CHALLENGES ASSOCIATED WITH HIV TREATMENT COMPLIANCE AMONG ADOLESCENTS AND YOUNG ADULTS LIVING WITH HIV IN EMFULENI, GAUTENG

by

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I further declare that I submitted the thesis to originality-checking software and that it falls within the accepted requirements for originality.

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ABSTRACT

The purpose of the study was to explore and describe the challenges associated with HIV treatment compliance among adolescents and young adults (AYAs) living with HIV aged between 18 to 24 years in Emfuleni, sub-district municipality, and to describe recommendations to overcome the challenges related to non-compliance to HIV treatment resulting from the findings.

The study took a form of an exploratory-descriptive contextual qualitative method attributed to the Health Belief Model's (HBM) theoretical underpinnings. The interview guide was developed and Individual interviews that were semi-structured with twenty participants were conducted for data collection following a thorough in-depth literature review. Data collected from the participants were analysed thematically. The findings revealed the need for improved support of AYAs living with HIV to improve treatment compliance and viral load suppression and recommendations were made to improve support and treatment compliance as well as for further research.

Key terms

Adolescents; AIDS; antiretroviral; HIV; HIV treatment; non-compliance; unsuppressed viral load; viral load; young adults.

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DEDICATION

This dissertation is dedicated to Diteboho, my son, Fumane, my daughter, and Thembani, my son-in-law, as I would like to see them continuing their different career paths, thus the only legacy I have for them is education.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ASRH	Adolescent sexual and reproductive health
AU	African Union
AYAs	Adolescents and young adults
AYFS	Adolescents and youth friendly services
ARVs	Antiretrovirals
CCMDD	Central chronic medicines dispensing and distribution
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
I-Act	Integrated access to care and treatment
mHealth	Mobile health
NHRD	National health research database
NSP	National Strategic Plan
PHC	Primary health care
PLWHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
POPI Act	Protection of Personal Information Act
RNA	Ribonucleic acid
RSB	Risky sexual behaviour
SRH	Sexual and reproductive health
TB	Tuberculosis
Tier.net	Three-tier health information system
UNAIDS	Joint United Nations programme on HIV/AIDS
UNISA	University of South Africa
VL	Viral load

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

South Africa has the highest number of people living with the Human Immunodeficiency Virus (HIV) in the world with a big proportion enrolled on antiretroviral treatment (ART) (UNAIDS 2018a:56). There is some progress made with HIV testing and initiating people on ART, but non-compliance to treatment remains a challenge. Non-compliance with HIV treatment often results from having to deal with complicated medication regimens; social or patient-related aspects, such as non-passive substance abuse, depression, or experiencing adverse effects of treatment; the health system's inadequate supply of medication and interference with access to treatment (UNAIDS 2019:12). The gradually increasing number of adolescents and young adults (AYAs) on antiretroviral therapy (ART) makes it difficult to maintain optimal levels of ART adherence. Improving treatment compliance remains a critical challenge in the fight against HIV incidence (new infections) and transmission, and further disrupts attempts aimed at alleviating HIV-related morbidity and mortality among the AYAS.

In the past, in most of the areas in South Africa, the main challenge in the health care system and management of AYAs on ART, was manual data collection of patient information regarding their treatment, compilation and capture of the patient information (Maphumulo & Bhengu. 2019). This, in turn, created another challenge in estimating the magnitude of poor treatment compliance. The advance of technology and availability of patient information systems, such as the Department of Health's (2019) three tier health information system, has facilitated the management of progress regarding the capturing of patient information. The patient information system enables health care professionals to:

- Review the total number of people retained on ART.
- Analyse their adherence level to therapy.
- Monitor the indirect biological marker of viral load.
- Identify patients who missed their appointments.

Although adherence is a behavioural problem, it can be monitored indirectly using the biological routine monitoring of viral load according to treatment guidelines in South Africa (Pillay, Cornell, Fox, Euvrard, Fatti, Technau, Sipambo, Prozesky, Eley, Tanser, & Johnson. 2020: 264). A review on the feasibility of ART monitoring in decentralised HIV care found that it ascertained the level of suboptimal therapy in the patient's system which could determine and provide an indication of the failure of treatment, or just non-compliance (Pham, Romero, Parnell, Anderson, Crowe & Luchters 2017:3). Various factors, such as HIV disclosure due to fear of being stigmatised, psychosocial factors, health care and physiological factors, can lead to non-compliance. This study wished to explore and describe the views of adolescents and young adults (AYAs) in Emfuleni, Gauteng Province, on challenges to their compliance with ART.

1.2 BACKGROUND TO THE PROBLEM

HIV remains a significant worldwide public health issue according to the 2022 statistics reported by the UNAIDS in July 2023.

Global HIV statistics

According to these stats, about 39.0 million people globally were living with HIV in 2022. Within the same year,1.3 million people became newly infected with HIV. The death toll of people who died from AIDS-related illnesses in 2022 was reported to be 630 000. UNAIDS (2023) further reported that 29.8 million people were accessing antiretroviral therapy in 2022; while 85.6 million people have become infected with HIV since the start of the epidemic; and 40.4 million people have died from AIDS-related illnesses since the start of the epidemic.

People living with HIV

According to the UAIDS (2023), in 2022, of the 39.0 million people living with HIV, 37.5 million were adults (15 years or older); and 1.5 million were children (0–14 years). The 53% of all people living with HIV were women and girls. The 86% of all people living with HIV knew their HIV status in 2022, while about 5.5 million people did not know that they were living with HIV in 2022.

Table 1.1 Global HIV data Source: UNAIDS 2023 epidemiological estimates.

	2022
People living with HIV	39.0 million [33.1 million - 45.7 million]
New HIV Infections	1.3 million [1.0 million - 1.7 million]
New HIV Infections (Adults, aged 15+)	1.2 million [900 000 - 1.6 million]
New HIV Infections (Children, aged 0- 14)	130 000 [90 000 - 210 000]
AIDS-related deaths	630 000 [480 000 - 880 000]

Source: UNAIDS 2023 epidemiological estimates.

In 2022, the estimated population of South Africa at the midyear point was 60 million, with an estimated 7.7 million people living with HIV/AIDS. of whom 4.7 million (56%) received ART (Statistics South Africa [Statssa] 2018; UNAIDS 2018a:56). In 2016, an estimated 270,000 new infections were reported in South Africa, of which 33.3% were among adolescents and young adults (UNAIDS 2018a:56). HIV distribution is uneven across the country, sustained by substantial ecological differences among different communities in South Africa (South Africa's National Strategic Plan (NSP) 2017-2022).

In pursuit of the 90/90/90 goals, South Africa has achieved 90% of the population knowing their HIV status, but still struggles with 61% of those who tested positive being initiated on ARVs and only 47% of those were reported to be virally suppressed (UNAIDS 2018a:57). The country still faces challenges with regard to unsuppressed viral load among adolescents accompanied by a treatment failure rate of >50% (Southern African HIV Clinicians Society [SAHCS] 2017:16).

In Uganda, the principal element causing a lack of viral suppression is poor compliance with treatment among AYAs (Natukunda, Kirabira, Ong, Shibanuma & Jimba 2019:2). The provision of ART has substantially decreased HIV-related morbidity and mortality and reduced the risk of HIV transmission (UNAIDS 2018b:5). Despite the benefits of taking ARVs, individuals with suboptimal compliance with ART were not able to sustain viral suppression. The interruption of treatment has been linked to rebound *viremia*, weakening of the immune system, and increased morbidity and mortality (Castillo-Mancilla, Phillips, Neaton, Neuhaus, Collins, Mannheimer, Pett, Touzeau-Römer, Polizzotto, Lundgren & Gardner 2018:275; UNAIDS 2018b:4). Once ART is initiated, it must be continued, with the following fundamental goals: achieve maximum viral load suppression; maximally and durably suppress plasma HIV RNA; recover and maintain the immunologic function; reduce HIV-related morbidity and mortality; extend the lifespan and quality of survival, and prevent new HIV transmissions (UNAIDS 2018b:3).

Regardless of the provision of appropriate ART, achieving viral suppression also requires optimal adherence to therapy by patients. The researcher believes that it is imperative that we understand the reasons behind AYAs' poor adherence to ARVs with ARVs if we are to have a generation free of HIV.

1.3 STATEMENT OF THE PROBLEM

According to Polit and Beck (2017:365), a research problem is “a problematic situation that can be resolved by producing evidence via research studies” (Polit & Beck 2017:365). Problem statements identify the issue and provide evidence for why a study is necessary, and should indicate the scope and importance of the problem clearly (Grove & Gray 2019:164).

AYAs living with HIV are the most susceptible group to adherence challenges due to their psychological, social and intrapersonal generative stages. AYAs who contracted HIV when they were teenagers as well as adolescents who were diagnosed HIV positive when they were pregnant, face numerous barriers to treatment compliance (Albright & Fair 2014:587). AYAs have one of the lowest percentages of viral suppression, and one of the highest rates of cases where the viral load was suppressed, then later became unsuppressed, missed appointments and cases of HIV treatment defaulters due to poor compliance (UNAIDS 2018b:2).

As the quality improvement mentor for the HIV programme in Sedibeng district, one of the researcher’s tasks was to improve the quality of care, treatment and support for adolescents and young adults. The researcher discovered that the most significant issues faced by health care professionals was non-compliance with treatment, evidenced by data from the computerised three interlinked electronic Registers for TB and HIV in August 2019 from five facilities in Emfuleni sub-district for two consecutive unsuppressed viral loads. The researcher observed 769 unsuppressed viral loads, of which 90% missed their appointments based on their last visit date. During engagements with health care workers and young adults who were receiving care and treatment in some health care facilities, the researcher discovered that there were multiple contributory factors to non-compliance, including HIV-related stigma, psychosocial, health care and physiological factors. Some adolescents and young adults admitted that they had intentionally stopped taking treatment for various reasons. The gaps observed prompted the researcher to consider exploring the views of AYAs regarding their challenges associated HIV-treatment compliance. The study focused on exploring and describing the challenges regarding the compliance with ART, for male and female young adults and adolescents, aged 18-24, living with HIV.

1.4 PURPOSE OF THE STUDY

The research purpose identifies the focus and goal of the study being conducted and should direct its development (Gray, Grove & Sutherland 2017:83). The purpose of the study was to explore and describe the challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni sub-district municipality, Gauteng and to make recommendations to overcome the challenges related to compliance with the treatment based on the findings.

The study set out to accomplish the following objectives in order to fulfil its intended purpose:

- Explore and describe the challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng.

In light of this, the research set out to respond to the following questions:

- What are the challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng?

1.5 IMPORTANCE OF THE RESEARCH

Research studies need to be relevant to the field of nursing and add to the pool of knowledge. (Brink, Van der Walt & Van Rensburg 2012:61). A study's importance can be measured by how it might advance our scientific understanding (Polit & Beck 2017:111).

The results of the study could improve health professionals' understanding of AYAs' perceptions regarding challenges in complying with HIV treatment. The recommendations may assist in overcoming challenges and barriers and may improve compliance with ART among adolescents and AYAs living with HIV, thereby decreasing morbidity and mortality and increasing their life expectancy.

1.6 PARADIGM

A paradigm is a mode of thinking or "a way of viewing natural phenomena that incorporates a set of logical presumptions and that guides one's approach to inquiry" (Kivunja & Kuyini 2017:26). The researcher's concentration on a phenomenon is made even more acute by paradigms, which are like lenses (Polit & Beck 2017:79). Assumptions are Principles that are accepted as true solely on reason or logic without supporting evidence Polit & Beck 2017:80). A research paradigm refers to a shared worldview which represents beliefs and agreements on how the problem is understood and solved (Patel 2015). The three main paradigms are positivism, constructivism, and pragmatism (Patel 2015).

Constructivism served as the study's theoretical framework, according to the researcher A naturalistic paradigm is another name for a constructivist paradigm. Polit and Beck (2017:80) According to Polit and Beck (2017:80), constructivism is an approach that considers that reality may be interpreted in many different ways and that the purpose of study is to comprehend how people interpret the world around them.

1.7 THE THEORETICAL FRAMEWORK OF THE STUDY

A framework is "a conceptual, logical arrangement of definition that guides the research study" (Grove & Gray 2017:24). A study's theoretical/conceptual framework is defined as "a structure of concepts and/or theories combined as a map for the study to provide the justification for the development of a research question or hypothesis" (LoBiondo-Wood & Haber 2017:57). The Health Belief Model (HBM) was chosen by the researcher as the study's theoretical foundation.

The Health Belief Model (HBM) is a theoretical framework which explains the way an individual behaves in relation to his or her wellbeing which expresses person's health

perception. HBM was developed to anticipate an individual’s health reaction, as well of health services utilisation, and to validate mediations to change defective health behaviour. The HBM has the following components:
Perceived susceptibility whereby an individual has own perception of susceptibility to a certain condition or disease, the perceived severity, perceived threat, perceived benefits and perceived barriers to preventive individual’s health behaviour, and the internal or external drives which later results in appropriate health response by the individual (*Mosby’s Medical, Nursing and Allied Health Dictionary* 2001:512).

Compliance with medication (e.g., ART) depends on individuals’ behaviour or understanding of treatment, as well as how individuals react to medication instructions, thus resulting in good clinical outcomes (Adefolalu 2018:3). The HBM attributed to individuals’ perception of being susceptible to a certain disease or condition and an individual’s understanding or perceptions for the benefits of avoiding the disease (Adefolalu 2018:4). Health perception or behaviour attributed to the perceived threat of the condition or disease. With regards to HBM, individuals’ perception of ill health, perceived benefits and barriers to action, and self-efficacy describe poor involvement in health-promotion-related issues. To promote active health behaviour, motivation or impulse to action must be available. Perceived vulnerability, perceived severity, perceived advantages, perceived obstacles, cues to action, and self-efficacy are the six essential constructs of. The six fundamental HBM constructs were employed by the researcher to guide the development of study tools and meeting the study exploring the challenges of adolescents and young people regarding HIV treatment compliance.

1.7.1 Perceived vulnerability

The term "perceived vulnerability" refers to people's arbitrary assessments of their likelihood of contracting a disease (Adefolalu 2018:4). In this study, the individuals had to assess and decide whether or not to take antiretroviral therapy in order to lessen the impact of HIV.

1.7.2 Perceived severity

Individuals' perceptions of a health issue's intensity or seriousness, as well as any potential repercussions, are referred to as perceived severity. In this study, the individuals had to assess the seriousness of untreated HIV and the likely effects thereof (LaMorte 2022).

1.7.3 Perceived threat

Perceived threat applies to assessment of individual personal vulnerability to the particular condition (HIV) and how likely their behaviour would lead to a negative outcome (Adefolalu 2018:4). In this study, perceived threat referred to non-adherence to treatment and participating in unprotected sexual intercourse, which places individuals at a higher risk of re-infection resulting in unsuppressed HIV viral load and eventually treatment failure. If individuals did not feel they were at risk for increased *viremia*, based on the fact that they had never had any symptoms, they would not be likely to change their sexual behaviour or take ARTs.

1.7.4 Perceived benefits vs perceived barriers

Perceived benefits is where an individual assess the rate or ability of engaging in a health-promoting behaviour in order to reduce risk of a particular disease. Perceived benefits influence Health-related behaviours (Adefolalu 2018:4).

Perceived barriers means assessment of problems encountered by individuals in modifying behaviour (Tarkang & Zotor 2015:5). Perceived barriers refer to the value of taking action and individuals assumption towards the benefits that outweigh the value (Tarkang & Zotor 2015:6). Chapter 3 discusses the HBM and its application in the study in full.

1.8 BRIEF DESCRIPTION OF THE RESEARCH DESIGN AND METHODOLOGY

A research design is defined as a plan or strategy that the researcher uses to conduct his or her own study to answer a research question and improve the integrity of the research (Polit & Beck 2017:741). According to Brink research design is a batch of reasonable that the researcher follows to respond to the research question (Brink et al 2012:92). Gray et al (2017:214) describes research design as the blueprint for conducting the research which takes a lead in controlling factors that may impede with research validity.

For the purpose of the research, the researcher used an exploratory, descriptive, and contextual qualitative design. The researcher believed that this was an effective method to explore, describe and comprehend the challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni sub-district.

Research methods are "the techniques researchers use to structure a study and to collect and analyse information pertinent to the research question, while research methodology is the plan for carrying out the phases of a study" (Polit & Beck 2017:741). Framework, population, sampling, selection, data collecting, data analysis, interpretation, and results are all included in the research technique. According to Gray et al (2017:129), the methodology for qualitative research is adaptable and changes as the researcher explores the breadth and complexity of the data they have gathered. Research design and methodology discussed in more details in Chapter 3.

1.8.1 Study setting

The researcher conducted the study in five public health facilities that provide an ART programme in the Emfuleni sub-district municipality in the Sedibeng District, Gauteng Province. The sites had to be primary health care (PHC) facilities and provide ART for HIV positive AYAs.

1.8.2 Population

A population is defined by Polit and Beck (2017:365) as “the set of cases in which a researcher is interested”. A research population is defined as “a collection of elements from which the sample is selected” (Babbie & Mouton 2012:199). In this study, the population comprised all adolescents and young adults with HIV and currently enrolled on the ART programme in the four selected clinics in Emfuleni municipality – Sedibeng District, Gauteng.

1.8.3 Sampling and sample

Sampling is the act of choosing examples to represent the whole population so that conclusions about the population can be drawn. Researchers select a sample, which is a portion of the population, from which data will be collected (Grove & Gray 2019:293).

In order to acquire a thorough grasp of the issue being studied, the researcher employed non-probability purposive sampling to select study participants, as alluded by Grinnell and Unrau (2018:380). The researcher purposively selected AYAs aged between 18 and 24 years, and who were identified as not compliant with ART with two consecutive unsuppressed viral loads (VL) on 1st line and 2nd line ART treatment at the time of the study.

1.8.4 Data collection

Data gathering or collection is the process of methodically compiling data pertinent to the study question in order to answer a research issue (Polit & Beck 2017:366). The researcher used semi-structured interviews to collect data from AYAs who were identified as not compliant with ART and had two consecutive unsuppressed viral loads (VL) on 1st line and 2nd line ART treatment at the time of the study.

1.8.5 Data analysis

Data analysis is the methodical data integration and organisation to give qualitative data gathered direction, structure, and meaning (Polit & Beck 2017:366). The researcher used thematic data analysis to analyse the data (refer to Chapter 3 for full discussion).

1.9 TRUSTWORTHINESS

Trustworthiness or rigour is "the level of trust that qualitative researchers place in the reliability, dependability, confirmability, transferability, and authenticity of their data (Polit & Beck 2017:724).

1.9.1 Credibility

In qualitative investigations, credibility refers to the level of trust in the veracity of the facts and the interpretations made of them. Credibility is a measure for assessing integrity and quality (Polit & Beck 2017:724). Credibility verifies that the researcher's rebuilding and depiction of the participants' experiences are accurate. Individuals in the study who were receiving HIV care and ART were subjected to in-depth interviews by the researcher.

By developing a relationship of trust and engaging with the participants, the researcher increased credibility of the study. To guarantee that the data had not been interpreted incorrectly, the researcher's supervisor evaluated, validated, and verified the research findings and conclusions as indicated in Brink et al (2012:119).

1.10.2 Confirmability

In qualitative research, confirmability refers to the objectivity or impartiality of the data and interpretations as a measure for integrity (Korstjens & Moser 2018:122). The researcher used a reflexive journal to document all the activities that occurred during the study, she took field notes and audio recordings including personal reflection and used participant quotes from the verbatim transcripts to support findings as indicated by the literature in Anney (2014:280). The study promoter also did the co-coding of data from the transcripts to confirm the codes, categories and themes.

1.10.3 Transferability

The term “transferability” relates to the generalisation of data, or the extent to which the results can be applied to or transferred to different contexts (Polit & Beck 2017:540). According to Anney (2014:277), “translatability” is the likelihood that the study's conclusions will be applicable to people in comparable circumstances. The researcher kept an audit trail of the research approach so that future researchers might use the same procedures in a related situation in order to attain transferability.

1.10.4 Dependability

Dependability is defined as the consistency of data over a period of time under many circumstances (Polit & Beck 2017:538). Should the study be conducted again with new subjects and in a different environment, the results would not alter. The study made use of audio recordings and the verbatim transcripts to ensure that the participants' voices are captured correctly. To verify information accuracy during data collection, participants were prompted with more questions for further information. Detailed description of the study's methods and procedures were also recorded so that others may follow the audit trail.

1.11 THE STUDY'S SCOPE AND LIMITATIONS

A study's limitations are any flaws, limits, or issues that could reduce the generalisation of its outcomes (Gray et al 2017:39). The study's scope was to explore and describe the challenges faced by participants who were identified as not compliant with ART with two consecutive unsuppressed viral loads (VL) on 1st line and 2nd line ART treatment at the time of the study, living with HIV in Emfuleni sub-district municipality and to make recommendations for possible interventions. The study was limited to four public health institutions from one sub-district in the province hence the results might not be applicable to some provinces, districts or health institutions.

1.12 DEFINITION OF KEY TERMS

The following terms are employed in this study and are clarified below:

Adolescents: Adolescents are defined as youngsters between the age range of 10 and 19 who are moving from childhood to adulthood with regard to developmental milestones by the World Health Organization (WHO 2013:vii). The definition was accepted as it is and the researcher sampled adolescents aged between 18 and 19 years who are having two consecutive unsuppressed viral load to describe their challenges and experience with HIV treatment compliance were used for investigations.

Young adults. Higley (2019:2) defines young adults as distinctive developmental ages between 18 to 25 years where the main developmental functions occur for a young adult to participate and explore. In this study, young adults are the persons aged between 20 to 24 years, who are virally unsuppressed.

Antiretroviral therapy (ART): ART is described as the medication/drugs used for the treatment of HIV. These drugs do not kill the virus, but suppress the virus thereby slowing HIV diseases down (International Association of Providers of Aids Care [IAPAC] 2021). Operationally in this study, ART will be the HIV medication that participants were taking to supress the viral load in the sampled facilities.

HIV treatment. This involves medicines/medication taken when a patient is diagnosed with HIV in order to stop the virus from spreading in the human body (HIV.gov 2022). In this study, HIV treatment is the treatment that the AYAs collect from the clinics to suppress their HIV viral load. The HIV treatment is provided by healthcare professionals.

Compliance with ART. Compliance refers to abiding by the rules and prescribed ART requirements; that is, taking treatment at the correct intervals, not missing doses, and collecting ARVs on the due date (HIV.gov 2022). In this study, compliance refers to adherence to the ART treatment as prescribed.

