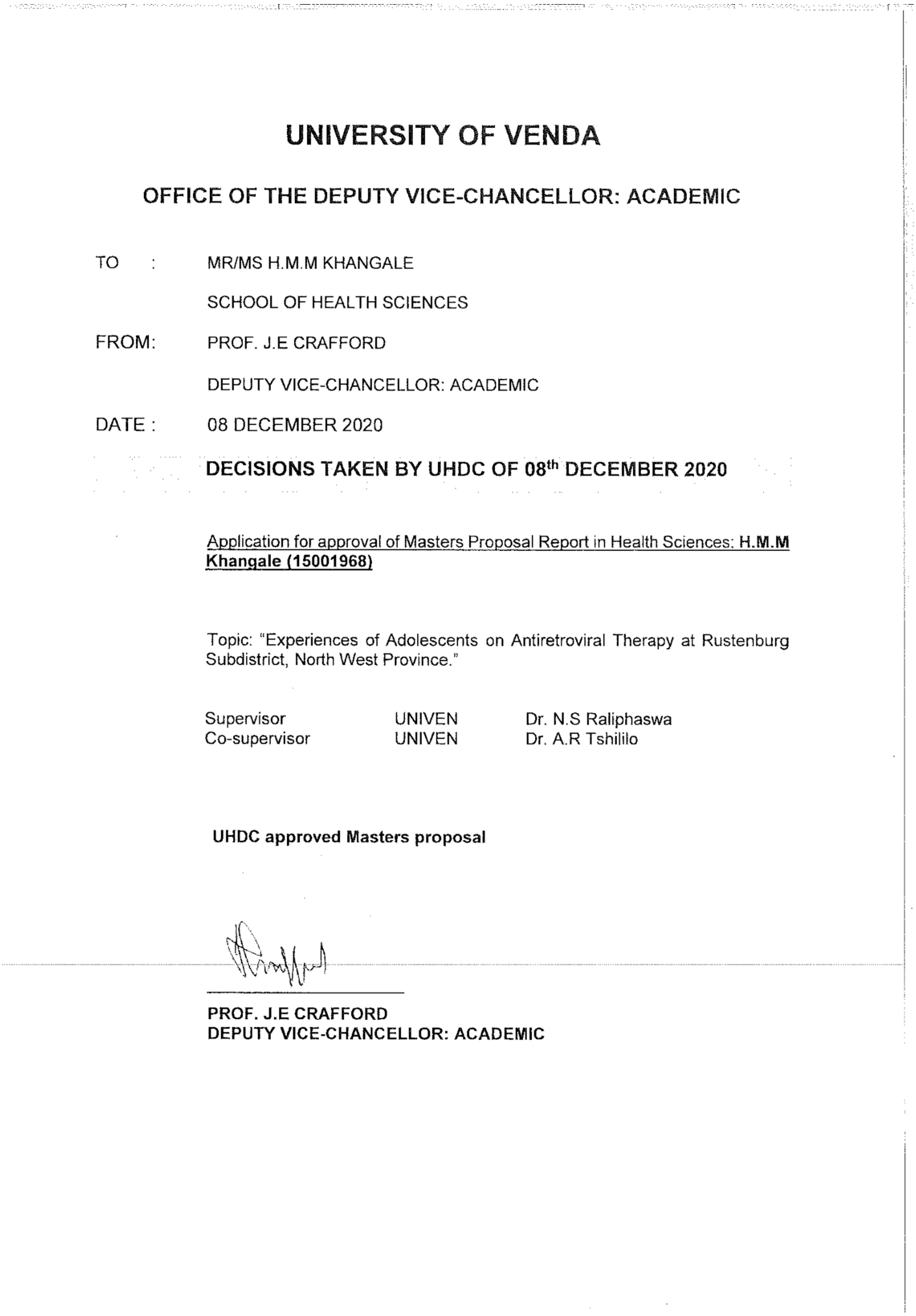
ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE
Date Considered: September 2020

UNIVERSITY OF VENDA
OFFICE OF THE DIRECTOR
RESEARCH AND INNOVATION
2020 -10- [illegible]
Private Bag X5050
Thohoyandou 0950

Name of the HCTREC Chairperson of the Committee: Prof MS Maputle

Signature: MSMaputle

ANNEXURE K: UHDC CERTIFICATE



UNIVERSITY OF VENDA

OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS H.M.M KHANGALE
SCHOOL OF HEALTH SCIENCES

FROM: PROF. J.E CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 08 DECEMBER 2020

DECISIONS TAKEN BY UHDC OF 08th DECEMBER 2020

Application for approval of Masters Proposal Report in Health Sciences: **H.M.M Khangale (15001968)**

Topic: "Experiences of Adolescents on Antiretroviral Therapy at Rustenburg Subdistrict, North West Province."

Supervisor	UNIVEN	Dr. N.S Raliphaswa
Co-supervisor	UNIVEN	Dr. A.R Tshililo

UHDC approved Masters proposal

PROF. J.E CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC

ANNEXURE L: LETTER FROM LANGUAGE EDITOR

ROSEMARY'S PROOFREADING
& EDITING SERVICES

☎ +27 83 215 6445
✉ Rosemarys.pes@gmail.com
📍 1 Richards drive
Midrand, 1684

29 JANUARY 2022

To Whom It May Concern:

RE: LANGUAGE EDITING

This letter serves as confirmation that language and technical editing was conducted by Rosemary's Proofreading and Editing Services. Further details of the study and the researcher have been provided below.

TITLE OF THE STUDY:

"EXPERIENCES OF ADOLESCENTS ON ANTIRETROVIRAL THERAPY AY RUSTENBURG SUB-DISTRICT, NORTH WEST PROVINCE, SOUTH AFRICA".

Researcher: **KHANGALE HAPPY MAYBE MAAMBIWA**

Student number: 15001968

Kind Regards

R MALULEKE (CODER & LANGUAGE EDITOR)