Non-compliance with ART. Non-compliance refers to not taking ART as prescribed after initiation of ARVs; that is, not taking the correct dose, missing one or more treatment doses, and not obeying dosages and intervals (HIV.gov 2022). This definition is taken as is for operational purposes in this study. The researcher interviewed AYAs non-compliance to ART as evidenced by unsuppressed VL retrieved from three-tier health information system.

1.13 ETHICAL CONSIDERATIONS

Researchers must exercise caution when using people as study subjects to ensure that their rights are upheld (Polit & Beck 2017:748). In order to protect the study participants, Babbie and Mouton (2012:62) note that the researcher must abide by predetermined guidelines or standards of ethical behaviour. As a result, the researcher received approval to carry out the study, attained informed consent, and adhered to ethical principles of beneficence and confidentiality.

- **Permission**

Permission refers to requesting access to conduct a study from a particular institution or district on specific population of interest (Liberty University 2022). The Department of Health Studies Research and Ethics Committee at the University of South Africa granted the researcher's study ethical clearance and permission to proceed (Annexure A). From the Sedibeng District Health Services, authorisation to perform the study was also requested and granted approval (Annexures B and D).

- **Informed consent**

This means participants should be given adequate information about the study to be conducted, they are also given information about potential risk and benefits of the research. The decision to participate in the study or to opt out is left up to each individual participant, and they should not be penalised for either choice (Nusbaum, Douglas, Damus, Paasche-Orlow & Estrella-Luna 2017:1). The study had 20 participants age between18 to 24, who could give their written agreement to participate in the study or to decline to do so. Participants were informed about participants' voluntary engagement without bias. To enrol in the study, the individuals were contacted and recruited, and provided with all the study relevant information which will allow them to make informed decision on whether to take part or not. All prospective participants were made aware of their ability to resign from the study at any time without interfering with their treatment at the facility. The participants were given a consent form to sign after being given the opportunity to ask questions.

- **Anonymity**

This principle applies when participants cannot be linked to their own data by the researcher. When that occurs participants’ personal information is strictly protected. As the qualitative study involves interviews, anonymity is sometimes impossible. However, the researcher ensured confidentiality by using only age and gender for participants’ demographics when collecting data (Polit & Beck 2017:223). The transcripts did not have participants’ real names. The researcher will assign and used numbers and pseudo-names to identify the participants and transcripts to make sure that the information given cannot be easily associated to a particular individual by someone else.

- **Beneficence**

This is the ethical principle where the researcher protects participants from exploitation and promote participants' welfare and their safety. The researcher minimises harm and maximises benefit (Polit & Beck 2017:211).

Participants were told by the researcher that their information would be kept private and confidential. Participants were urged to merely be honest during the interview, which was conducted in a non-threatening manner, as there were no right or incorrect responses. The researcher explained that she needed the data to understand their views and reasons for non-compliance with ART. In addition, the researcher explained how the study would benefit them and other patients who would be initiated on ART and adherence, which further enhanced their understanding of the importance of ART adherence.

- **Research integrity**

This is when research is being carried out in a manner that participants build trust and confidence on methods used. The researcher managed to achieve the research integrity by applying key elements of integrity which are rigour transparent, honesty and respect (Policy Brief 2018:2). The researcher understood clearly the critical applicable principles of research study and the ethical consideration pertaining to the nature of the study and adhered to those principles.

- **Confidentiality**

This is the researcher's commitment that any information provided by participants won't be disclosed or made accessible to non-authorised people (Polit & Beck 2017:223). The researcher reassured the participants that any information they provided would be handled in the strictest of confidence and would not be shared with or made available to unauthorised individuals. Field workers were recruited from the respective facilities and were trained by the researcher on confidentiality and voluntary participation for participants as per Annexure E.

The data was verified with the participants during interview discussions, and the numbers and pseudo-names to identify those who participated and transcripts to ensure anonymity and confidentiality.

The study promoter and co-coder were given the numbered transcripts with pseudo-names. For the protection of human dignity, ethical principles were strictly considered. Participants were selected based on the study requirements such as age requirements of 18-24 years, was strictly taken into consideration. The researcher also asked participants to give their informed consent in order to take part and were given clear information on the consent form using the language they would understand. Participants' right to privacy, secrecy, and confidentiality was all the time observed. Individuals were not asked to identify themselves during the interview and their responses was not shared with anyone to avoid breaching their privacy. Participants' right to self-determination was clearly explained to them; therefore, individuals were full freedom to decide whether or not to engage in a study at their own discretion without any penalties was ensured. The researcher provided participants with a chance to ask questions and provided a thorough explanation of the study's objectives.

1.14 DESIGN OF THE DISSERTATION

Five chapters constitute the dissertation.

Chapter 1 presents the study problem, research design and research techniques or methodology, and ethical issues, and glossary of relevant terms.

Chapter 2 covers review of the literature.

Chapter 3 explains the study design or strategy and research methodology or technique.

The data analysis, presentation, and comprehension of the research findings are covered in Chapter 4.

In Chapter 5, recommendations for practice and additional research are made after a brief discussion of the study's findings and limitations.

1.15 CONCLUSION

Chapter one provided an overview of the study by describing the problem, purpose and significance of the study as well a brief description of the research design and methods. It went on to discuss the study's theoretical underpinnings, limitations, and ethical considerations. The literature review done for the study is covered in Chapter 2 of the study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The subject matter or research topic, objectives, and significance of the study, as well as the research design and technique, were all discussed in Chapter 1.The literature review that was done for the study is covered in this chapter. An arranged, written description of what has been published about a subject is known as a literature review, and it entails finding, reading, and comprehending literature that is pertinent to a study (Grove & Gray 2017:120). A literature review helps researchers understand and gain additional knowledge about the phenomenon being studied by outlining what is currently known about the topic of interest (Booth, Sutton, Clowes & Martyn-St James 2022:2).

The review of the literature addressed the prevalence of HIV/AIDS among adolescents and young adults worldwide, the incidence of HIV/AIDS among young people in sub-Saharan Africa, the stages of HIV infection vulnerability, viral suppression, barriers to HIV prevention among young people, and barriers to HIV treatment compliance among young people.

Different search engines like google scholar were used to retrieve some literature related to HIV treatment non-compliance using key concepts ‘barriers to HIV treatment’, ‘poor compliance to ART’, ‘poor adherence to ART’, ‘HIV among AYAs’, and ‘magnitude of HIV’. Relevant information related to HIV/AIDS, barriers to HIV treatment compliance and ART poor adherence were identified and downloaded from united nations publications such as UNICEF, UNAIDS, and STOP AIDS. More data retrieved using articles from 2017 to 2022. About 20 articles were used from international and national publishers such as Journals of International AIDS Society, European Journals of General Practice, South African Journals of HIV Medicine and African Journals of Primary Health and Family Medicine. Other sources such as Statistics South Africa, BMJ Global, HIV.gov, and textbooks were used to retrieve the literature related to HIV among AYAs as well as challenges related to HIV treatment compliance.

2.2 MAGNITUDE OF HIV/AIDS AMONG ADOLESCENTS AND YOUNG ADULTS

Adolescents and young people represent a growing portion of people living with HIV (PLWH) worldwide. HIV/AIDS is the leading cause of death among adolescents and young adults between the ages of 10 and 24 years in Africa, and the second leading cause globally (UNICEF 2020a). The number of adolescent deaths due to AIDS-related illnesses tripled between 2000 and 2015 (UNICEF 2019). In 2014, UNAIDS set the 90-90-90 targets of having 90% of all PLWH knowing their status; 90% of PLWH who know their status being on ART, and 90% of them achieving sustained virology suppression. The 90-90-90 strategy aimed to end the HIV pandemic by 2030 (UNAIDS 2017:8-9).

In 2021, an estimated 1.71 million adolescents aged 10-19 were living with HIV; approximately 86% live in sub-Saharan Africa. Outside of sub-Saharan Africa, the highest numbers of HIV-positive adolescents are in Asia and Latin America (UNICEF 2022). In 2021, an estimated 1.5 million people were newly infected and 49% of all new infections were women and girls (UNAIDS 2022:1). In 2021, 410,000 young people, aged 10 to 24 years were newly infected with HIV, with 160,000 aged between 10 and 19. Moreover, only 25% of adolescent girls and 17% of adolescent boys aged 15 to 19 in Eastern and Southern Africa, the region most affected by HIV, had been tested for HIV in the previous twelve months and received the result of the last test. The testing rates in West and Central Africa and South Asia were even lower. Globally, adolescent girls accounted for 75% of all new HIV infections among adolescents (UNICEF 2022).

2.2.1 Global incidence of HIV among adolescents and young adults

Adolescents and young adults are the most affected by HIV. In 2021, 38.4 million people globally were living with HIV: 36.7 million were adults aged 15 years and older; 1.7 million were children aged 0-14 years, and 54% of all people living with HIV were women and girls (UNAIDS 2022:1-4). In 2018, 540,000 young women and 180,000 young men were living with HIV (UNAIDS 2018a). Morris and Rushwan (2015:S40) state that globally adolescents are the most vulnerable group severely impacted by HIV/AIDS. Despite the serious risks that countries run by ignoring adolescent sexual and reproductive health (ASRH), this issue has received little attention. Adolescents encounter a number of obstacles, such as early motherhood and pregnancy, getting contraception is difficult, and there are high prevalence of sexually-transmitted infections (STIs) and HIV. Various factors restrict the delivery of information and services thereby failing to provide supportive youth-appropriate services (Morris & Rushwan 2015:S41).

Compared to adolescent males and young men, adolescent girls and young women had a greater prevalence of HIV. Young women usually start HIV treatment earlier than men and achieve viral suppression while men usually start ARVs at an older age when their condition is advanced and have a higher mortality rate (UNICEF 2020b).

2.2.2 Adolescents and young adults and HIV in sub-Saharan Africa

Most of AYAs with HIV are found in countries with low or middle incomes, particularly in sub-Saharan African countries, including Kenya, Tanzania Mozambique and Nigeria (UNAIDS 2016). In 2016, more than 66% of new HIV infections worldwide were in sub-Saharan Africa (UNAIDS 2017; UNICEF 2019).The majority of those affected by interacting types of discrimination and inequality in society are teenagers and young adults, which increases the likelihood of becoming susceptible to HIV.

Substantial physical as well as emotional shifts affect adolescence along with the early years of adulthood. Transitioning from childhood to adulthood is a challenging time of navigating and exploring peer relationships, sexuality, gender norms, and economic responsibility (STOP AIDS 2018). Sex workers including those they serve, homosexual men who are having sex with other men, injection drug users, are among the key demographics who are susceptible to being infected with HIV (STOP AIDS 2018).

2.3 STAGES OF HIV INFECTION VULNERABILITY

The WHO (2020) estimates that young individuals between 15 and 25 years of age account for over 30% of all new HIV infections worldwide. Others are infected at birth due to failed prevention of mother-to-child transmission (PMTCT) programme, which they grow with HIV and later have to deal with HIV status in their adolescent years.

2.3.1 Perinatal/vertical transmission

Adolescents and young adults are more susceptible to HIV in two phases of their lives: early in their initial decade of life, when HIV can be passed vertically from mother to child during pregnancy, delivery, or breastfeeding, and in the later years of life, when adolescence brings an additional susceptibility to HIV. About 70% of adolescents and young adults living with HIV acquired HIV through vertical transmission, which means they have been living with the HIV since birth (STOP AIDS 2018). The recent introduction of PMTCT programmes has been effective, but lowering the incidence of new infections amongst adolescents remains a challenge (Pellowski, Wedderburn, Stadler, Barnett, Stein, Myer & Zar 2019:4).

2.3.2 Behavioural/horizontal transmission

Apart from vertical transmission, behavioural or horizontal transmissions are the most common HIV infection modes for adolescents and young adults (Vesser 2017:72). Horizontal transmission is associated with behaviours such as experimenting with risky sexual behaviours, unprotected sex, age-disparate relationships, multiple sexual partners and early sexual debut. Due to lack of open information sharing and sexual education, these behaviours have become a norm followed by sharing infected needles being the second mode of transmission resulting from not having the correct information on HIV and HIV prevention strategies (Simbayi, Zuma, Zungu, Moyo, Marinda, Jooste, Mabaso, Ramlagan, North, Van Zyl, Mohlabane, Dietrich & Naidoo 2019:139). Some infections are a result of sexual abuse (Simbayi et al 2019:139).

2.3.3 Biological vulnerability

Biological vulnerability in HIV for women is high due to physiological risks. This is caused by increased vaginal tissue injury and prolonged mucosal surface exposure to microorganisms and contagious fluids during sexual activity (Mall, Habte, Mthembu, Peacocke & De Beer 2017:192). In some cases, HIV acquisition by women have been associated with genital tract infections that are prone to induce genital tract inflammation which increase the potential for contracting HIV. Due to these being asymptomatic, the prescribed syndromic management reduces chances of early identification of genital tract inflammation, thereby leaving young women at risk of acquiring HIV (Kaida, Dietrich, Laher, Beksinska, Jaggernath, Bardsley, Smith, Cotton, Chitneni, Chitneni, Closson, Lewis, Smit, Ndungu, Brockman & Gray 2018:499).

2.3.4 Social and structural vulnerability

As the world's largest AIDS epidemic, the HIV pandemic continues to be centred in South Africa, where 20% of all HIV-positive people reside as well as 20% of new infections. (Kim, Tanser, Tomita, Vandormael & Cuadros 2021:2). In addition, the country has a significant number of cases of TB, notably multi-drug resistant TB, which exacerbates its HIV pandemic (Allinder & Fleischman 2019). In some communities in KwaZulu-Natal Province, 60% of women have HIV (Allinder & Fleischman 2019). Over 4,000 South Africans are infected every week, of whom 30% are adolescent girls and young women aged 15-24 (Allinder & Fleischman 2019). However, the spread of HIV is not regarded as an existential threat (Allinder & Fleischman 2019). In many settings gender inequalities and discrimination remain a barrier to access fundamental human rights and economic opportunities for young girls and women (UNAIDS 2021:8). Socio-economic and cultural factors, especially social inequality and exclusions, and having older partners increase adolescents' and young adults' susceptibility to HIV transmission (WHO 2018:5).

Globally, fatalities amongst children from AIDS and adults declined, the adolescent mortality rate rose and HIV is far from over for young people (UNICEF 2018). Adolescents are more vulnerable to contract HIV infection as most become sexually active by late adolescence. Between 30%-50% of girls experience their first pregnancy and give birth before 19 years of age (STOP AIDS 2018). Although 11% of teenagers start having relationships before the age of 15, some children are exposed to sexual activities as young as 5 years, directly or indirectly (STOP AIDS 2018). Child marriage is the main challenge of early sexual debut, of which up to 45% of adolescent girls stated that their initial sexual engagement had not been negotiated (STOP AIDS 2018).

2.4 VIRAL SUPPRESSION

In sub-Saharan Africa, AIDS is the number one killer of adolescents and young adults. (Eba & Lim 2017:2). The availability of HIV treatment worldwide transformed HIV into a chronic illness even though there are still some adherence challenges, particularly in perinatally infected children as they enter adolescence (Galea, Wong, Muñoz, Valle, Leon, Perez, Kolevic & Franke 2018:3).

To achieve successful viral load suppression requires maximal and durable suppression of plasma *viremia*. Treatment compliance delays or prevents drug-resistance mutations while, in the meantime, preserving or improving CD4 T lymphocyte (CD4) cell numbers (Bossard, Schramm, Wanjala, Jain, Mucinya, Opollo, Wiesner, Cutsem, Poulet, Szumilin, Ellman & Maman 2021:886). This results in positive and substantial clinical benefits, which are important treatment goals. HIV suppression with ART may also decrease inflammation and immune activation, which is perceived as a contributory factor to higher rates of cardiovascular and other end-organ damage, which have been widely reported in HIV-infected cohorts (UNAIDS 2018b:2).

A study in Uganda aimed to identify the factors associated with viral load suppression among HIV-positive adolescents (aged 10-19) on ART, established that most adolescents who have detectable viral load and with proper adherence to HIV treatment initially had their first viral load unsuppressed (Natukunda et al 2019:8). The study found participants who experienced virological failure with a history of treatment interruption due to religious beliefs as they reported missing their treatment doses when fasting, after being baptised or after receiving healing prayers (Natukunda et al 2019:8).

Most adolescents acquire HIV infection through sexual activity, although there are still adolescents who acquired HIV in utero during their mother’s pregnancy or during breastfeeding. In the US, about 15 cities reported a high unsuppressed viral load amongst adolescents living with HIV (UNAIDS 2018b:6). The average VL for adolescents was 94398 copies/ml, and 30% of the sample populations were not in care. The result of resistance testing reveals primary genotypic mutations at 18% (UNAIDS 2018b:6).

The ARV cohort treatment trial on ARV naïve adolescents with behavioural problems had substantial multiclass resistance, which explained the transmission of resistant virus (Foster, Ayers & Fidler 2020:1). Adolescents who acquire HIV infection at this stage are at risk of acquiring a resistance virus as they are likely to have older sexual partners (UNAIDS 2018b:7).

2.5 BARRIERS TO HIV PREVENTION AMONG ADOLESCENTS AND YOUNG ADULTS

HIV prevention remains a highly effective approach to HIV control. The WHO (2022:1) recommends the use of combination prevention approaches that are targeted and specific population focused while reflecting the epidemiology of the setting. Despite all the approaches in place, the existence of country rigid legislative and normative environments remains one of the major obstacles to accessing services for marginalised populations in the Eastern and Southern African Region (Govender, Masebo, Nyamaruze, Cowden, Schunter & Bains 2018:67).

2.5.1 Sexual education limitations

Globally, an estimated 4 million of the 35 million people living with HIV are between 15 and 24 years old (Pharr, Enejoh, Mavegam, Olutola, Karick & Ezeanolue 2017:3). Nigeria has the second largest burden of HIV in the world with an estimated 3.2 million living with HIV (Pharr et al 2017:3). Pharr et al (2017:3) evaluated HIV knowledge, identified deficiencies in knowledge, and examined the relationship between HIV knowledge and risky sexual behaviour (RSB) of 361 participants from nine high schools in Jos Plateau state. The study found that adolescents with higher HIV knowledge had low RSB which indicated the importance of including interventions to increase HIV knowledge.

In 2015, UNAIDS and the African Union (AU) included age-appropriate CSE as one of five key recommendations for improving the HIV response and many countries in Asia and the Pacific, Europe and West Africa revised their policies and approaches to improve CSE. However, population-based surveys between 2011 and 2016 indicated that few young women and men had a comprehensive knowledge of HIV (UNAIDS 2019:12).

In South Africa, several behaviours are considered key drivers of HIV epidemic, including sexual debut, age-disparate relationships, multiple sexual partners, low or inconsistent condom use, awareness status and HIV risk perception (Simbayi et al 2019:139).

2.5.2 Sexual debut

Early sexual debut refers to having sexual relations (intercourse) before 15 years of age. In 2022, Appollis, Jonas, Beauclair, Lombard, Duby, Cheyip, Maruping, Dietrich and Mathews (2022:242) compared first sex experiences and wellbeing of adolescent girls and young women who had an early sexual debut with those who had a later sexual debut. The study found that early sexual debut was associated with coercion at first sex and a lower average well-being score compared with a later debut (Appollis et al 2022:253).

In Nigeria, Yaya and Bishwajit (2018:171) found that early sexual debut and multiple sexual partnerships increased risky sexual behaviours and the risk of HIV acquisition.

2.5.3 Age-disparate relationships

Integrational relationships especially for adolescent girls in many setups predispose them to HIV infections. In rural South Africa, transactional sex was found to be the main cause of HIV transmission among young women and older men influenced by socioeconomic, behavioural and cultural factors (Mampane 2018:4).

Age desperate relationship is associated with HIV risk infection as it becomes difficult for adolescents girls and young women to negotiate safer sex. The study conducted in sub-Saharan Africa attest that age desperate relationships is associated with unsafe sex resulting in increased HIV incidence among adolescent girls and young women. The study further explains the concern regarding inaccurate information among AYAs on sexual reproductive health, limited access to education, early marriage and biological makeup of the females' genitalia pre-disposed AYAs to HIV infections (Bajunirwe, Semakula & Izudi 2020:1546).

2.5.4 Parental guidance on sexual relationships

In Nigeria, a study found poor parental oversight, guidance and approval of romantic partners at an early age increased adolescents' sexually risky behaviour which exacerbated the risk for HIV acquisition (Folayan, Sam-Agudu & Harrison 2022:1198). Communication remains a hindrance to HIV prevention as most adolescents and young people report finding it difficult to express their feelings regarding HIV and sex, leading to ineffective disclosure (Ndlazi & Masango 2022:1377).

HIV is a chronic illness and adolescents living with HIV need the support of the whole family to self-manage (i.e., handle, direct and control) their chronic illness. In 2019, Adams and Crowley explored the self-management needs of adolescents living with HIV in two PHC clinics in the Nelson Mandela Bay area of the Eastern Cape. The study found that the participants had limited knowledge and understanding about HIV and sexual reproductive health (SRH); HIV services were not adolescent friendly, with long queues and no dedicated services for adolescents (Adams & Crowley 2021:2756).

2.5.5 Health care system barriers

HIV/AIDS is one of the leading causes of death among adolescents aged between 20 to 19 years in sub-Saharan Africa with 40% of new HIV infections globally from the same age group (UNAIDS 2018c). Poor access to HIV services among adolescents contributes to HIV exposure. The prevalence of undiagnosed HIV is considerably higher in adolescents than in adults (Chikwari, Dringus & Ferrand 2018:257). There are substantial individual, health system and legal barriers to HIV testing and counselling (HTC) among adolescents, and stigma by providers and communities remains an important obstacle (Chikwari et al 2018:257).

Poor access to HIV services among adolescents and young adults and age restriction laws on HIV testing and treatment contributed to HIV exposure (UNAIDS 2017). In 2016, over 50% of countries required parent or legal guardian consent for adolescents to access sexual and reproductive health (SRH) services and 71% of countries required parental consent for adolescents to access HIV testing (UNAIDS 2017). Progress has been made in recent years in developing strategies that address some of the barriers and increase uptake of HTC, including targeted approaches focused on provision of HTC among those at higher risk of being infected (Chikwari et al 2018:262). Community-based HIV-testing approaches including HIV self-testing and incentives have been found to increase uptake of HTC (Chikwari et al 2018:262). In implementing HTC strategies, consideration must be given to scalability and cost-effectiveness. HTC approaches must be coupled with linkage to appropriate care and prevention services (Chikwari et al 2018:264).

2.6 BARRIERS TO HIV TREATMENT COMPLIANCE AND ADHERENCE AMONG ADOLESCENTS AND YOUNG ADULTS

Despite global availability of ART, adolescents and young people still face various challenges related to HIV treatment compliance and adherence. Treatment compliance and adherence is the centre of HIV treatment and management (WHO 2013). The initiation of treatment needs to be followed by rigorous, patient cantered and holistic counselling and support. Supporting adherence to treatment requires a reasonable amount of health care providers and cadres that are trained to deliver such services (WHO 2013).

2.6.1 Health care system barriers

Health care system for adolescents refers to access to treatment, availability of support services and provision of adolescent- and youth-friendly services (National Adolescents and Youth Health Policy 2017:1). Despite all measures taken to address adherence to ART issues to combat HIV viral replication, maintain health, and reduce onward viral transmission, ART adherence among AYA remains a global challenge (Azia, Mukumbang & Van Wyk 2016:1). In a study done by Galea et al 2018:14) in Peru, identifying barriers to ART among adolescents living with HIV affirms the history of declining health due to suboptimal ART compliance, inadequate information to ART side effects from antiretroviral drugs, ART misinformation and lifestyle-related issues among AYAs on ART.

In a study in Vredenburg Western Cape, South Africa, Azia et al (2016:1) examined the challenges to ART adherence with 18 non-adherent participants. The participants reported stigma, disclosure, unemployment, lack of transport, insufficient feeding, disability grants, inadequate follow-ups and lack of patient confidentiality as major barriers. Azia et al (2016:8) recommended that interventions to address poverty, stigma, discrimination and disclosure should be integrated with group-based ART adherence models in Vredenburg and further investigation into the extent to which these factors impede adherence in the community.

In their study with adolescents aged 10-19 years at a primary health care (PHC) clinic in a low socioeconomic setting in Cape Town, South Africa (Van Wyk & Davids 2019:3) found school commitments, strained teacher-learner relationships, negative household dynamics, and ill treatment by non-biological caregivers were major barriers to ART adherence. In addition, poor service delivery, missing or misplaced files, long waiting times, fear of unintended disclosure, stigma, discrimination and treatment fatigue influenced adherence (Van Wyk & Davids 2019:4).

Adolescents experience disproportionately high rates of poor ART outcomes compared to adults despite prolonged use of ART in Southern African treatment programmes, which presents a significant challenge to national efforts to meet the UNAIDS 90-90-90 targets (Maskew, Fox, Evans, Govindasamy, Jamieson, Malete, Mongwenyana & Technau 2016:5). In a cohort study among adolescents aged 12-20 years accessing ART at two public health centres in Johannesburg, South Africa, between September and December 2013, Maskew et al (2016:2) identified factors associated with poor attendance at clinic visits. The study explored participants' demographic characteristics, socio-economic features of participants' households, caregiver issues and problems with service delivery at the treatment facility. The study found that older participants (aged 18-20) were more likely to miss clinic appointments, than younger participants (aged 12-14) participants who had difficulty in taking medication and who were more likely to miss a visit. Long travelling distance to the clinic; possibility that friends or members of the school would notice their attendance at the clinic; having an elderly caregiver; high transport costs, and long waiting queues were part of the identified barriers. Maskew et al (2016:13) concluded that awareness of treatment fatigue, challenges to taking ART, and caregiver difficulties are important when considering interventions to improve treatment outcomes among adolescents.

2.6.2 HIV status disclosure

Long-term success of HIV antiretroviral treatment requires near-perfect adherence, maintained throughout the lifetime. In 2016, Inzaule, Hamers, Kityo, De Wit and Roura (2016:10-12) assessed long-term antiretroviral treatment adherence in HIV-infected adolescents and adults in three regional treatment centres in Uganda. The study found delays in disclosure of HIV status by caretakers, stigma (mainly in boarding schools), and diminishing or lack of clinical support. Both adolescents and young adults had challenges with disclosure in close or intimate relationships, treatment-related factors, including side effects and supply of single tablets in place of fixed-dose combined drugs, and missed opportunities for counselling due to shortage of staff.

2.6.3 Personal HIV treatment experience

HIV treatment experiences differ from person to person and their background. HIV management and ART adherence is a major challenge for adolescents and young adults in South Africa where the paediatric HIV burden is marked (Hornschuh, Dietrich, Tshabalala & Laher 2017:5). In their study in Soweto, South Africa, Hornschuh et al (2017:5) found that the participants had a need for correct knowledge about how to be adherent, benefits, and non-adherence consequences, experienced social, personal, and medication-related barriers to adherence, and lacked reminder, concealment, and motivational strategies to optimise adherence. The study recommended that interventions to improve adolescent and young adult adherence should focus on practical strategies, including status disclosure and medication concealment.

2.6.4 Socio-economic status

Socio-economic status has a significant impact on treatment compliance. Understanding the circumstances of adolescents living with HIV is critical in designing adolescent-friendly services. A study in Phnom Penh, described the access, utilisation and ongoing social support needs of adolescents living with HIV aged 15-17 in Cambodia (Toth, Mburu, Tuot, Khol, Ngin, Chhoun & Yi 2018:8). The study found that multi-sectoral interventions to support school attendance, adolescent-friendly clinic scheduling, mitigation of HIV stigma, and strengthening of peer-to-peer counselling were required to improve social protection and treatment adherence (Toth et al 2018:10).

2.7 THEORETICAL FRAMEWORK

A framework is described as the “overall foundation of the research abstract, logical structure of meaning” (Polit & Beck 2017:115). A framework also referred to as theoretical framework. Theory development depends on facts, observable evidence the conceptual or and the originator’s ingenuity in pulling facts together and making sense theoretical framework of them (LoBiondo-Wood & Haber 2017:57). A theory comprises of integrated concepts and statements to define, explain, predict or control the phenomenon under discussion (Gray et al 2017:117).

Nursing theory refers to the body of knowledge that is used to support nursing practice. Theory is the creative and systematic way of looking at the world or an aspect of it to describe, explain, predict or control it. In nursing studies, the health belief model has gained popularity as a framework, with an increased emphasis on patient compliance and preventative healthcare procedures (Polit & Beck 2017:191).

In order to explore how perceptions of threat from a health concern (non-adherence to HIV treatment) and the value of interventions to reduce that threat affect health-seeking behaviour, the researcher employed the HBM as a theoretical framework for this study.

2.7.1 Overview of the Health Belief Model (HBM)

The HBM was initially developed in the 1950s by a group of social psychologists in the United States Public Health Service to explain the widespread failure of people to participate in programmes to prevent or detect disease (Abraham & Sheeran 2015:99; Conner & Norman 2015:30; Tarkang & Zotor 2015:2). HBM relies on people's views of their susceptibility to certain diseases and conditions, as well as how such perceptions affect their motivation to take action. The prospect of a sickness is what motivates people to act in a healthy way. The prospect of a disease is what drives people to act in a healthy way. According to the HBM, people's attitudes on health issues, their perceptions of the advantages and disadvantages of interventions, and their level of self-efficacy all contribute to their commitment − or lack thereof − to engaging in behaviours that promote good health. There must also be a motivation or indication to act in order to initiate health-promoting behaviours (Abraham & Sheeran 2015:100).

The HBM has six fundamental constructs: perceived susceptibility; perceived seriousness; perceived benefits; perceived barriers; cues to action, and self-efficacy. Perceived susceptibility refers to subjective assessment of risk of developing a health problem (Daragmeh, Sági & Zéman 2021:132). The HBM proposes that individuals who perceive a given health problem as serious are more likely to engage in behaviours to prevent the health problem from occurring (or reduce its severity). Perceived severity refers to the assessment of the severity of a health problem and its potential consequences (Adefolalu 2018:3). Health behaviours are influenced by an individual's beliefs or assessments of the seriousness of a health issue, an illness, or the consequences of not treating it. In this study, the individuals had to assess and decide whether or not to take antiretroviral treatment to reduce the severity of HIV.

An individual's perception of the value or efficacy of a practise that promotes health in lowering the risk of disease is referred to as the perceived benefit (LaMorte 2022). Perceived advantages of interventions have an impact on behaviour connected to health. The participants in this study were required to evaluate the gravity of HIV infection and its potential repercussions.

Perceived barriers or impediments or obstacles are the person's perceptions of the challenges they experience when trying to change their behaviour. (Adefolalu 2018:4). Individuals must think that the advantages outweigh the costs when determining whether a barrier is seen to exist. Therefore, the combination of vulnerability and problem severity gives people the motivation to act, and the sense of benefit gives people a better approach to take action. (Adefolalu 2018:4).

HBM believes that timely engagement with health-promoting practises requires the presence of a cue or stimulus (Mukumbang, Van Belle, Marchal & Van Wyk 2017:10). Other aspects or cues to take action, such as perceived vulnerability and benefit, influence one's willingness to act (Abraham & Sheeran 2015; Tarkang & Zotor 2015).

Figure 2.1 illustrates the way the HBM was applied in this study

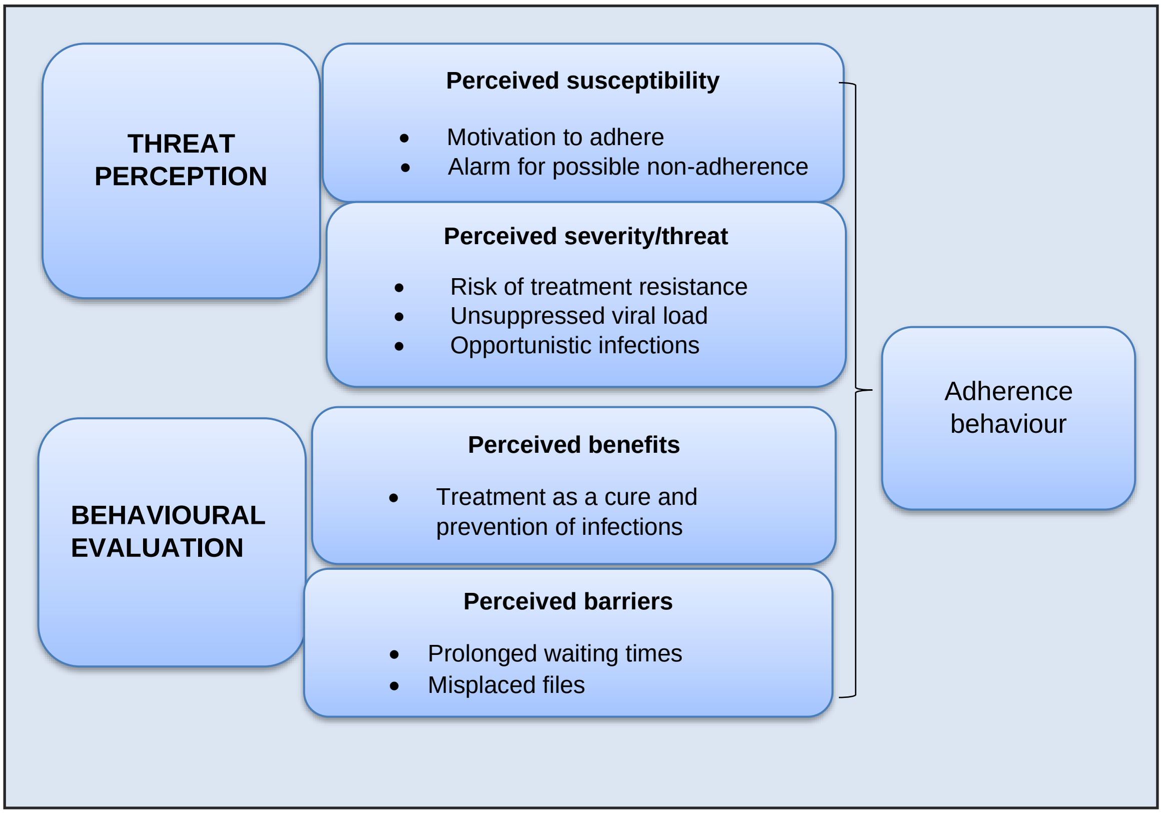

Figure 2.1 Application of the Health Belief Model

The main focus of the health belief model is on the concepts of health and health behaviour (Abraham & Sheeran 2015:99). The four basic HBM elements—perceived vulnerability, perceived severity/threat, perceived benefits, and perceived barriers—were applied in this study. Two essential beliefs—perceived vulnerability or susceptibility and anticipated illness severity—were used to differentiate the threat perception. The second component was behavioural review that also included two distinct sets of beliefs: the advantages or efficiency of health behaviour and the expenses or obstacles to putting the activity into practise (Abraham & Sheeran 2015:99).

- **Perceived vulnerability**

Perceived vulnerability referred to an individual's (participants') recognition that HIV was personally relevant, including diagnosis, and a reason to be concerned about it and possible harm.

A study grounded in research theories on ART adherence, discovered that perceived susceptibility in relation to ART poor adherence linked to individuals’ assessment of personal risk in developing a problem towards ART medication (Mukumbang et al 2017:5). Assessment findings could be a critical measure of self-perceived risk and serve as motivation to treatment adherence, while low perceived risk might be an alarm for possible non-adherence and assist in developing specific and focused interventions.

- **Perceived severity/threat**

Perceived threat was equated with the individuals’ (the participants’) realisation that they might be personally vulnerable to HIV and their opinion and perception of the likelihood of their behaviour leading to a negative outcome. This means that even if they recognised susceptibility, action will not occur until they perceived the severity to be high enough to have serious implications. This has been identified by the outcomes of the themes, categories and sub-categories.

Individuals are more readily proactive towards the prevention of serious diseases than of diseases perceived as less serious, resulting in perceived threat. Perceived threats of being infected with HIV/AIDS are opportunistic infections, pain, disability, lifelong therapy on ARVs and eventually death (Adefolalu 2018:4).

The researcher was concerned over patients’ defaulting HIV treatment after realising they were out of danger with reduced or undetectable viral load and physically well. This poses a risk of resistance to treatment in the case of prolonged or repeated personal treatment cessation or abrupt stop.

- **Perceived benefit**

The term "perceived benefits" refers to how people assess the potential benefits against the expense of changing their behaviour (Adefolalu 2018:4).The study found that perceived action benefits affected health-related activity. Cases with immediate effects, such as the use of antibiotics in treating HIV/AIDS-related opportunistic disease, could create a belief that choosing to adhere to the medication has instant rewards (Adefolalu 2018:4). However, long-term treatment with ART does not usually provide instant benefits, thus resulting in patients being demotivated to continue ART, this was evidenced by the patients’ verbatim quotes in the themes, categories and sub-categories.

Perceived barriers

Perceived barriers include issues relating to accessibility of treatment (Akinoye, Amosu & Amodemaja 2020:2014). In the results of this study, barriers have been found to include a lack of transportation to the nearest health clinic, poor support from the family, long waiting periods at the clinic, and conflicting work/school schedules.

2.8 CONCLUSION

This chapter covered the literature review that was done for the study, covering topics like the magnitude of HIV/AIDS among adolescents and young adults, global incidence, incidence of adolescent and young adult HIV, stages of the susceptibility to contracting HIV, viral suppression, and obstacles to HIV prevention among AYAs, and factors that affect AYAs' compliance to HIV treatment.

The study's methodology and research strategy are covered in Chapter 3.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The literature review that was done for the study was addressed in Chapter 2. The literature review covered the magnitude of HIV/AIDS; global incidence of HIV/AIDS among adolescents and young adults (AYAs); AYAs and HIV in sub-Saharan Africa; stages of vulnerability to HIV infection; viral suppression; barriers to HIV prevention among AYAs, and barriers to HIV treatment compliance among AYAs.

The research design and technique are covered in this chapter, together with the demographic information, sampling procedures, sample size, theoretical model, paradigm, data collection and analysis.

3.2 PURPOSE OF THE STUDY

The objective of the study should identify its main focus, its purpose, and how it will be carried out (Gray et al 2017:83).

The purpose of the study was to explore and describe the challenges associated with HIV treatment compliance among AYAs living with HIV in Emfuleni, sub-district municipality and to make recommendations to overcome the challenges related to non-compliance with the treatment, based on the findings.

The study's goals, in order to fulfil its mission, were:

- Describe and explore Emfuleni adolescents' and young adults' views on challenges to compliance with ART.
- Develop recommendations to overcome the challenges to non-compliance with ART.

3.3 PARADIGM

A paradigm is a worldview or also known as “a perspective on phenomena of nature that incorporates a number of philosophical presumptions and directs one's method of inquiry” (Polit & Beck 2017:79). According to Polit and Beck (2017:79), paradigms serve as glasses that let the researcher narrow down on a particular phenomenon. Principles that are assumed to be true based on logic or reason but have not been demonstrated are known as assumptions (Polit & Beck 2017:80). A research paradigm refers to a shared worldview which represents beliefs and agreements on how the problem is understood and solved (Patel 2015). The three main paradigms are positivism, constructivism, and pragmatism (Patel 2015).

The study's framework was constructivism, according to the researcher. A naturalistic paradigm is another name for a constructivist paradigm. According to Polit and Beck (2017:80), constructivism is an approach that holds that reality may be interpreted in many different ways and that the purpose of study is to comprehend how people construct reality in their setting. In order to explore and gather information about participant AYAs' perceptions and experiences of difficulties in compliance with ART, the researcher determined that constructivism was appropriate for this study (Kivunja & Kuyini 2017:33).

The researcher followed the following constructivism tenets:

- Qualitative methods promoted the naturalism of the study.
- Understanding of human experience.
- The data was gathered and then thematically analysed using qualitative approaches.
- Field-rich data were gathered using semi-structured interviews to shed light on the phenomenon's various aspects and experiences.
- Thematic analysis of data was done.

3.4 RESEARCH DESIGN

A research design is the general strategy for responding to a research question and includes guidelines for enhancing the study's objectivity (Polit & Beck 2017:739). Brink et al (2012:92) define a research design as “a series of logical steps the researcher takes to answer the research question”. According to Grove and Grey (2017:214), a research design is a strategy for carrying out a study that enables control over variables that could compromise the validity of the findings.

The participant's issues with HIV treatment compliance were explored and described using a qualitative, exploratory, and descriptive study approach. The purpose of qualitative research is to comprehend people's experiences and demands from the entirety of their lifestyles, taking into account the dynamic interaction of different lifestyles, hence the researcher thought this approach was appropriate (Polit & Beck 2017:739). The research strategy enabled the researcher to explore participant views and comprehension of HIV treatment non-adherence. The researcher was able to relate the individuals' psychosocial, physiological, and economic reality using emic probing.

3.4.1 Qualitative

Qualitative research is the collection of rich narrative data utilising a flexible research design to examine phenomena, usually in-depth and holistically (Polit & Beck 2017:739). Qualitative studies look at the participants' perceptions and practises in the field as well as their knowledge and practises. The current study looked at the challenges associated with compliance to HIV treatment among HIV positive adolescents as experienced and described.

3.4.2 Exploratory

Exploratory studies concentrate on examining a phenomenon or circumstance (Akhtar 2016:73). Exploratory research examines the phenomenon in its entirety, the way it manifests itself, and individuals’ feelings, thinking and perception of what was observed and experienced (Polit & Beck 2017:739). Using the HBM, the approach enabled the researcher to engage and probe regarding the AYAs’ thinking, experiences and individual views of HIV treatment.

3.4.3 Descriptive

Descriptive studies aim to accurately observe, describe, and reproduce the characteristics of certain situations and phenomena as they occur in nature (Polit & Beck

2017:739). This would enable the researcher to describe the factors contributing to participants’ ART non-compliance.

3.4.4 Contextual

In this study, the researcher examined the challenges pertaining to HIV treatment compliance of a population of AYAs in a specified district, Sedibeng in Gauteng province.

3.5 RESEARCH METHODOLOGY

The “steps, procedures, and strategies for investigating the problem under study and analysing the data collected” are referred to as research methodology by Polit and Beck (2017:741). The approaches researchers employ to structure a study as well as to gather and analyse data pertinent to the research issue are known as research methodologies (Polit & Beck 2017:741). A plan of action or strategy called a methodology connects techniques to outcomes (Babbie & Mouton 2012:647). The setting, population, sampling, sample, and data gathering and analysis make up the research process.

3.5.1 Setting

The physical location or place where a study is conducted and where data collection takes place" is referred to as a setting (Polit & Beck 2017:743). The study was conducted in Gauteng Province, Sedibeng district focused on four health facilities that provide an ART programme in the Emfuleni sub-district municipality in Sedibeng District. The researcher used the National Health Research Database (NHRD) to submit a research proposal (reference: GP_202009_047) (Annexure C). The approval letter of the Sedibeng District Health was then distributed to the relevant facilities where the study was going to be conducted (Annexure D). After receiving National Health Research Database (NHRD) approval for the research proposal (Annexure C), the application was submitted to the Sedibeng District Health Services for local final approval in terms of district research procedures.

Afterwards, the Sedibeng District Health Services Research Committee granted their approval to the research proposal on 15 March 2021 (Annexure D). Although the researcher requested the participation of five facilities, only four were approved since there was a study that was being conducted in the fifth facility. The district approvals were obtained for easy tracking of all research projects within the district. This enabled operational managers to review whether the study focused on the same population as existing studies in the healthcare facility.

3.5.2 Population

A research population is any component, person, or thing that shares some of the qualities the researcher is interested in (Polit & Beck 2017:745). Between the target population and the achievable population, Polit and Beck (2017:365) draw a distinction. The group of cases about which the researcher wants to draw generalisations constitutes the target population (Polit & Beck 2017:745; Guest & Namey 2015:515). The subset of the entire population to whom the researcher has access is referred to as the accessible population (Polit & Beck 2017:745). In this study, the population was AYAs living with HIV in Emfuleni, sub-district municipality.

3.5.3 Sampling and sample size

Sampling is the method of choosing cases that are representative of the full population with the aim of drawing conclusions about the population. Sample is a portion of a population that is chosen to be representative of the population and satisfies certain inclusion criteria (Polit & Beck 2017:745).

The researcher selected participants using a non-random, purposive sample to gain a deeper understanding of the problem under study (Grinnell & Unrau 2018:380). In qualitative research, the goal is to measure the characteristics and relationships of the population, which requires selecting a representative sample to ensure that the measurements can be generalised to that population and are an accurate reflection. In purposive sampling, participants are selected from the targeted population who are both relevant to the study and easily reachable by the researcher due to their understanding of the subject matte. (Polit & Beck 2017:745). In order to be eligible for the study, the participants needed to be:

- In the age range of 18 to 24.
- Living in Gauteng Sedibeng district.

- Living with HIV, not compliant with ARVs with two consecutives unsuppressed VL on 1st line and 2nd line of ART treatment at during the period of the research study.
- Getting HIV treatment, assistance, and encouragement in all participating facilities.
- Willing and able to participate fully and give detailed responses.

The main principle in qualitative research is to continue gathering data until it reaches a point of data saturation. Data saturation is the stage in data collection where the gathered information becomes unnecessary or repetitive. When the study no longer yields any new information, it is said to have reached data saturation (Moser & Korstjens 2018:11). The initial sample size for this study was 25 participants. However, data saturation was reached after interviewing a total of 20 participants.

3.5.4 Data collection

Data collection refers to the accurate and organised collection of information that is pertinent to the research goals or objectives of the study (Polit & Beck 2017:365). Semi-structured interviews were conducted by the researcher to collect data.

Two research assistants were appointed by the researcher to help her collect data. They were selected for their positions because they a minimum of one year of experience in conducting qualitative data collection and data capturing. In addition, they possessed the skills to speak and interpret the local languages of Sotho and Zulu, and both had successfully completed their matriculation. Moreover, the researcher gave specialised training to the assistants to guarantee a consistent understanding and the accurate order of questions, which encompassed the use of probing methods.

Data collection took place at the facilities as follows:

Table 3.1 Data collection at facilities

Facility	Date	Facility face to face interview	Telephonic interview
Community Health Centre (CHC) 1	March – May 2021	4	1
CHC 2	March – June 2021	3	2
CHC 3	April – June 2021	5	0
CHC 4	June – August 2021	4	1

3.5.4.1 Data-collection instrument

The researcher created a partially structured set of questions for collecting data, which was reviewed and approved by the supervisor. This guide enabled the participants to share their experiences and perspectives, while also allowing them to think deeply about their responses through discussions with the researcher.

The researcher created a partially-structured set of questions for data collection, which was reviewed and approved by the supervisor. This guide enabled the participants to share their experiences and perspectives, while also allowing them to think deeply about their responses through discussions with the researcher (Annexure F). The questions aimed to examine the participants' context of life-long HIV treatment. The interview guide was created in English, but the questions were interpreted and presented to the participants in their preferred local languages, Sotho and Zulu, to ensure that they comprehended and interpreted them in a similar way. The interview guide was composed of six guiding questions which were open to further probing depending on the responses (Annexure F):

1. Tell me about your HIV treatment history.
    a. When did you start receiving and taking the HIV treatment?
    b. Did you know or were told what was the treatment for?
    c. What was your health status at the time?
        i. Low CD4 count?
        ii. Hospitalised? etc
2. What were your expectations when taking Antiretroviral Treatment (ART)?
    a. Is there anything that happened that you were list expecting?

    b. Are there any changes in your treatment you wish or would like to see?
3. Have any thoughts altered with the pattern on how you take the ARV treatment?
    a. defaulting treatment (clinic visit)?
    b. not taking the treatment correctly (at home)?
4. Have you ever stopped or considered stopping taking ARV treatment?
    a. If yes, what were the challenges?
5. How has taking ARV treatment affected or improved your quality of life?
6. What are your experiences regarding HIV services offered in the Sedibeng district health clinic that you are attending?
    a. What do you think should have or be done differently, and how?
    b. How would the mentioned change improve your experience?

The questions were intended to provide a complete description of the challenges associated with HIV treatment compliance among the participants.

3.5.4.2 Data-collection method

The researcher arranged with health care facility operations managers to carry out the interviews in a private and safe room or space. The purpose was to maintain confidentiality and privacy and prevent interruptions. As part of Covid-19 prevention, the researcher negotiated access to a well-ventilated room with a hand washing basin, soap and running water for the interviews. In addition, the surfaces were cleaned and disinfected, and the participants and researcher sanitised their hands. The researcher or interviewer wore a mask and provided masks to the participants. Social distancing was observed during the interviews by maintaining a space of 1.5 m to 2 m between the researcher and the participant.

In order to prevent excluding potential participants who were unable to access or reach the interview venue, four participants were provided with a chance to take part telephonically. Telephonic interviews are described as the conversation between participants and the researcher in which the researcher poses the question, and the participants respond telephonically (Moser & Korstjens 2018:4). On receipt of the districts' ethics approval, the researcher approached the participating facilities to gain access to the folders and the relevant patient clinical stationery. The researcher retrieved the participants' contact details from their patient information folder with strict adherence to the Protection of Personal Information (POPI) Act. Consent was obtained from virtual participants through telephone conversations and recorded, while participants who were interviewed in person provided their consent in a written format as well. Before providing informed consent, they were also given information about the purpose of the study and were given the opportunity to ask questions. They were also given the contact information of the researcher should they have further enquiries. In order to protect the identity of the participants, unique numbers were allocated to them which were then utilised on the consent form as well. To ensure anonymity and confidentiality, the researcher safeguarded the audio recorder and notes by placing them in a locker at the researcher's residence. Additionally, the consent forms were also securely stored, but separately from the audio recordings and notes.

The researcher conducted semi-structured interviews, using the interview schedule. The participants were asked to:

- Describe their expectations from taking the antiretroviral treatment, any challenges they encountered and if those were reported.
- Share their personal encounters concerning the quality of service they received during their HIV treatment, care, and support at the facilities.
- State what they thought should be done differently and how they saw that changing their follow-up visit experience and eventual adherence to treatment.

To ensure that all the data was captured, the interviews were recorded in audio format with the participants' consent, and the filed notes were taken for validation during data analysis. The following measures were implemented to prevent data loss and was easy to link to the recordings:

- Each completed interview schedule with notes was labelled with a special number which was similar to the one allocated to the recording.
- All information gathered including audio recordings and field notes were stored safely in the locked area accessible only to the researcher.

The researcher securely stored all the gathered information, including the audio recordings and field notes, in a restricted area that only the researcher could access.

3.5.4.3 Data management

In qualitative research, data management involves the transformation of the collected data into a more concise and easily accessible form that retains its significance. (Gray et al 2017:76). Safekeeping of the audio recordings was maintained as they were securely locked to ensure privacy and confidentiality. All collected data was labelled according to the facility where it was collected for easy identification and future follow-up, if required. Transcribed notes and recordings were kept separately from participants' details and were labelled using the participants' assigned numbers for coding and analysis. As an additional method of safekeeping, the transcribed notes were scanned and kept in electronic portable document format (pdf) files and the password was created to open the folder in the researcher's computer in order to limit access by other people who might have gotten the researcher's laptop with or without her permission.

3.5.5 Data analysis

Qualitative research uses inductive thinking, which involves thematic data grouping and analysis (Gray et al 2017:77). The process of analysing qualitative data allows the researcher to arrange, interpret and communicate information with the purpose of uncovering significance, acquiring insight, and generating factual knowledge (Polit & Beck 2017:749). The process of analysing qualitative data enables the researcher to arrange, comprehend, and effectively convey information with the purpose of uncovering significance, acquiring insight, and generating factual knowledge.

The researcher followed the approach of conducting thematic data analysis for analysing qualitative data. The researcher utilised thematic data analysis to identify participants' challenges and experiences. This method enables the researcher a flexibility to interpret data. The method, originally created by Virginia Braun and Victoria Clarke for psychology research, consists of six steps: becoming familiar with the data (familiarisation), coding, identifying themes, reviewing themes, defining and naming themes (themes definition), and writing up about them (Caulfield 2019:1).

Familiarisation: this denotes the initial stage of data analysis where the researcher gets thoroughly engages with the information for better understanding and verbatim transcribing of the audio recorded data (Caulfield 2019). For this analysis, the researcher engaged and familiarised herself with the data by reading through the information written down as field notes and carefully reviewing audio recordings while transcribing exactly as spoken (Annexure G).

Coding: is the second step in which the researcher identifies initial codes, or features of the data that seems to be intriguing and meaningful from the interviews (Caulfield 2019).

Identifying themes: this refers to the analysis and interpretation of the compiled codes. The relevant data extracts from the recorded data and notes were gathered by the researcher and combined based on the overacting themes (Caulfield 2019).

Reviewing themes: this refers to engaging on a deeper review of the extracted themes and determine whether the themes must be combined, separated or even discarded. This was done to ensure coherence and identifiable distinctions between themes (Caulfield 2019).

Themes definition: In this step, the researcher undertook the process of refining and clarifying the themes that were identified previously by organising them into different categories and subcategories within the dataset (Caulfield 2019).

Writing up: During the last phase of analysis, the researcher proceeded to convert the analysed data into interpretable categories and subcategories in accordance with the study goals and the literature that was reviewed (Caulfield 2019).

The researcher underwent thematic analysis of data before developing themes to identify participants’ challenges, views and experiences, then generated codes. The researcher followed a six-step process to analyse data thematically and divided the themes into categories and sub-categories to reduce the number of themes and develop topics.

3.6 TRUSTWORTHINESS / RIGOUR

Cope (2014) in LoBiondo-Wood and Haber (2017:152) views trustworthiness as a means to showcase the integrity and credibility of research process including data collection. To ensure trustworthiness, the researcher started by thoroughly reviewing the pertinent literature which was in line with the research topic and results in Chapter 4 were also compared to other already existing literature.

3.6.1 Credibility

In the process of conducting a study, all systems and procedures must be implemented and applied in a manner that instils trust in the participants regarding the study's finding from data and is interpreted (Brink et al 2012:172). To ensure credibility, the researcher applied the following strategies:

- Field notes and data from audio were compared with the interpreted data to correct any potential data errors and interpretations in order to seek additional information from participants.
- The researcher gathered information until reaching a point of data saturation. A grand total of 20 participants took part.
- Member checking was conducted for data verification with participants.

3.6.2 Transferability

The concept of transferability, as defined by Bobbie and Mouton (2012:277), pertains to the likelihood that the results of a study will hold the same significance when applied to a different setting and involve different participants (Bobbie & Mouton 2012:277). The researcher used purposive sampling in order to gather the most comprehensive information about the phenomenon. The data gathering processes and the time allocated for engagement with various groups within the chosen sample were extended to ensure that data saturation was achieved, meaning that no new themes or findings were emerging. The researcher gave a comprehensive account of the entire research procedure.

3.6.2.1 Selection bias

Purposive sampling was used by the researcher to choose eligible participants by considering both their availability and selection criteria.

3.7 ETHICAL CONSIDERATIONS

Participation in research should never place participants at a disadvantageous position or subject them to any risk. Protecting people taking part in any study requires more than just laws and regulations but also the application of ethical research principles (Grove & Gary 2017:134). The researcher ensured adherence to all the critical ethical principles in the study such as the participant's right to self-determination and full disclosure, fair treatment, and beneficence.

3.7.1 Scientific integrity of the research

The Higher Degrees Committee of the Department of Health Studies at the University of South Africa (HSHDC/996/2020) granted the researcher ethical clearance and approval to carry out the study (Annexure A). The Sedibeng District Health Services Ethical Committee approved the request for permission to carry out the study and gather the necessary data on March 15, 2021 (Annexures B and D).

3.7.2 Self-determination and full disclosure rights

Regard for human dignity is founded on the moral precept of regard for an individual and refers to the right to self-determination and full transparency. In this regard, people should be provided a space for autonomy during research processes (Grove & Gary 2017:134). The following was implemented:

Each participant received a pamphlet with.

- Participants were made aware of their right to opt out the study whenever they desired and that would not affect their treatment in the facility.
- The researcher gave each participant a pamphlet with information and a consent form which they were required to sign (Annexure E).
- Participants had an access to the researcher’s contacts information so that they could contact her at any time.
- As evidence of their voluntarily taking part in the study, participants signed the informed consent form.

3.7.3 Beneficence

Beneficence simply means that the researchers need to minimise harm and to maximise the study benefits to participants (Joubert & Ehrlich 2007:32). Facility management offered secure private room or area where the interviews were held. All participants were asked to report discomfort and ask that the interview be stopped. The researcher was the only person with access to the locker where the data was kept.

3.7.4 Risk avoidance

Research subjects have a full right to anonymity and assurance that their information will be kept confidential (Grove & Gary 2017:138). The participant’s complete information was included on the consent forms, which were kept apart from the notes’ transcriptions to maintain participants’ anonymity. In addition, recorded data was uploaded to a personal computer one drive encrypted with a password only known by the researcher.

3.8 CONCLUSION

The research technique and design were covered in this chapter. According to the researcher described that an exploratory descriptive qualitative research was followed. Purposive sampling of 20 participants was done. Participants were interviewed using a semi-structured in-depth interview guide (Annexure F). Audio recording of interviews was done, field notes and verbatim transcription of transcripts followed in order to get the data ready for analysis. Thematic technique or method of analysing data was followed. Chapter 4 presents an analysis of the data and interpretation of results.

CHAPTER 4

DATA ANALYSIS, PRESENTATION AND INTERPRETATION OF RESEARCH FINDINGS

4.1 INTRODUCTION

The study's methodology and research design were covered in detail in chapter 3. Analysis, interpretation and conclusions of the data are covered in this chapter. The results are addressed in relation to the literature review which was used for data verification.

4.2 MANAGEMENT OF DATA AND ANALYSIS

Concurrent data gathering and analysis took place. Semi-structured interviews which were audio-recorded were done by the researcher. A semi-structured interview guide containing questions derived from the HBM was used to collect data (Annexure F). Data analysis, according to Polit and Beck (2017:749) is the methodical synthesis and organisation of research. Analysing data requires classifying, organising, rearranging, summarising, and describing the data in comprehensible words (Brink et al 2012:170).

The themes, categories, and subcategories that surfaced during data analysis were made clear. 20 interviews were conducted by the researcher, then the study reached data saturation, where there were no longer new data generated.

In this study, the researcher's preferred approach was thematic data analysis as it enables the researcher an opportunity to identify participants' opinions, views and experiences towards HIV treatment. The researcher conducted a thematic analysis using the six steps of familiarisation, coding, identifying themes, reviewing themes, defining and naming themes (themes definition), and writing up.

4.3 PARTICIPANTS’ CHARACTERISTICS

The participants were recruited from four facilities in the Sedibeng district. Eleven of the participants were females and nine were males, and their ages ranged from 18 to 24. Of the participants, one was diagnosed through the PMTCT programme, 15 were tested by parents and caregivers while they were still young as they were vertically infected, and two underwent testing in order to learn their status or not being well in terms of viral load suppression. Of the participants, one disclosed a past of drug misuse, while the other disclosed having been the victim of sexual assault. According to the laboratory results, all individual viral load was > 1000 copies, and all of them were virally unsuppressed.

4.4 FINDINGS

Interviews were used to gather the data, and a questionnaire was used. (Annexure F). The interview guide consisted of six questions:

- 1: Participants’ HIV treatment history
- 2: HIV treatment expectations
- 3: Medication compliance behaviour
- 4: HIV treatment defaulting
- 5: Quality of life
- 6: Health care facility experience

The questions wished to obtain a complete description of challenges associated with HIV treatment compliance among the participant AYAs. The researcher identified themes that were related and divided them into categories. The findings are supported by participants’ statements. Table 4.1 lists the themes, categories and sub-categories.

Table 4.1 Themes, categories and sub-categories

Theme	Categories	Sub-categories
1 Lifelong treatment	1.1 Personal Expectations 1.2 Treatment access	• Treatment exhaustion • Vertical/maternal transmission • Lack of transport money to the facility • Closure of Central Chronic Medicines Dispensing and Distribution (CCMDD) site due to Covid-19
2 Treatment interruption	2.1 Skipped doses and took a break	• Disclosure issues • Angry at own parents
3 Quality of life	3.1 Treatment side effects 3.2 Frequent illnesses	• Sleeping in class • General malaise • Immuno-reconstitution inflammatory syndrome
4 ARV clinic services	4.1 Health care worker attitude 4.2 Long waiting hours	• Angry nurses • Exhausting waiting periods
5 Treatment counselling and support	5.1 Age difference 5.2 Availability of more HIV counsellors and nurses	• Difficulty in communicating some challenges with older nurses • Easy access to someone to talk to at the facility

The results are explored in terms of the themes, categories and sub-categories, supported by participants' comments. Numbers were employed to preserve the participants' identities, privacy and confidentiality.

4.4.1 Theme 1: Lifelong treatment

The success of HIV treatment highly depends on it taken as lifelong therapy that never cease which then results in virological suppression and immune reconstructions (Kim et al 2017:2). In this regard, AYAs living with HIV are expected to be fully aware of the expectations, including the advantages and disadvantages.

The categories under this theme were (1) expectations, and (2) treatment access.

4.4.1.1 Category 1.1: Personal expectations

Expectations refers to one's perceived benefits of a treatment programme or any interventions. This comes from health education provides, general information from the radio and other misconceptions (Adefolalu 2018:4). It is understandable why the study's participants' had other expectations regarding this treatment as they never expected to be taken for a long time. Participants in this study described their expectations and challenges they had for lifelong treatment. The participants expected that the HIV treatment would keep them healthy and prolong life until there was a cure available. This was an indication of wanting to remain on treatment with the hope that it will be stopped at some point of their live. Participants in this study described the obstacles and aspirations they had for lifelong therapy. One participant was quoted saying,

> "I am taking this treatment with an expectation that it will keep me healthy until there's permanent cure". (Participant 6, 20-year-old female)

There was also a clear purpose and the drive to get better and have an ordinary life. This was demonstrated by one participant saying,

> "I want to get better and live a normal life like other people of my age." (Participant 15, 18-year-old female)

For some participants, being on treatment also brought along some unexpected challenges, which at some point might have resulted to poor compliance. Some participants said,

> "It is very sad to learn that I will have to be on treatment for my entire life. I had hoped that at some point I will be told to stop treatment and be healed. The nurses keep introducing different kinds of treatment which is really confusing at times." (Participant 5, 19-year-old male)

For some participants, personal expectations and perceptions of treatment led to treatment exhaustion as they couldn't wait for the day they are told to stop it or have something to be taken as a once off intervention. The unmet personal expectations led some participants to view their medication as some form of punishment, and to ease the burden, some even took a few days break. This was noted as some participants saying:

> "I wish for a permanent cure for HIV rather than this life sentence I am living. Being on this medication is really draining to a point where I even forget treatment collection dates and appointments." (Participant 14, 18-year-old female)

> “I wouldn’t say I stopped taking my treatment but would just hide it, skip a few days and sometimes weeks. I was tired of these pills. They are too big, taste awful and have to be taken every day without a break”. (Participant 8, 20-year-old female)

4.4.1.2 Category 1.2: Treatment access

According to the WHO (2013), treatment access refers to a smooth continuum of care starting with diagnosis, initiation of treatment and continued care with proper monitoring. In this category participants relates how access to treatment was denied. According to participants,

> “I was on CCMDD programme used to get my treatment at the pharmacy which was closed on two occasions due to Covid-19 pandemic as staff members were on isolation, and I stayed without treatment for a while.”

HIV treatment could be very confusing for those that vertically contracted the virus as they transition to adolescence and eventually to adulthood. This is merely because they start questioning their circumstances. One participant said,

> “I was told that I contracted HIV during my mother’s pregnancy hence I was initiated on treatment while still a child. But growing up, I learnt that HIV is sexually transmitted and at the time I did not even have a boyfriend. I asked few of my peers about this kind of HIV and none of them knew about it and were on such treatment. It is from there I made a decision to stop taking it”. (19-year-old female)

The findings reflects the findings from the Ugandan study where adolescent struggled with adjusting while transitioning to the adult service point as they did not know what to expect and felt they were still too young to transition (Mbalinda; Bakeera-Kitaka; Lusota. Namusoke; Magongo; Musoke & Kaye 2020). In contrary to this , another study in Cape Town reported smooth transition of adolescent patients with support and counselling (Mark; Amstrong; Andrade; Penazzato; Hutane; Taing, Runciman & Ferguson 2017)

4.4.2 Theme 2: Treatment interruption

The HIV.gov (2021:164) describes treatment interruption as a planned break of taking treatment or drug holiday. Treatment interruption and taking breaks is a common behaviour in AYAs when dealing with the pressure of taking daily medication.

One category emerged which was skipped doses to take a break.

4.4.2.1 Category 2.1: Skipped doses to take a break.

Poor compliance and adherence such as frequent skipping of HIV treatment doses could have detrimental consequences, including less effective viral suppression, poor health outcomes and possible risk of developing treatment resistance (Schaecher 2013:s231). Participants reported to have stopped, taken a break, or skipped a number of their treatment doses for different reasons. Some indicated HIV-related stigma, confusion over form of transmission, and changed family circumstances. One participant was quoted saying,

> "I have in the past stopped taking my treatment a few times and this was because of my family attitude towards me after I had disclosed. I received no support whatsoever from my family. I realised that I had no reason to live looking at the way I was being treated." (Participant 17, 23-year-old female)

Anger and internalised stigma led to some if the participants decide to stop taking their treatment. A participant went on saying,

> "I once stopped taking my treatment as I was angry at my parents when I learned from TV that the pills I am drinking are for HIV and that was when my grandmother told me that I was born with HIV." (Participant 2, 19-year-old female)

Taking the daily was also found to be exhausting, leading to some of the clients wishing for long term injectable, as one female participant stated,

> "It would be great if I can get treatment that can be taken occasionally like injectable contraceptive to avoid having us going to the clinic for collection all the time." (Participant 19, 21-year-old female)

Social dynamics were also found to contribute to treatment interruptions resulting in some patients unintentionally stopping taking their medication. This was noted from a participant saying,

> “At some point my dad decided that we are moving back home in Zimbabwe since he had no job at the time. This was an abrupt decision and he forgot to collect a transfer letter for me which was then a challenge to get treatment until we arranged for someone to collect and send it. I was forced to stay for a few months without it.” (Participant 16, 20-year-old male)

The results of this study are in concurrence with those from the research done in Uganda where HIV-positive AYAs confirmed the exhaustion that comes along with a long-term commitment to treatment which led to drug-taking pill breaks (MacCarthy, Saya, Samba, Birungi, Okoboi & Linnemayr 2018:1158).

4.4.3 Theme 3: Quality of life

Quality of life refers to different dimensions and life experiences of an individual psychological, social and physical functional alterations that could develop over time in a variety of diseases, in this case HIV. As the management of HIV advances in many areas, measuring their conditions of life and determining contributing elements of those on HIV treatment becomes essential for gaining a good insight of their experiences (Mokgethi; Christofides; Machisa; Akpomiemie & Lalla-Edward 2022). In this study, participants believed that taking the antiretroviral treatment has improved their quality of life even though they had at some point had considered stopping taking treatment due to side effects and sometimes illnesses.

Under this theme there were two categories (1) treatment of side effects, and (2) frequent illnesses.

4.4.3.1 Category 3.1: Treatment side effects

Taking medication usually has some undesirable effects on individuals. Some participants explained the challenges they experienced with HIV treatment adverse effects that were thought to prevent them from complying with their treatment.

> "So far, I have not seen any change since starting this treatment except for discomfort from side effects." (Participant 18, 23-year-old female)

Experienced side effects were viewed as uncomfortable with some participants wishing for the availability of treatment with no side effects and taken at least once. This was noted as one participant stated,

> "It would be great if we could have treatment or therapy that has less or no side effects and prevents infections and be taken once a week at least." (Participant 8, 20-year-old female)

Some of the side effects experiences were reported to be happening more often by other participant. One participant said,

> "Treatment side effects are a problem every time. An hour after taking my pill, I feel like a zombie and forced to go to bed. Sometimes I feel like I am losing my mind." (Participant 3, 24-year-old female).

Although the study's participants appreciated and valued the advantages aware HIV treatment, it was however noted that it comes with a certain degree of discomfort for some. One female participant went on saying,

> "I really appreciate this treatment despite the nuisance of taking it daily as it makes me drowsy, nauseas and tired at times." (Participant 4, 18-year-old female)

The results of this investigation are comparable to those of a study carried out in Cape Town, South Africa.

The results of this investigation are similar to those of the study performed in Cape Town, South Africa, where most pregnant women reported side effects such as dizziness, nausea, vomiting and insomnia (Adeniyi, Ajayi, Goon, Owolabi, Eboh & Lambert 2018).

4.4.3.2 Category 3.2: Frequent illnesses experiences

It is common for patients who are on HIV treatment to experience frequent minor ailments due to their compromised immune system. The participants expressed mixed feelings about their quality of life. Some believed that taking the antiretroviral treatment had improved their quality of life and some did not.

According to participants,

> "I used to be constantly sick, which was really affecting my life and school performance, but since starting treatment, I no longer get sick frequently." (Participant 12, 19-year-old male)

It was also noted that though some participants were experiencing different ailments before taking the HIV treatment, some reported to have not seen a difference as one participant said,

> "I have no idea if this treatment has made any difference in my life. However, I am still alive, maybe that's the only thing that's there as a benefit." (Participant 9, 20-year-old female)

For some participants, it appeared that they had noted a change as they were no longer experiencing other infections and ailments. One participant mentioned:

> "I don't know whether it's the ARVs that are working or the other meds I was given at the clinic, but I no longer experience the recurring sores or wounds. That has at least got better." (Participant 8, 20-year-old female)

Health education provided by HIV counsellors was also mentioned by one participant,

> "Oh well, the counsellor from I-Act told me that the treatment is actually protecting me from getting other infectious diseases." (Participant 13, 22-year-old female)

4.4.4 Theme 4. ARV clinic services

The health care facility services including the way patients are treated are always crucial as part of health care provider-client relationship building. Through that, trust is developed and used to facilitate open discussions pertaining to the patients' needs and facility processes. During the interviews, two categories merged from this theme which were (1) health care worker attitude, and (2) long waiting hours.

4.4.4.1 Category 4.1: Health care worker attitude

The participants indicated that health care providers' attitudes changed when clients missed their appointments. According to one participant,

> "The nurses at the facility are very good and great when starting treatment, but once you are on treatment for a longer period, their attitude changes. It gets worse when you missed your appointment, you immediately get a new name, "defaulter". (Participant 13, 22-year-old female)

This was also alluded by the statement from another participant, saying,

> "I understand that nurses are doing their job and want what's best for us but they become very rude when you've missed your appointment and that makes it even scarier to go back." (Participant 19, 21-year-old female)

This findings are in concurrence with those of the Eastern Cape study where lack of counselling, clinic operating hours, attitudes were found to be contributing to non-adherence (Adeniyi et al 2018).

4.4.4.2 Category 4.2: Long waiting hours

Waiting hours in the public health facilities has always been observed as a priority indicator by the department of health. In most cases, long waiting hours can have a detrimental effects on treatment compliance. Some participants reported that the services were not flexible and convenient for young people. Some found long waiting periods demotivating for them to come to the facility or honour their appointments. According to a participant,

> "Coming to the facility is a challenge for school-goers because that means missing classes the whole day. It might be a good idea, although it also might expose us to others, to have the school health nurses delivering our treatment at schools and also collect our blood in a safe and private space organised with the principal. In this case, I get to miss a few minutes of classes but also get my clinic services conveniently." (Participant 16, 23-year-old male).

Poor file management was also reported by some participants as one said,

> "My clinic is good and has good people working there, but their filing system is a mess. My file always gets lost. You even get surprised when it is found without it being a mission." (Participant 6, 20-year-old female).

One participant even mentioned his wish to take his file home for safe keeping as he felt that was a better option.

> "It would be great if we can take our files home after being seen by the nurse because they are always missing, resulting in delays to see the nurse." (Participant 16, 23-year-old male)

Limited number of health care providers was also viewed as limiting access and delivering of efficient services timely as noted from the participant saying,

> "The service here is slow and you end up spending almost the whole day in the clinic when you have to renew your prescription, although there's a men's clinic on the other side but it is also understaffed which doesn't really help." (Participant 7, 24-year-old male).

Long waiting hours were reported to have a detrimental effect on clinic attendance according to the study performed in Zambia as young would opt not to return to the facility as they believed they were made to wait unnecessarily (St Clair-Sullivan, Mwamba, Whetham, Moore, Darking & Vera 2019:45).

4.4.5 Theme 5: Treatment counselling and support

Treatment support, education and counselling from an integral part of HIV treatment management, which if not properly managed could lead to poor treatment compliance and non-adherence (Adeniyi et al 2018). Gaps in counselling and support were found as the fifth of the themes identified.

Under theme 5 there were two categories: (1) age difference, and (2) availability of more HIV counsellors and nurses.

4.4.5.1 Category 5.1: Age difference

The generational gap between healthcare providers and AYAs poses numerous challenges pertaining to communication, guidance and understanding of behaviour. Participants felt that age difference between them and clinic staff is a challenge coming to treatment outcomes.

> "Most of the nurses are of my mother's age and that pose communication barrier, as I am afraid to ask questions for I feel like I will be judged." (Participant 4, 18-year-old female)

> "I wish we could be separated from adults so that we can support each other." (Participant 5, 19-year-old male)

Transitioning patients from adolescent clinics to adult service points was also found to be depressing for adolescents in a Ugandan qualitative study as adjustment became a challenge as they were used to be given individual attention in adolescent clinics (Inzaule et al 2016).

4.4.5.2 Category 5.2: Availability of more HIV counsellors and nurses

Continuous support and counselling is the crucial part in the management of HIV. Participants indicated different experiences and views of the services provided and the accessibility of counselling and support from staff members in different facilities. According to participants,

> “The services I receive in the clinic are good and I am happy about the clinic staff. The only problem is that at times there’s only one nurse working, and we have to wait longer to get assisted because the same nurse also takes bloods from all the patients.” (Participant 20, 19-year-old female)

Some participants reported that facilities do not have enough and accessible counsellors to provide continuous treatment support when needed and are made to wait when requesting for counselling services. One participant mentioned,

> “When referred for counselling, one has to wait on another long queue as there is always a shortage of counsellors.” (Participant 10, 22-year-old female)

Participants needed to have a valid reason to see the counsellor as they are always busy. One participant stated,

> It is not easy to see the counsellor, nurses would refer you only when you have a valid reason.” (Participant 17, 23-year-old female)

The results of this study were alluded through the Ugandan research which found counselling to be only limited to those who have already defaulted treatment but not accessible to prevent treatment no-adherence (Bukenya, Mayanja, Nakamanya, Muhumuza & Seeley 2019).

4.5 ANALYSIS OF THE FINDINGS

The results are summarised in this section.

4.5.1 Theme 1: Participants’ views of lifelong treatment

The participants had different expectations of being on lifelong treatment and deficiencies with regard to family support and continuous counselling. The general expectation was that the antiretroviral treatment would prolong life and keep them healthy. Several participants wished for a permanent cure as they had not anticipated spending the rest of their lives receiving ART medication.

Some participants had noted a distinctions in their quality of life since being on treatment. However, others felt that being on lifelong treatment felt like a life sentence due to challenges, such as side effects.

The participants' of the study performed in Kampala, Uganda by MacCarthy et al (2018) discovered four obstacles to ART adherence, namely poverty, which hampered the participants' access to care, attendance at school restricted privacy and ART compliance issues; poor support from the family prevented regular and sustained support, and being burdened by taking numerous daily medications irritated adolescents which frequently resulted in the alleged "drug holidays".

4.5.2 Theme 2: Treatment interruption

It has been successful to provide ART to patients with HIV in South Africa's public sector on a big scale, but failing to keep these patients, particularly adolescents, in care remains a critical challenge to achieving the second and third 90-90-90 UNAIDS targets, namely HIV treatment initiation and retention on treatment (Maskew et al 2016:1).

This study found both social and systemic barriers to treatment compliance. Some participants reported having stopped, taken a break or just run out of medication with no access. Transition to adolescence was indicated as one of the reasons for questions about treatment and HIV diagnosis, and talking with peers sometimes led to confusion.

Treatment exhaustion is a common cause of treatment non-compliance. Some of the participants indicated getting tired of taking treatment at some point as this felt like a life sentence. Some of the exhaustion was based on individual expectations that ART would eventually cure the virus, or the hope that a cure would eventually be discovered.

In Uganda, MacCarthy et al (2018:1158) found that participants indicated pill burden as a cause of treatment interruption, and reported exhaustion to taking lifelong treatment and fatigue as the reason for taking what they called "drug holidays".

Some of the participants understood the value of taking the treatment as it had improved their wellbeing. At the same time, some participants wished for a once-off medication that would last longer in their system without being taken daily, and gave contraceptive injections as an example.

Some of the participants stated that the pill size was a problem to swallow which then discouraged them from taking it.

Some of the participants also indicated instabilities resulting from life-changing circumstances such as Covid-19 and job losses contributed to treatment interruption. One participant indicated treatment interruption by the parents' abrupt decision to relocate back home without a referral letter. Country to country transfers and linkages remain a barrier to treatment compliance and continuation for some patients.

4.5.3 Theme 3: Quality of life

Although some participants' alluded to have noticed a positive change in the life since on treatment, it was also clear that some of the participants were not really convinced that taking treatment is indeed a better option. Some of the participants felt that being on lifelong treatment felt like a life sentence than a life-saving option and this was due to a numerous challenges including the experienced side effects that they encountered. A Ghana study also found exhaustion from long term treatment as the cause for non-compliance to treatment which led to youth taking "drug holidays" (MacCarthy et al 2018:1158).

Treatment side effects require good management and counselling so that patients know what to expect from their treatment. The participants felt that their treatment was a nuisance because it interrupted their daily activities at times. Some indicated sleeping pattern disturbances, concentration alteration at school resulting in skipping doses to at least have what they referred to as "better days".

4.5.4 Theme 4: ARV clinic services

Despite systemic advancements, there are still impediments to young people adhering to treatment regimens by way of caregiving, helping with initiatives, and other factors. In this study, the participants referred to long waiting times, facility hours, staff shortages, unavailability of counsellors, and missing files.

According to the participants, at times there was only one nurse working, and they had to wait longer to get assisted because the same nurse also took bloods from all the patients; the service was slow and it took almost the whole day to renew their prescription.

The facility-based filing system was also a challenge. Some participants indicated that their files were always missing, which resulted in delays to see the nurse.

Van Wyk and Davids (2019:2) conducted their study in a low socio-economic urban area of Cape Town and found that significant obstacles to adherence included time obligations to school, poor teacher-learner interactions, unpleasant household dynamics and mistreatment by non-biological caregivers. The participants reported that unstructured lives negatively impacted adherence, as did poor service delivery, missing or misplaced files, lengthy wait times, fear of unintentional disclosure, stigma and prejudice, exhaustion from treatment, and treatment fatigue (Van Wyk & Davids 2019:3).

Collecting treatment for working and school-going adolescents remains a challenge in many health care facilities. Some of the study's participants admitted that they sometimes had to face a difficult choice of whether to miss classes or the clinic. In most cases they opted for going to class as they had had limited contact since Covid-19.

Madiba and Josiah (2019:6) in their research in Botswana discovered that most of the participants indicated challenges relating to keeping health care facility appointments during school days as they hadn’t revealed their HIV status to teachers. Participants indicated that the use of school health services could be beneficial for treatment deliveries at school and collection of treatment while negotiating with school management to provide a private space that could also allow for venepuncture blood collection.

4.5.5 Theme 5: Treatment counselling and support

Progressive and continuous counselling on living with HIV and adherence remains the cornerstone of the HIV treatment, care and support programme. Counselling and group support is a valuable support tool for HIV positive AYAs. The participants indicated that the facilities did not have enough and accessible counsellors to provide continuous treatment support.

The acceptability and practicality of adopting mHealth to increase retention in care and ART adherence for HIV positive AYAs, aged between18 to 24, were examined in a study conducted in Lusaka, Zambia (St Clair-Sullivan et al 2019:45). Early mHealth programs had been demonstrated to improve the quality of health outcomes in various disease areas and healthcare environments. mHealth is the use of mobile and wireless technologies to assist in accomplishing health objectives. The study discovered that stigma was the key factor supporting barriers to HIV care and adherence; Participants highlighted that facilities did not support confidentiality, waiting times and clinic operating hours were inconvenient and the attitudes of the medical personnel were unfavourable. All the participants felt that mHealth would improve retention in care and ART compliance among AYAs (St Clair-Sullivan et al 2019:46).

In this study, some participants felt that the facilities provided good HIV services, but staff shortages caused long waiting times and slow service. Some participants were told that they had contracted HIV in utero, but there was no follow-up counselling during the transition to adolescence. This would have provided an opportunity to clarify misconceptions about HIV and serve as a question-and-answer session for patients.

Some of the participants felt that the age difference between them and the clinic staff played a role in treatment outcomes. The age difference made communication and asking questions difficult for them and they felt they would be judged.

Family HIV-related stigma was another reason for treatment non-compliance. Some individuals had revealed their HIV status to their family members and were met with unwelcoming comments and attitude. This left them feeling resentment towards life and their family members. Some participants indicated that they had to hide their medication from other family members and siblings which resulted in them skipping treatment for a day and sometimes longer when sharing a bedroom.

For AYAs, maintain in ART compliance is a significant challenge. A study conducted in Soweto identified three key themes: hurdles connected to one's personal circumstances and medications, as well as reminder, concealment, and motivational strategies to optimise adherence (Hornschuh et al 2017:1). According to Hornschuh et al (2017:5), interventions to increase AYA adherence should concentrate on doable tactics such status disclosure and medication concealment.

A study on cognitive-behavioural factors associated with adherence to antiretroviral medication among HIV-infected patients in Ibadan, Oyo state, Nigeria, found that 55.2% of the participants had negative perceptions of susceptibility to opportunistic infections, drug-resistant HIV and increased viral load. The participants believed that taking ARV regularly could not prevent opportunistic infections and maintained that if they did not take their ARVs they would not develop drug-resistant HIV (Akinoye et al 2020:2015-2016). The findings indicated the need to upscale health and treatment adherence education and the consequences of non-adherence. In South Africa where the CCMDD programme is currently being implemented, it is crucial to conduct perceived susceptibility assessments to make sure patients are aware of the significance of treatment compliance.

In Malawi, Kim, Mazenga, Yu, Ahmed, Paul, Kazembe and Abrams (2017:5) found forgetting, travelling long distances from home, and feeling depressed, overwhelmed and stigmatised outside and at home were barriers to ART adherence. Other independent factors included drinking alcohol, missed clinic appointments, having witnessed or experienced family violence at home, and poor self-treatment efficacy (Kim et al 2017:5). According to a study conducted in Botswana, the adolescents' adherence was impacted by their fear of stigma. The frequency and location of medication intake, clinic visits, and self-disclosure of HIV status were all impacted by perceived stigma (Madiba & Josiah 2019:6-8).

4.6 CONCLUSION

Data analysis and the method used for analysing data were covered in this chapter, and interpretation and brief summary of themes from participants, and the summary of findings. The constraints of the study, the findings and conclusions, and the recommendations are all briefly presented in Chapter 5.

CHAPTER 5

FINDINGS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter provides suggestions for future research studies and practice as well as a brief discussion of the study's contributions, limits, findings and conclusions.

5.2 PURPOSE AND RESEARCH DESIGN

The purpose of the study was to explore and describe the challenges related to HIV treatment compliance among adolescents and young adults (AYAs) living with HIV in Emfuleni, sub-district municipality and to make recommendations to overcome the challenges related to non-compliance with the treatment, based on the findings. In order to achieve the purpose of the study, the data gathering and study design methods were designed and modified to meet the listed study objectives:

- Explore and describe the challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng.
- Describe recommendations to overcome the challenges to compliance with ART.

The participant's challenges associated with HIV treatment compliance were explored and described by the researcher using a qualitative, exploratory, and descriptive study approach. The approach provided the researcher the chance to explore the participants' perspectives and comprehension of treatment compliance. Using an interview guide that was semi-structured, data was gathered through in-depth interviews (Annexure F).

5.3 FINDINGS

The findings indicated the need for ongoing patient counselling and for HIV treatment support; systematic barriers to treatment adherence; treatment interruption, and the participants’ views of lifelong treatment.

5.3.1 Participants' views of lifelong treatment

The participants had different expectations of being on lifelong treatment and deficiencies with regard to family support and continuous counselling. The general expectation was that the antiretroviral treatment would prolong life and keep them healthy. Several participants wished for a permanent cure as they had not anticipated being on lifelong treatment. Some participants had noted an improvement in their health condition since being on treatment. However, others felt that being on lifelong treatment felt like a life sentence due to challenges, such as side effects. The findings indicated the need for patient-focused treatment literacy to improve knowledge of treatment and the importance of treatment adherence.

5.3.2 Treatment interruption

Being on lifelong treatment frequently becomes a pill burden. Some participants from this study reported using treatment or pill breaks in order to experience what they referred to as better days. Treatment side effects and the pill size led to treatment interruption. Treatment literacy for AYAs living with HIV requires structure and focus on the needs of this group for effectiveness. Some participants reported having stopped, taken a break or just run out of medication with no access. Treatment side effects require good management and counselling so that patients know what to expect from their treatment.

5.3.3 Quality of life

Some participants had noted an improvement in their quality of life since being on treatment. However, others felt that being on lifelong treatment felt like a life sentence due to challenges, such as side effects. The findings indicated the need for patient-focused treatment literacy to improve knowledge of treatment and the importance of treatment adherence.

5.3.4 ART Clinic Services: Systematic barriers to treatment adherence

The study found that despite the promotion of adolescent and youth friendly services (AYFS) in South Africa, system-related barriers to treatment access impeded the standard of support given to this group. The results indicated that there is a need for improved adolescent services based on school hours. This would prevent AYAs having to choose between attending school or going for treatment collection on the same day. Missed clinic appointments resulted in fear of going back to the facilities and facing the nurses. Clinic waiting times remain a problem in most health care facilities and a priority for the Department of Health. The participants reported lengthy waits and missing or misplaced files as discouraging attendance and adherence. AYAs attending HIV treatment facilities require services centred and focusing on their needs.

5.3.5 HIV Treatment counselling and support

The study revealed a need for ongoing (continuous) counselling and support for AYAs. Many of the participants had acquired HIV infections vertically (perinatally), which left them with unanswered questions. Some of the participants reported being resentful and angry with their parents upon learning about their status, which was aggravated by internalised and family stigma. AYAs on HIV treatment require understanding and continuous counselling to address and cope with their mental and treatment-related challenges and promote adherence.

Family HIV-related stigma was another reason for treatment non-compliance. Some participants had revealed their HIV status to their relatives and were met with unwelcoming comments and attitude. This indicated the need for treatment support both from and for families with HIV-positive adolescents and young adults. Treatment support from families is vital for treatment adherence.

Some of the participants indicated that the age difference between them and the clinic staff played a role in treatment non-adherence and outcomes. The age difference made communication and asking questions difficult for them and they felt they would be judged.

5.4 RECOMMENDATIONS

The researcher offers the following suggestions for practice and further research studies in light of the findings.

5.4.1 Ongoing counselling and psychosocial support

Psychosocial support is required for young people living with HIV particularly since many have lost their parents through death. Psychosocial support should begin earlier to build confidence and allow for honest discussions regarding their sexual and reproductive health. This should include guidance on age-appropriate zero status disclosure for parents, caregivers and health care professionals. This could be achieved by:

- Establishing support groups and adherence clubs for AYAs living with HIV.
- Providing parents' or caregivers' preparation for age-appropriate disclosure and support.

5.4.2 Youth-friendly services

The AYFS approach should focus on addressing the issues of HIV positive AYAs in order to improve treatment adherence. This could be achieved by:

- Opening in the afternoons to accommodate school going adolescents for treatment collection.
- Having flexi hours to accommodate young people that are due for collection of their routine blood monitoring to align with the laboratory courier collection times.
- Opening facility-based youth zones to ensure separation of AYAs from adult patient waiting areas, which would facilitate open discussion of challenges with clinicians and other facility staff.

5.4.3 Intensified and patient-centred treatment literacy

Full, continuous patient-centred and age-appropriate treatment literacy should be provided for AYAs as they progress with their treatment to assist understanding and guide status disclosure. Treatment literacy training should cover crucial components such as:

- Pill burden
- Pill breaks
- HIV treatment as a chronic medication

- Viral load suppression
- HIV status disclosure and dating

AYFS counsellors who know and understand the HIV management programme should be available for effective support of AYAs.

5.4.4 Parental or caregiver support

Parent or caregiver support groups should be established and facilitated by healthcare personnel to serve as a platform for HIV treatment education and guidance on handling different stages of AYAs living with HIV. This should include:

- Parent or caregiver education on age-appropriate HIV status disclosure for support and guidance.
- Parent or caregiver training and guidance on family-related stigma prevention and early identification of mental distress for referral.

5.4.5 Reduction of waiting times through system strengthening

There is a need for improved patient administration and community system strengthening to promote an accepting and conducive environment for AYAs with HIV. This could be achieved by:

- Introducing a fully functional and effective appointment system to accommodate school holidays and examination periods.
- Implementing an improved filling system to prevent loss and missing files during patient visits.
- Developing adolescent-to-adult clinic transition plans.
- Identifying and decanting all virally suppressed patients through strengthening the central chronic medicines dispensing and distribution programme (CCMDD).

5.4.6 Implementation of the welcome back strategy

Health care workers and administration staff needs to be trained on the welcome back strategy aimed at ensuring that traced missed appointments are received and assisted without being “punished”. A contact person or champion should be identified to receive returning treatment defaulters.

5.4.7 Further research study

The researcher suggests that additional study be done on the following topics:

- An analysis of the problems with HIV treatment non-compliance among (AYAs) living with HIV in various South African areas and provinces.
- An analysis of the problems related to HIV treatment non-compliance among (AYAs) living with HIV in other districts in South Africa.
- An examination of the challenges faced by AYAs with treatment adherence and experiences.
- A mixed method approach to explore and describe contributory factors to HIV treatment interruption among AYAs.
- An examination of parents or caregivers of AYAs on HIV treatment experiences and challenges in encouraging and supporting treatment uptake and compliance.

5.5 CONTRIBUTION OF THE STUDY

The study explored and described challenges associated with HIV treatment compliance among AYAs living with HIV. The findings should contribute to better comprehension of the phenomenon and the development of practical guidance and ways to prevent treatment non-compliance and improve adherence for viral load suppression.

5.6 RESTRICTIONS OF THE STUDY

The study was restricted to four facilities in one semi-urban district in one province and cannot be applied in other locations. The study only selected participants identified with two consecutive unsuppressed viral load.

Due to the Covid-19 lockdown, physical meetings were prohibited, which delayed approval from the district research committee, access to facilities and data collection as planned.

5.7 CONCLUDING REMARKS

The findings of this study have indicated that there’s a need for improved support of AYAs living with HIV to improve treatment compliance and be virally suppressed. There is a need for the adoption of the AYFS into the HIV management programme for better facilitation of routine visits and management of AYAs with HIV. The findings also highlight the necessity for treatment literacy in order to promote effective treatment coping strategies and a better understanding of the benefits of compliance in viral load suppression.

We must change our direction if we are to get back on track to end AIDS. It's important to recognise the disparities that significantly influence who has access to HIV services that are appropriate for their needs, who contracts HIV, and who dies from the virus. The AIDS response must therefore be modified to prioritise the programs, legislation, policies, and services that will most effectively empower people who are still left behind and end these injustices.

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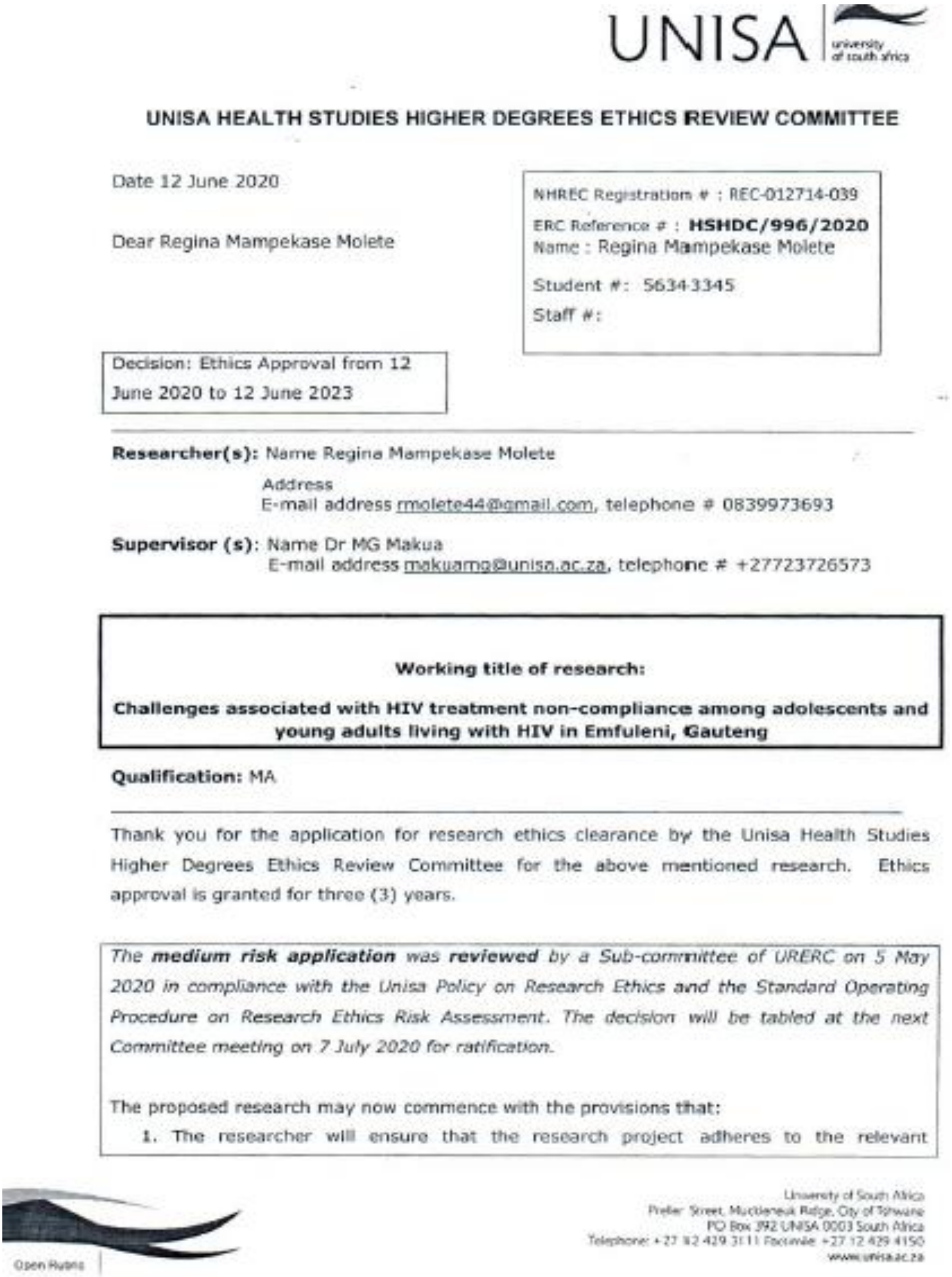
ANNEXURES

ANNEXURE A: Ethical Clearance Certificate from the University of South Africa



UNISA university of south africa

UNISA HEALTH STUDIES HIGHER DEGREES ETHICS REVIEW COMMITTEE

Date 12 June 2020

Dear Regina Mampekase Molete

NHREC Registration # : REC-012714-039
ERC Reference # : **HSHDC/996/2020**
Name : Regina Mampekase Molete
Student #: 56343345
Staff #:

Decision: Ethics Approval from 12 June 2020 to 12 June 2023

Researcher(s): Name Regina Mampekase Molete
Address
E-mail address rmolete44@gmail.com, telephone # 0839973693

Supervisor (s): Name Dr MG Makua
E-mail address makuamg@unisa.ac.za, telephone # +27723726573

Working title of research:

Challenges associated with HIV treatment non-compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

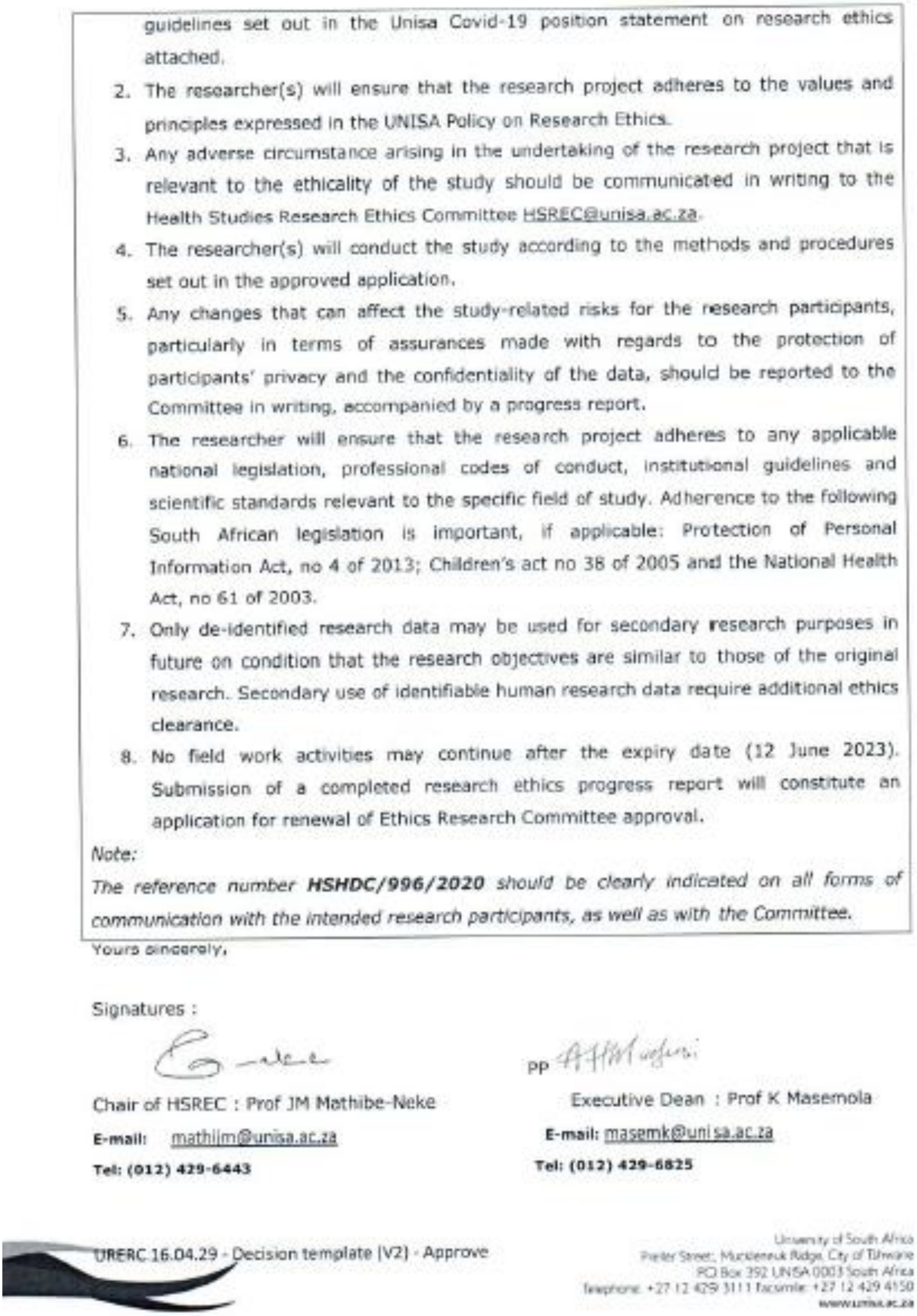
Qualification: MA

Thank you for the application for research ethics clearance by the Unisa Health Studies Higher Degrees Ethics Review Committee for the above mentioned research. Ethics approval is granted for three (3) years.

The ***medium risk application*** *was* ***reviewed*** *by a Sub-committee of URERC on 5 May 2020 in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment. The decision will be tabled at the next Committee meeting on 7 July 2020 for ratification.*

The proposed research may now commence with the provisions that:

1. The researcher will ensure that the research project adheres to the relevant



guidelines set out in the Unisa Covid-19 position statement on research ethics attached.

2. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
3. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the Health Studies Research Ethics Committee HSREC@unisa.ac.za.
4. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
5. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.
6. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
7. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
8. No field work activities may continue after the expiry date (12 June 2023). Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

The reference number ***HSHDC/996/2020*** *should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signatures :

pp

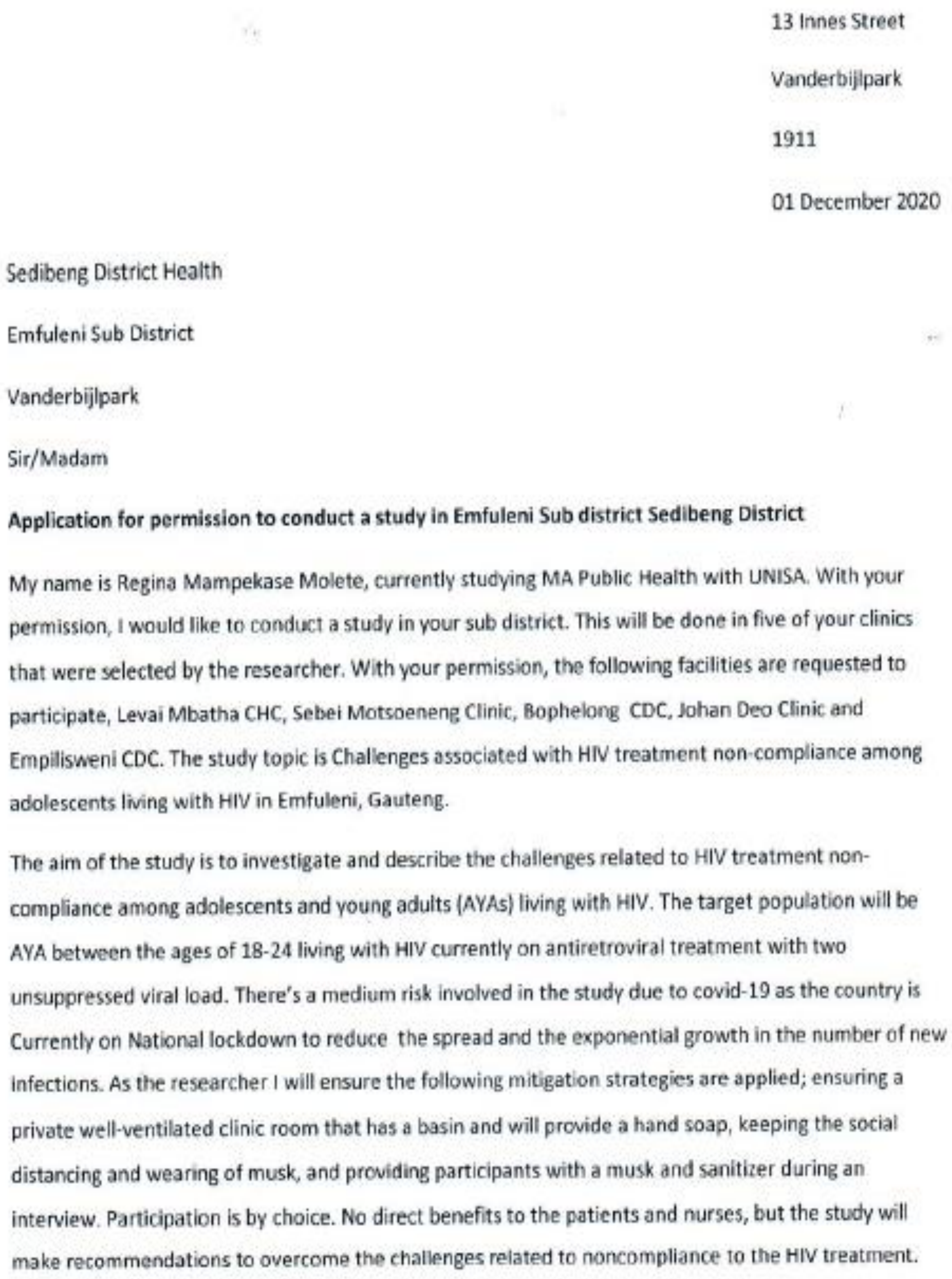
Chair of HSREC : Prof JM Mathibe-Neke
E-mail: mathijm@unisa.ac.za
Tel: (012) 429-6443

Executive Dean : Prof K Masemola
E-mail: masemk@unisa.ac.za
Tel: (012) 429-6825

URERC 16.04.29 - Decision template (V2) - Approve

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

ANNEXURE B: Permission requested from Sedibeng District Health Services to conduct a study



13 Innes Street

Vanderbijlpark

1911

01 December 2020

Sedibeng District Health

Emfuleni Sub District

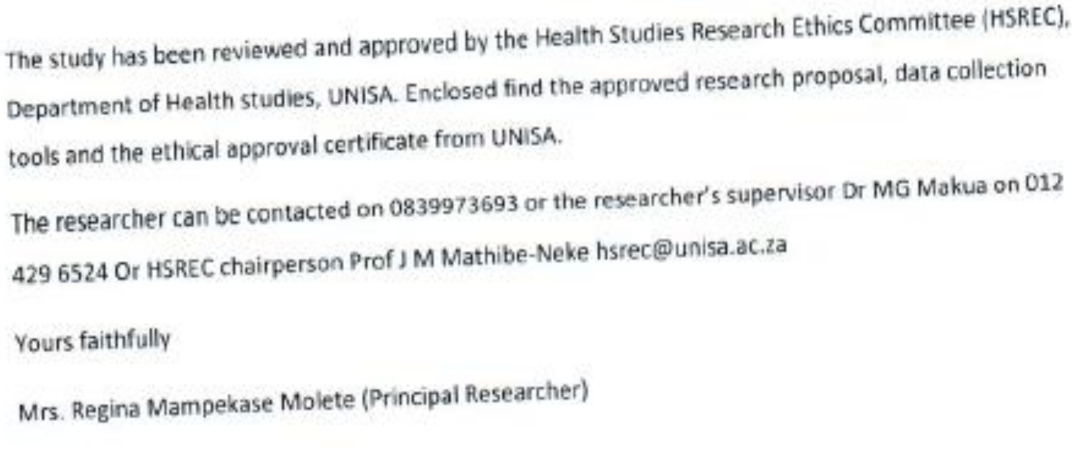
Vanderbijlpark

Sir/Madam

Application for permission to conduct a study in Emfuleni Sub district Sedibeng District

My name is Regina Mampekase Molete, currently studying MA Public Health with UNISA. With your permission, I would like to conduct a study in your sub district. This will be done in five of your clinics that were selected by the researcher. With your permission, the following facilities are requested to participate, Levai Mbatha CHC, Sebei Motsoeneng Clinic, Bophelong CDC, Johan Deo Clinic and Empilisweni CDC. The study topic is Challenges associated with HIV treatment non-compliance among adolescents living with HIV in Emfuleni, Gauteng.

The aim of the study is to investigate and describe the challenges related to HIV treatment non-compliance among adolescents and young adults (AYAs) living with HIV. The target population will be AYA between the ages of 18-24 living with HIV currently on antiretroviral treatment with two unsuppressed viral load. There's a medium risk involved in the study due to covid-19 as the country is Currently on National lockdown to reduce the spread and the exponential growth in the number of new infections. As the researcher I will ensure the following mitigation strategies are applied; ensuring a private well-ventilated clinic room that has a basin and will provide a hand soap, keeping the social distancing and wearing of musk, and providing participants with a musk and sanitizer during an interview. Participation is by choice. No direct benefits to the patients and nurses, but the study will make recommendations to overcome the challenges related to noncompliance to the HIV treatment.



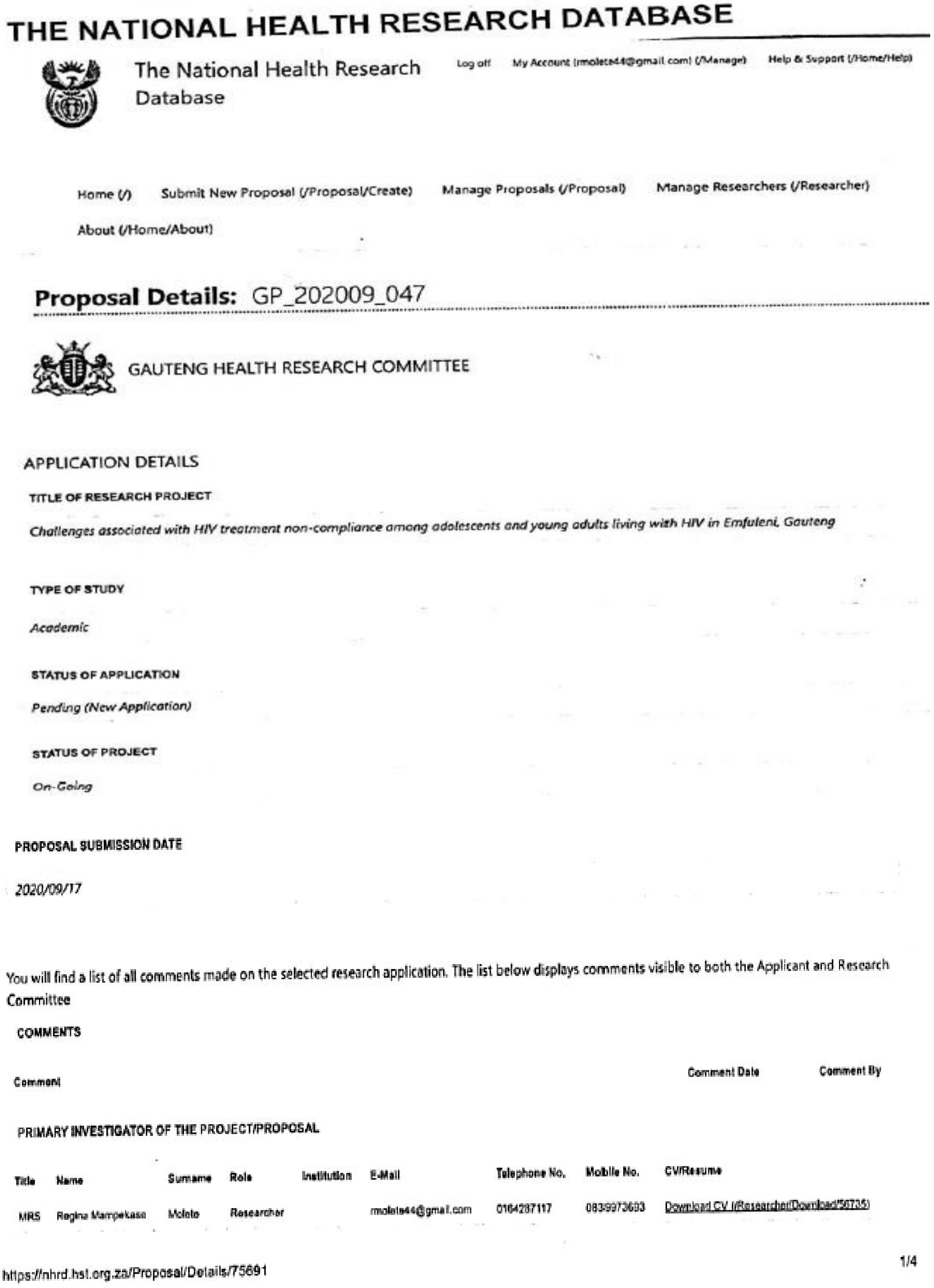
The study has been reviewed and approved by the Health Studies Research Ethics Committee (HSREC), Department of Health studies, UNISA. Enclosed find the approved research proposal, data collection tools and the ethical approval certificate from UNISA.

The researcher can be contacted on 0839973693 or the researcher's supervisor Dr MG Makua on 012 429 6524 Or HSREC chairperson Prof J M Mathibe-Neke hsrec@unisa.ac.za

Yours faithfully

Mrs. Regina Mampekase Molete (Principal Researcher)

ANNEXURE C: Approval from the National Health Research Database to conduct the study



THE NATIONAL HEALTH RESEARCH DATABASE

The National Health Research Database

Proposal Details: GP_202009_047

GAUTENG HEALTH RESEARCH COMMITTEE

APPLICATION DETAILS

TITLE OF RESEARCH PROJECT

Challenges associated with HIV treatment non-compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

TYPE OF STUDY

Academic

STATUS OF APPLICATION

Pending (New Application)

STATUS OF PROJECT

On-Going

PROPOSAL SUBMISSION DATE

2020/09/17

You will find a list of all comments made on the selected research application. The list below displays comments visible to both the Applicant and Research Committee

COMMENTS

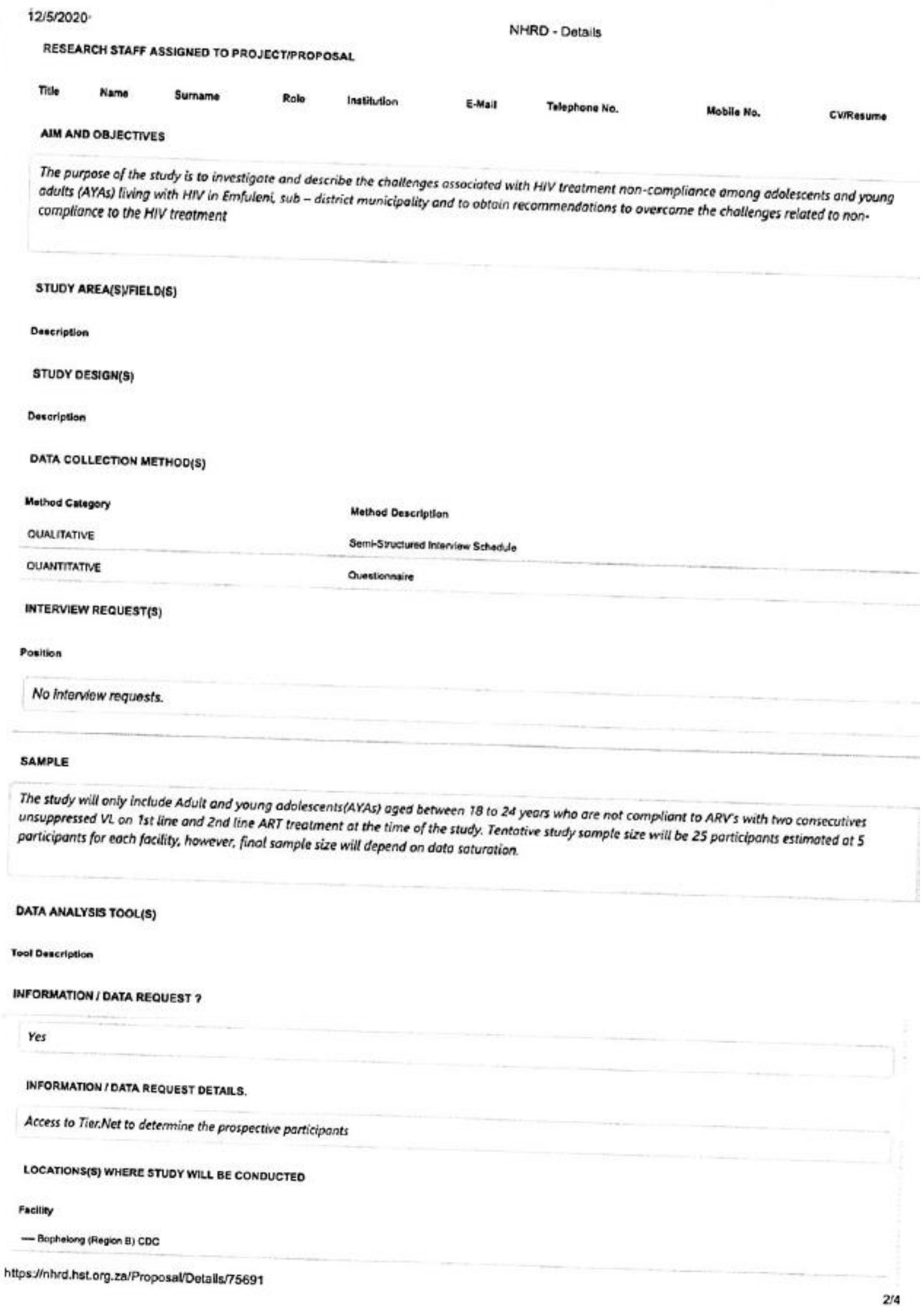
Comment	Comment Date	Comment By

PRIMARY INVESTIGATOR OF THE PROJECT/PROPOSAL

Title	Name	Surname	Role	Institution	E-Mail	Telephone No.	Mobile No.	CV/Resume
MRS	Regina Mampekaso	Molete	Researcher		rmolete44@gmail.com	0164287117	0839973603	Download CV (/Researcher/Download/50735)

https://nhrd.hst.org.za/Proposal/Details/75691

1/4



12/5/2020 NHRD - Details

RESEARCH STAFF ASSIGNED TO PROJECT/PROPOSAL

Title	Name	Surname	Role	Institution	E-Mail	Telephone No.	Mobile No.	CV/Resume

AIM AND OBJECTIVES

The purpose of the study is to investigate and describe the challenges associated with HIV treatment non-compliance among adolescents and young adults (AYAs) living with HIV in Emfuleni, sub – district municipality and to obtain recommendations to overcome the challenges related to non-compliance to the HIV treatment

STUDY AREA(S)/FIELD(S)

Description

STUDY DESIGN(S)

Description

DATA COLLECTION METHOD(S)

Method Category	Method Description
QUALITATIVE	Semi-Structured Interview Schedule
QUANTITATIVE	Questionnaire

INTERVIEW REQUEST(S)

Position

No interview requests.

SAMPLE

The study will only include Adult and young adolescents(AYAs) aged between 18 to 24 years who are not compliant to ARV's with two consecutives unsuppressed VL on 1st line and 2nd line ART treatment at the time of the study. Tentative study sample size will be 25 participants estimated at 5 participants for each facility, however, final sample size will depend on data saturation.

DATA ANALYSIS TOOL(S)

Tool Description

INFORMATION / DATA REQUEST ?

Yes

INFORMATION / DATA REQUEST DETAILS.

Access to Tier.Net to determine the prospective participants

LOCATION(S) WHERE STUDY WILL BE CONDUCTED

Facility

— Bophelong (Region B) CDC

https://nhrd.hst.org.za/Proposal/Details/75691

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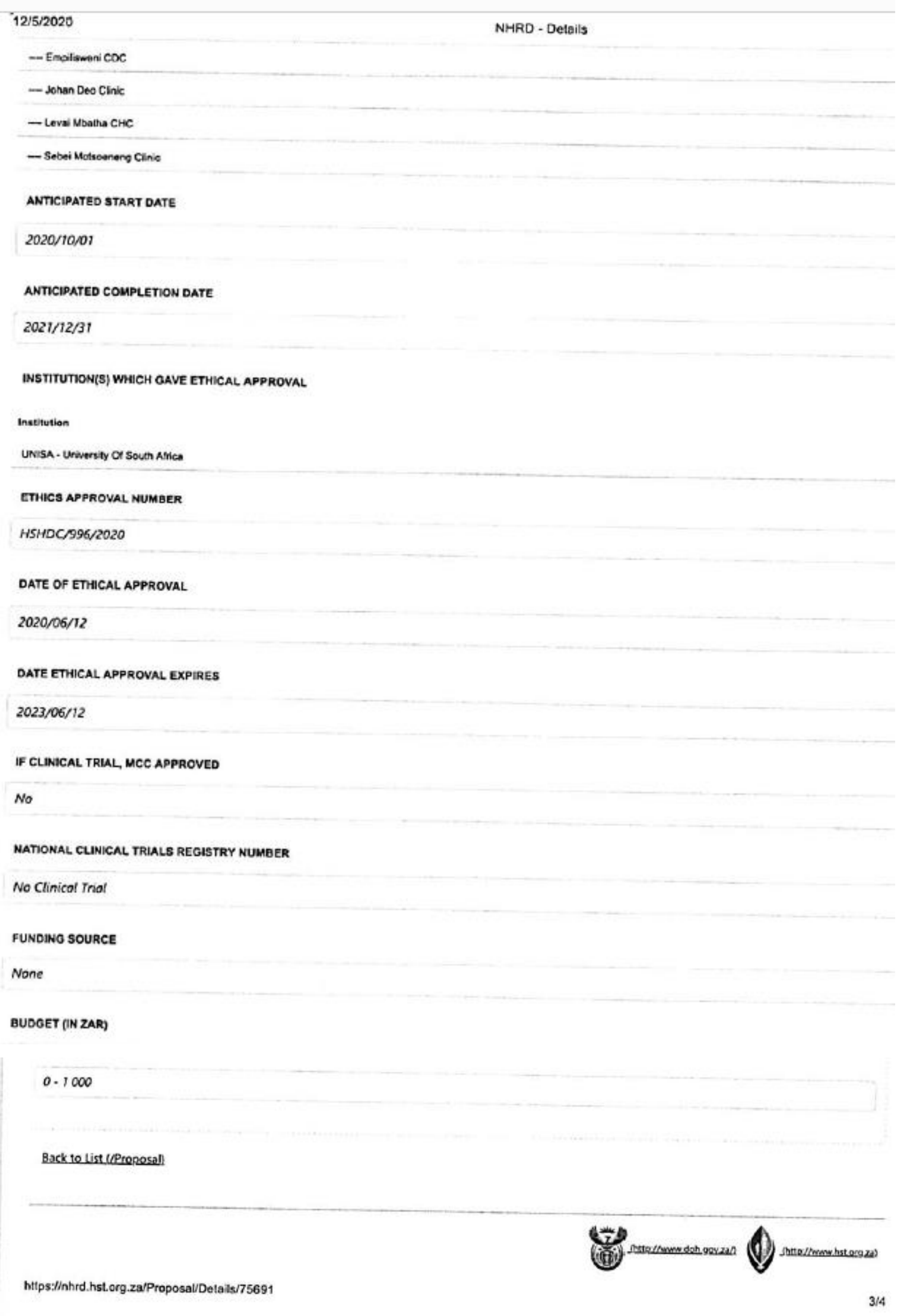

— Empilisweni CDC

— Johan Deo Clinic

— Levai Mbatha CHC

— Sebei Motsoaneng Clinic

ANTICIPATED START DATE

2020/10/01

ANTICIPATED COMPLETION DATE

2021/12/31

INSTITUTION(S) WHICH GAVE ETHICAL APPROVAL

Institution

UNISA - University Of South Africa

ETHICS APPROVAL NUMBER

HSHDC/996/2020

DATE OF ETHICAL APPROVAL

2020/06/12

DATE ETHICAL APPROVAL EXPIRES

2023/06/12

IF CLINICAL TRIAL, MCC APPROVED

No

NATIONAL CLINICAL TRIALS REGISTRY NUMBER

No Clinical Trial

FUNDING SOURCE

None

BUDGET (IN ZAR)

0 - 1 000

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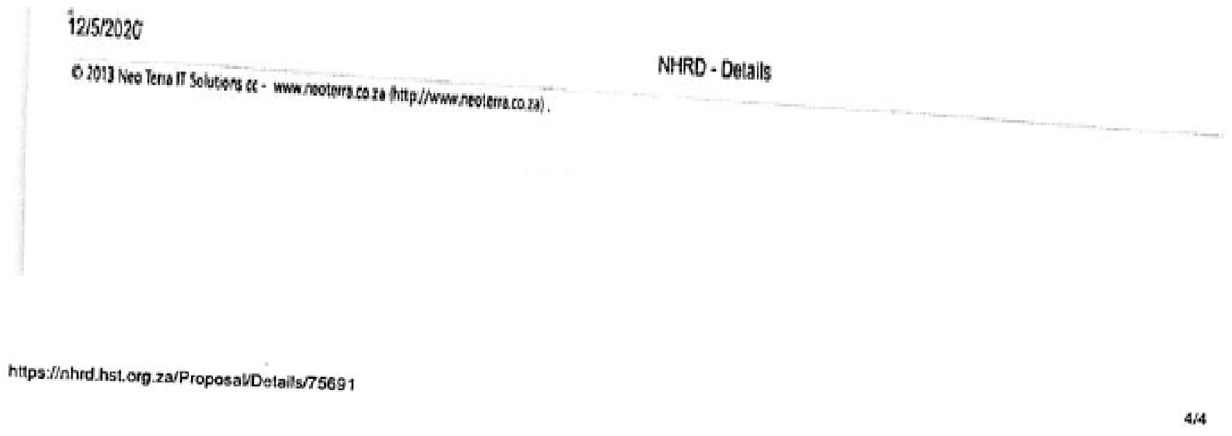
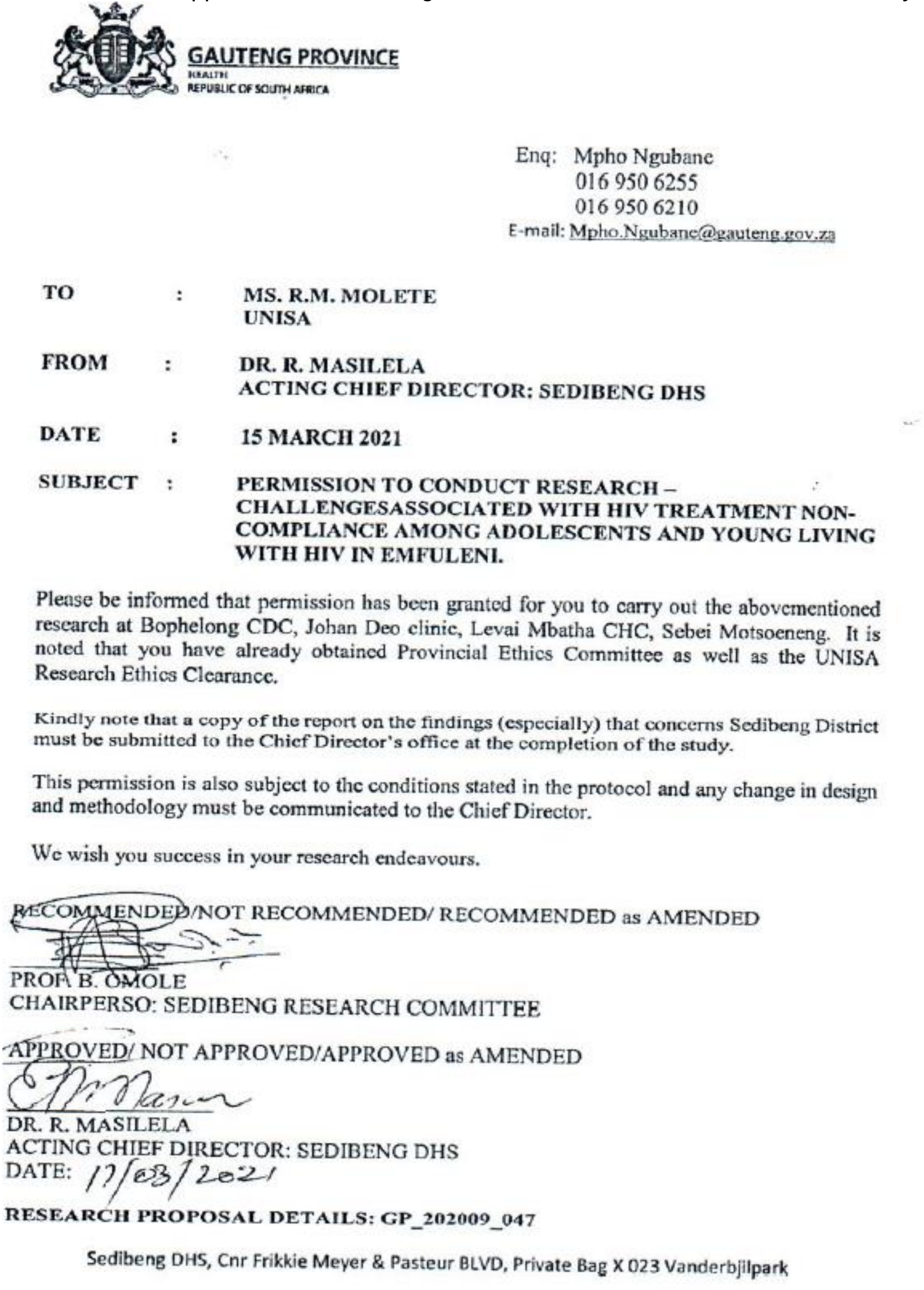
(http://www.doh.gov.za/) (http://www.hst.org.za)



ANNEXURE D: Approval from Sedibeng District Health Services to conduct the study



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enq: Mpho Ngubane
016 950 6255
016 950 6210
E-mail: Mpho.Ngubane@gauteng.gov.za

TO : **MS. R.M. MOLETE**
UNISA

FROM : **DR. R. MASILELA**
ACTING CHIEF DIRECTOR: SEDIBENG DHS

DATE : **15 MARCH 2021**

SUBJECT : **PERMISSION TO CONDUCT RESEARCH – CHALLENGESASSOCIATED WITH HIV TREATMENT NON-COMPLIANCE AMONG ADOLESCENTS AND YOUNG LIVING WITH HIV IN EMFULENI.**

Please be informed that permission has been granted for you to carry out the abovementioned research at Bophelong CDC, Johan Deo clinic, Levai Mbatha CHC, Sebei Motsoeneng. It is noted that you have already obtained Provincial Ethics Committee as well as the UNISA Research Ethics Clearance.

Kindly note that a copy of the report on the findings (especially) that concerns Sedibeng District must be submitted to the Chief Director's office at the completion of the study.

This permission is also subject to the conditions stated in the protocol and any change in design and methodology must be communicated to the Chief Director.

We wish you success in your research endeavours.

[✓ RECOMMENDED]/NOT RECOMMENDED/ RECOMMENDED as AMENDED

PROF B. OMOLE
CHAIRPERSO: SEDIBENG RESEARCH COMMITTEE

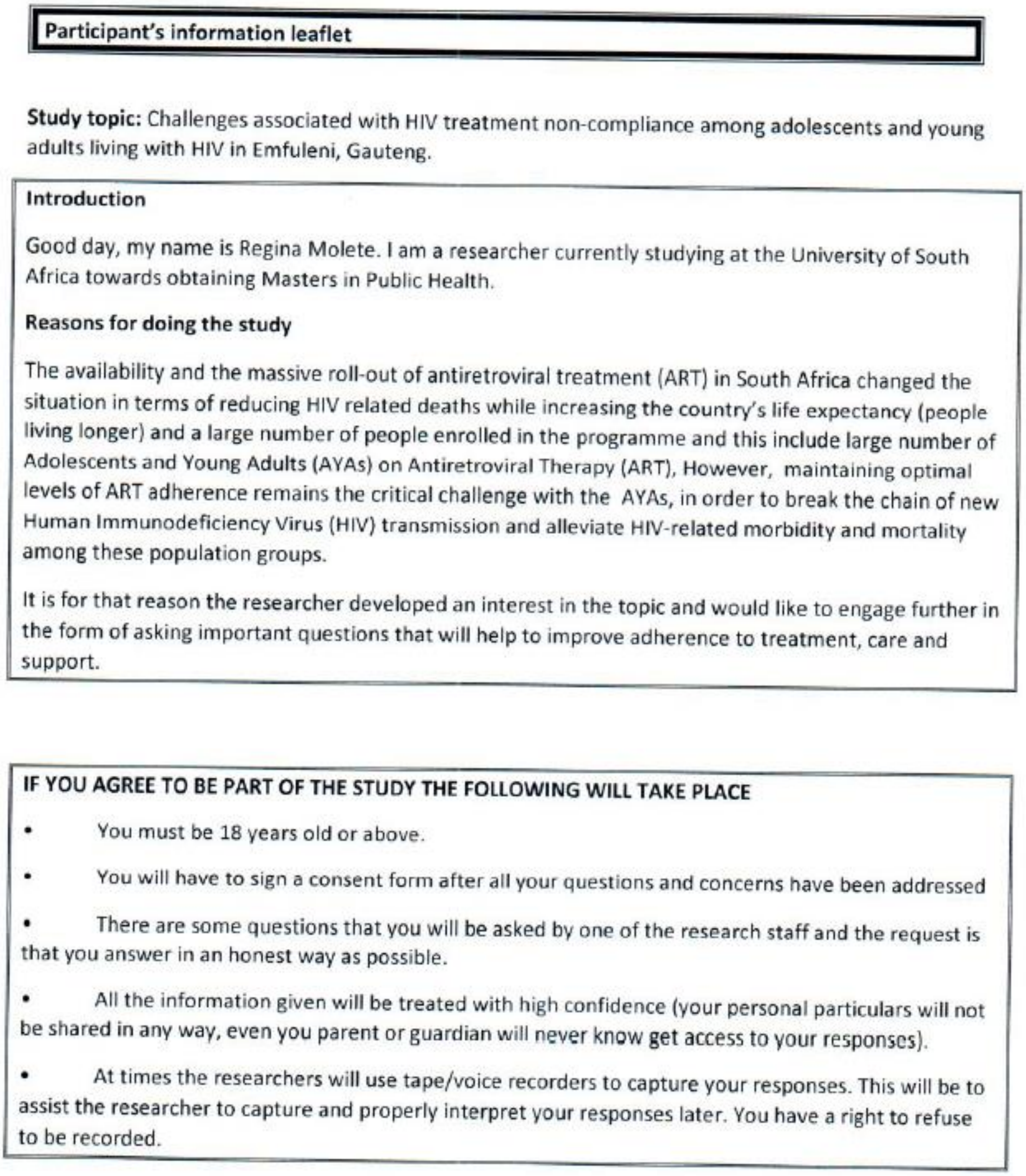
[✓ APPROVED]/ NOT APPROVED/APPROVED as AMENDED

DR. R. MASILELA
ACTING CHIEF DIRECTOR: SEDIBENG DHS
DATE: 17/03/2021

RESEARCH PROPOSAL DETAILS: GP_202009_047

Sedibeng DHS, Cnr Frikkie Meyer & Pasteur BLVD, Private Bag X 023 Vanderbjilpark

ANNEXURE E: Information leaflet and consent form



Participant's information leaflet

Study topic: Challenges associated with HIV treatment non-compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng.

Introduction

Good day, my name is Regina Molete. I am a researcher currently studying at the University of South Africa towards obtaining Masters in Public Health.

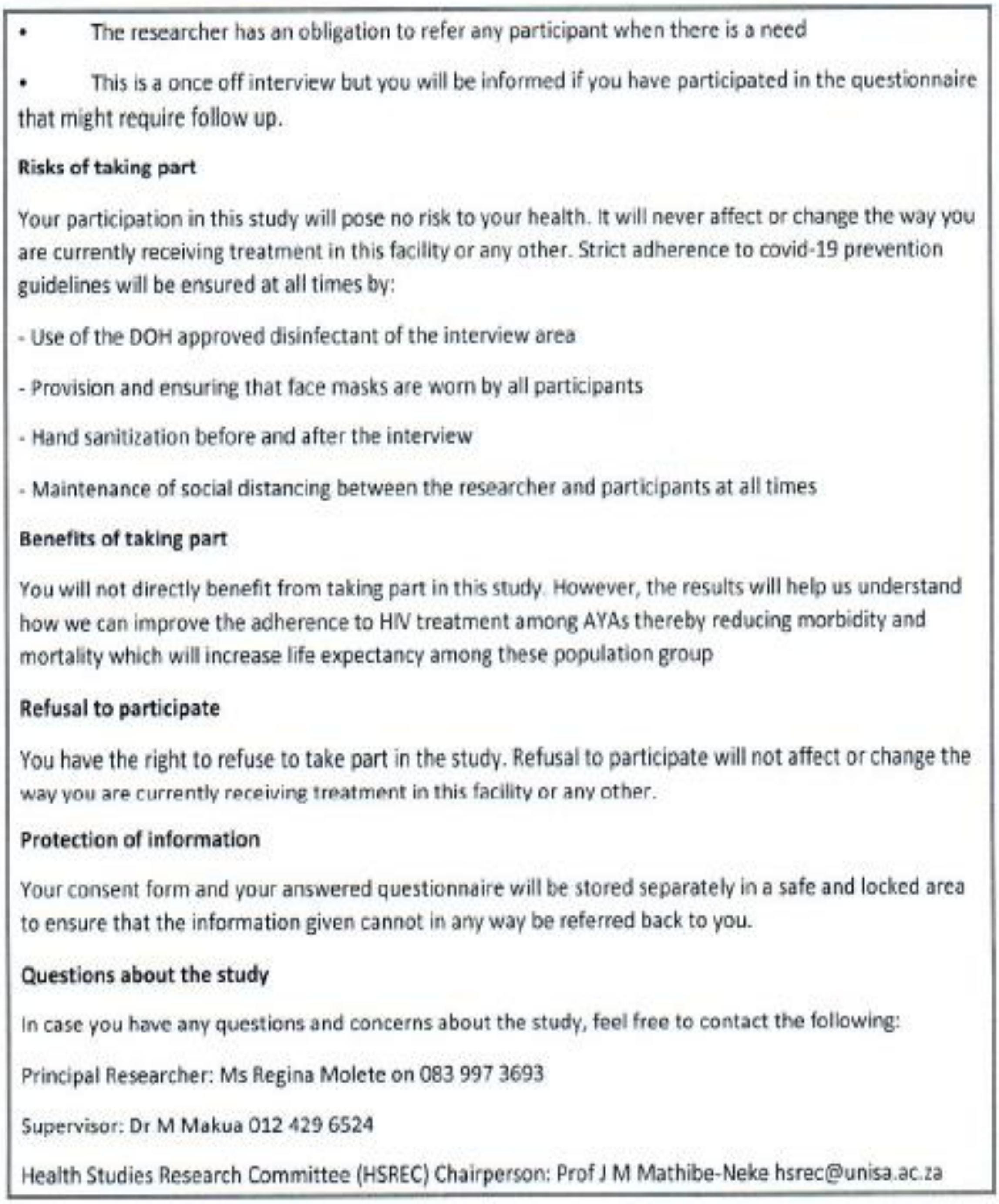
Reasons for doing the study

The availability and the massive roll-out of antiretroviral treatment (ART) in South Africa changed the situation in terms of reducing HIV related deaths while increasing the country's life expectancy (people living longer) and a large number of people enrolled in the programme and this include large number of Adolescents and Young Adults (AYAs) on Antiretroviral Therapy (ART), However, maintaining optimal levels of ART adherence remains the critical challenge with the AYAs, in order to break the chain of new Human Immunodeficiency Virus (HIV) transmission and alleviate HIV-related morbidity and mortality among these population groups.

It is for that reason the researcher developed an interest in the topic and would like to engage further in the form of asking important questions that will help to improve adherence to treatment, care and support.

IF YOU AGREE TO BE PART OF THE STUDY THE FOLLOWING WILL TAKE PLACE

- You must be 18 years old or above.
- You will have to sign a consent form after all your questions and concerns have been addressed
- There are some questions that you will be asked by one of the research staff and the request is that you answer in an honest way as possible.
- All the information given will be treated with high confidence (your personal particulars will not be shared in any way, even you parent or guardian will never know get access to your responses).
- At times the researchers will use tape/voice recorders to capture your responses. This will be to assist the researcher to capture and properly interpret your responses later. You have a right to refuse to be recorded.



- The researcher has an obligation to refer any participant when there is a need
- This is a once off interview but you will be informed if you have participated in the questionnaire that might require follow up.

Risks of taking part

Your participation in this study will pose no risk to your health. It will never affect or change the way you are currently receiving treatment in this facility or any other. Strict adherence to covid-19 prevention guidelines will be ensured at all times by:

- Use of the DOH approved disinfectant of the interview area

- Provision and ensuring that face masks are worn by all participants

- Hand sanitization before and after the interview

- Maintenance of social distancing between the researcher and participants at all times

Benefits of taking part

You will not directly benefit from taking part in this study. However, the results will help us understand how we can improve the adherence to HIV treatment among AYAs thereby reducing morbidity and mortality which will increase life expectancy among these population group

Refusal to participate

You have the right to refuse to take part in the study. Refusal to participate will not affect or change the way you are currently receiving treatment in this facility or any other.

Protection of information

Your consent form and your answered questionnaire will be stored separately in a safe and locked area to ensure that the information given cannot in any way be referred back to you.

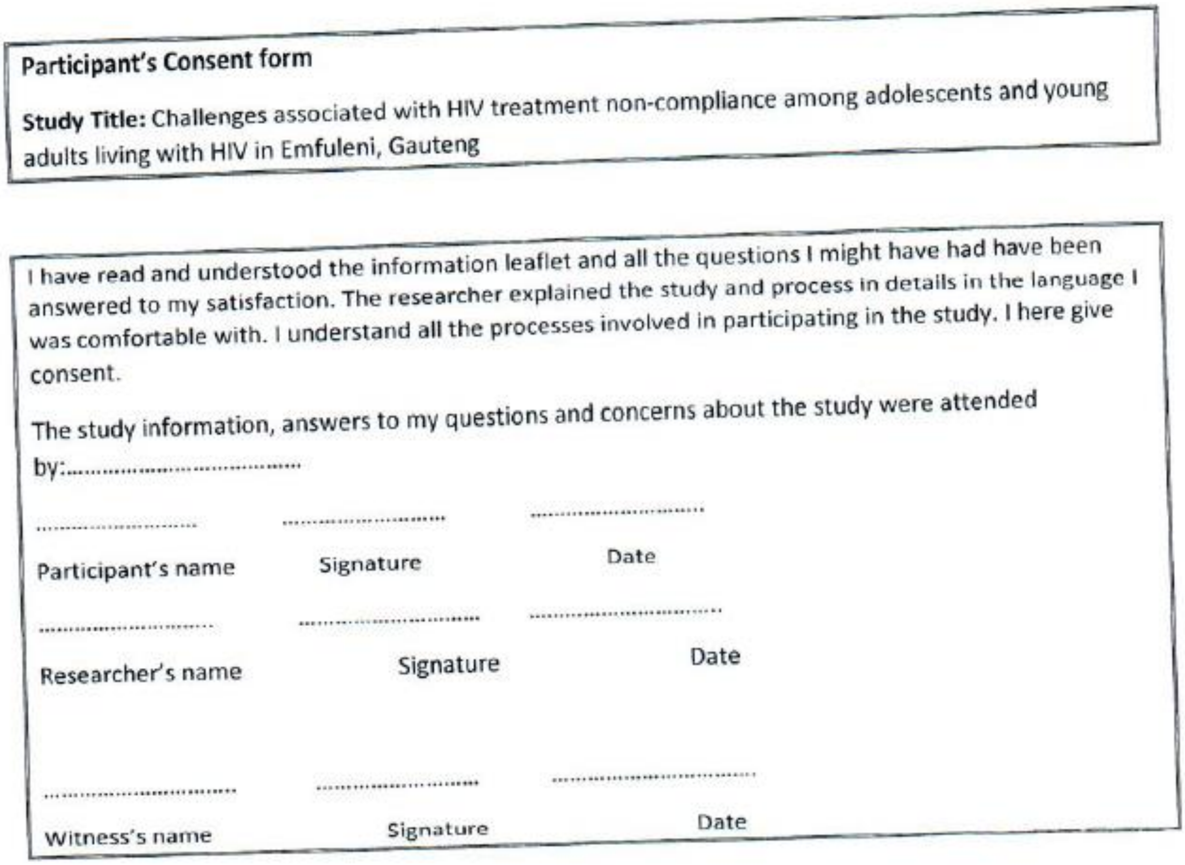
Questions about the study

In case you have any questions and concerns about the study, feel free to contact the following:

Principal Researcher: Ms Regina Molete on 083 997 3693

Supervisor: Dr M Makua 012 429 6524

Health Studies Research Committee (HSREC) Chairperson: Prof J M Mathibe-Neke hsrec@unisa.ac.za



Participant's Consent form

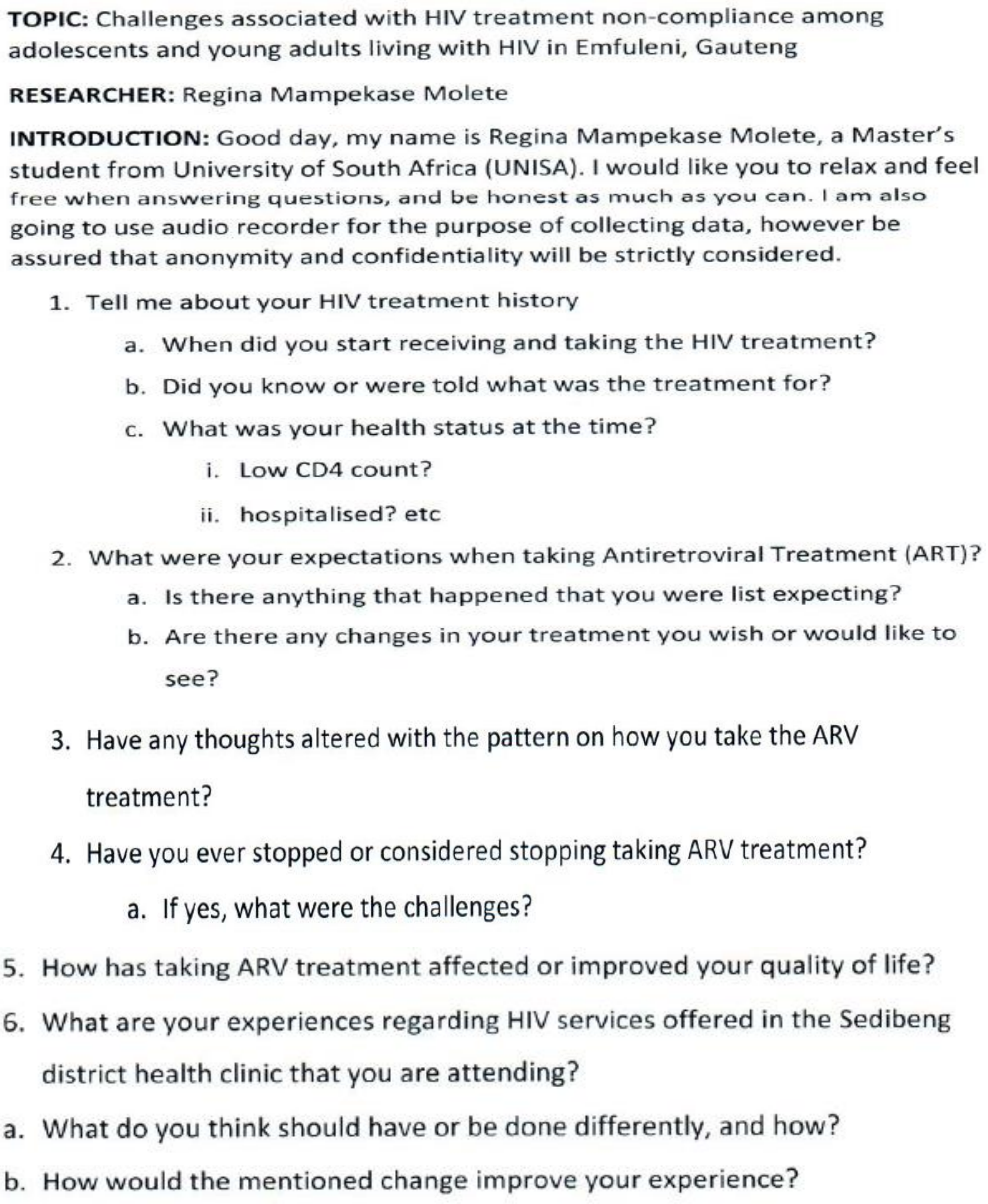
Study Title: Challenges associated with HIV treatment non-compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

I have read and understood the information leaflet and all the questions I might have had have been answered to my satisfaction. The researcher explained the study and process in details in the language I was comfortable with. I understand all the processes involved in participating in the study. I here give consent.

The study information, answers to my questions and concerns about the study were attended by:……………………………………

………………………	………………………	………………………
Participant's name	Signature	Date
………………………	………………………	………………………
Researcher's name	Signature	Date
………………………	………………………	………………………
Witness's name	Signature	Date

ANNEXURE F: Interview guide



TOPIC: Challenges associated with HIV treatment non-compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

RESEARCHER: Regina Mampekase Molete

INTRODUCTION: Good day, my name is Regina Mampekase Molete, a Master's student from University of South Africa (UNISA). I would like you to relax and feel free when answering questions, and be honest as much as you can. I am also going to use audio recorder for the purpose of collecting data, however be assured that anonymity and confidentiality will be strictly considered.

1. Tell me about your HIV treatment history
    a. When did you start receiving and taking the HIV treatment?
    b. Did you know or were told what was the treatment for?
    c. What was your health status at the time?
        i. Low CD4 count?
        ii. hospitalised? etc
2. What were your expectations when taking Antiretroviral Treatment (ART)?
    a. Is there anything that happened that you were list expecting?
    b. Are there any changes in your treatment you wish or would like to see?
3. Have any thoughts altered with the pattern on how you take the ARV treatment?
4. Have you ever stopped or considered stopping taking ARV treatment?
    a. If yes, what were the challenges?
5. How has taking ARV treatment affected or improved your quality of life?
6. What are your experiences regarding HIV services offered in the Sedibeng district health clinic that you are attending?

a. What do you think should have or be done differently, and how?

b. How would the mentioned change improve your experience?

ANNEXURE G: Transcriptions

Participant 01

TOPIC: Challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

RESEARCHER: Regina Mampekase Molete

INTRODUCTION: Good day, my name is Regina Mampekase Molete, a Master's student from University of South Africa (UNISA). I would like you to relax and feel free when answering questions, and be honest as much as you can. I am also going to use audio recorder for the purpose of collecting data, however, be assured that anonymity and confidentiality will be strictly considered.

7. Tell me about your HIV treatment history
    a. When did you start receiving and taking the HIV treatment?
    I was told that I started ART when I was 5 years
    b. Did you know or were you told what the treatment was for?
    Was told 5 years later by granny
    c. What was your health status at the time?
    Sick
        i. Low CD4 count? Can't remember
        ii. Hospitalised? Once but can't remember when

8. What were your expectations when taking Antiretroviral Treatment (ART)?

To be healed after 10 years

   c. Is there anything that happened that you were list expecting?
   Yes, to be told that I am going to take this treatment for life
   d. Are there any changes in your treatment you wish or would like to see?
   Wish alluvia could be changed due to side effects

9. Have any thoughts altered with the pattern on how you take the ARV treatment?
   Time of taking treatment as I don't have the phone to remind myself

10. Have you ever stopped or considered stopping taking ARV treatment?

    Yes

    b. If yes, what were the challenges?

       I was angry when my granny told me that I contracted HIV when my mom was pregnant and was never told until I was 15 years

11. How has taking ARV treatment affected or improved your quality of life?

    Feels strong and coping well at school

12. What are your experiences regarding HIV services offered in the Sedibeng district health clinic that you are attending?

    We always spend long time in the queues waiting for missed files

    c. What do you think should have or be done differently, and how?

       If there is proper filling system at the clinic, one won't have to wait long hours.

    d. How would the mentioned change improve your experience?

       Long waiting hours will be reduced and I won't have to miss classes at school

Participant No: 02

TOPIC: Challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng

RESEARCHER: Regina Mampekase Molete

INTRODUCTION: Good day, my name is Regina Mampekase Molete, a Master’s student from University of South Africa (UNISA). I would like you to relax and feel free when answering questions, and be honest as much as you can. I am also going to use audio recorder for the purpose of collecting data, however, be assured that anonymity and confidentiality will be strictly considered.

1. Tell me about your HIV treatment history
   a. When did you start receiving and taking the HIV treatment?
      When I was 10 years
   b. Did you know or were you told what the treatment was for?
      I didn’t know, only told by my grandmother after noticing on TV that I am drinking same treatment and they said they are for HIV. My mother died when I was a child
   c. What was your health status at the time?
      I was sick and had TB
      i. Was told my CD 4 was low but not sure how much was it
      ii. Hospitalised? Yes when I was having TB

2. What were your expectations when taking Antiretroviral Treatment (ART)?
      To be cured of HIV
   a. Is there anything that happened that you were list expecting?
      Yes, to be told that I am going to take this treatment for life
   b. Are there any changes in your treatment you wish or would like to see?
      Wish the treatment could be changed to injectables like family planning where one takes it once in three months

3. Have any thoughts altered with the pattern on how you take the ARV treatment?

   Yes the thought of taking treatment everyday is tiring

4. Have you ever stopped or considered stopping taking ARV treatment?

   Yes

   a. If yes, what were the challenges?

      I had a challenge taking treatment when I am with friends as I have not disclosed my HIV status to them

5. How has taking ARV treatment affected or improved your quality of life?

   I am no longer sick as I used to be before

6. What are your experiences regarding HIV services offered in the Sedibeng district health clinic that you are attending?

   Its good but we are mixed with adults and are expected to arrive in the morning so one has to miss classes to honour clinic appointments

   a. What do you think should have or be done differently, and how?

      If we can be separated from adults and be allowed to attend the clinic in the afternoon hours

   b. How would the mentioned change improve your experience?

      It would be easy to discuss our challenges with our peers and we won't have to miss classes.

ANNEXURE H: Letter from the language editor

Cell/Mobile: 073-782-3923

53 Glover Avenue
Doringkloof
0157 Centurion

3 February 2023

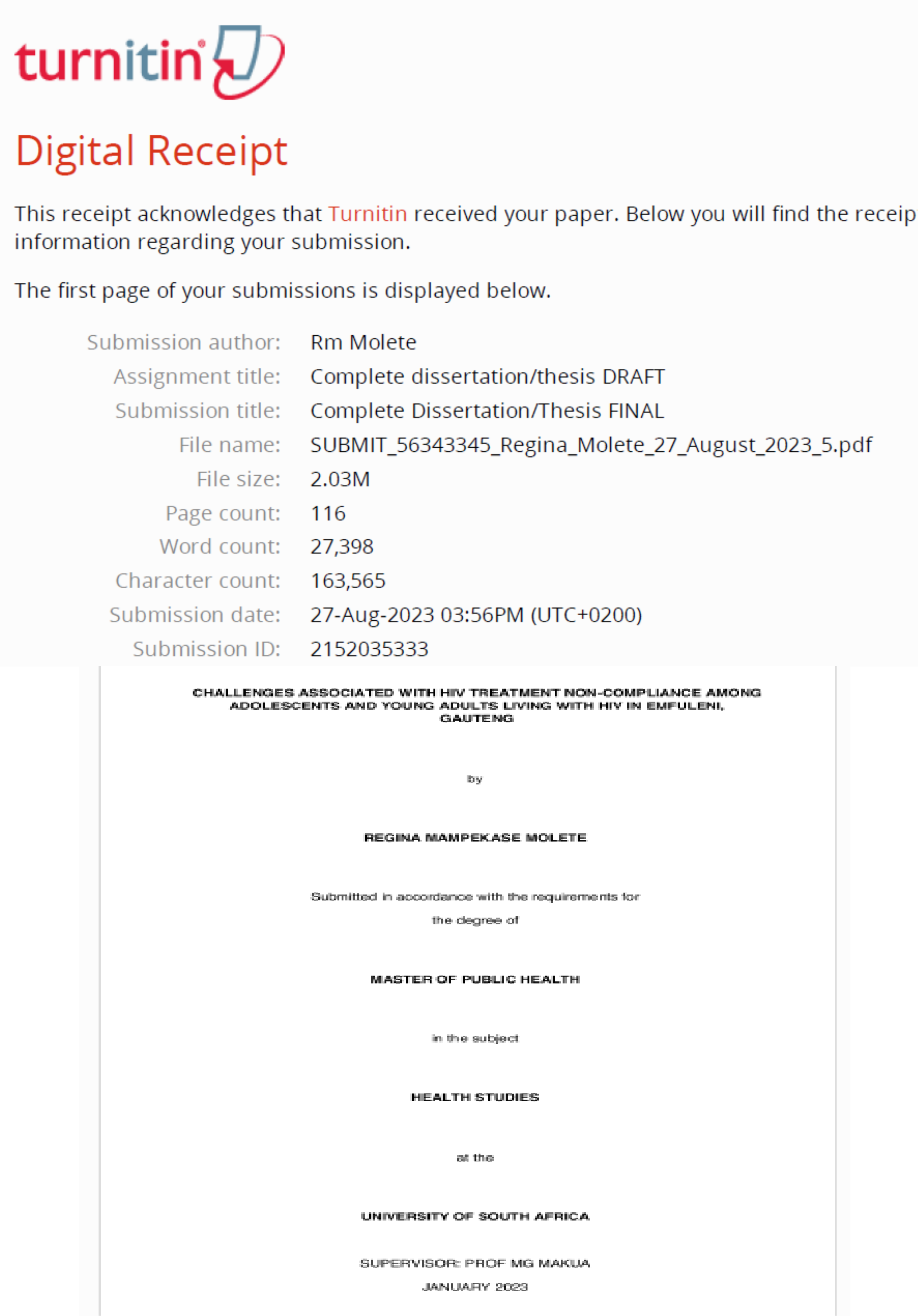
TO WHOM IT MAY CONCERN

I hereby certify that I have edited Regina Molete’s master’s dissertation, **Challenges associated with HIV treatment compliance among adolescents and young adults living with HIV in Emfuleni, Gauteng**, for language and content.

IM Cooper

Iauma M Cooper
192-290-4

ANNEXURE I: Turnitin originality report



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CHALLENGES ASSOCIATED WITH HIV TREATMENT NON-COMPLIANCE AMONG ADOLESCENTS AND YOUNG ADULTS LIVING WITH HIV IN EMFULENI, GAUTENG

by

REGINA MAMPEKASE MOLETE

Submitted in accordance with the requirements for
the degree of

MASTER OF PUBLIC HEALTH

in the subject

HEALTH STUDIES

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROF MG MAKUA
JANUARY 2023

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